Adjustment to child autism diagnosis during parent-mediated intervention

A thesis submitted as partial fulfillment of the requirements of the degree of Master of Clinical Psychology/Doctor of Philosophy

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Statement of Originality

This is to certify that the content of this thesis is my own work. This thesis has not been submitted for any other degree or purpose.

I certify that the intellectual content of this thesis is the product of my own work, and that all assistance received in preparing this thesis and all sources have been acknowledged.

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Elysha Clark Whitney, September 26 2025

Acknowledgements

To my supervisors, Mark Dadds and Lucy Tully, thank you for always striking the perfect balance between inspiring me and keeping me reined in. I have learned so much from both of you, and know that so much of your guidance will stay with me as I (hopefully) continue along with my own research. Your warmth and humour has also made this a much more enjoyable process! Mark, your ability to simultaneously see the big picture and the individual pieces has been invaluable to my research, and am important reminder to always look for the 'why'. Lucy, you always go above and beyond for your students, and I am incredibly grateful for your guidance, support, and TV series recommendations.

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It's said that doing a PhD can be a lonely endeavour, but that hasn't been the case for me, thanks to the wonderful team at the Sydney Child Behaviour Research Clinic. Particular thanks to Jaimie Northam for helping me and the other PhD students make sense of the wild world of academia, and for your kindness. I have been lucky to have a wonderful cohort of fellow CBRC PhD students – Adrienne, Alex, Jess, Janice, Rebecca, and Torunn, thank you for the lunch chats and for helping to make sense of the milestones along the way. Rebecca, I have been especially grateful to go through these last few months before submission together.

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Authorship Attribution

This thesis includes an Introduction, three studies which have been written as articles intended for publication in peer-reviewed journals, and a General Discussion. The Introduction and General Discussion components of this thesis were prepared with input from my primary supervisor, Mark Dadds, and auxiliary supervisor, Lucy Tully. I wrote the full drafts of each of these sections, and my supervisors contributed to editing drafts.

The research reported in Study 1 is also reported in a published, peer-reviewed article, which was published in January 2026, after initial thesis submission and before submission of thesis amendments. The citation for this work is: Clark-Whitney, E., Tully, L. A., Turnell, A. I, Leonard, B. E., Moelle, E. C., & Dadds, M. R. (2026). Systematic review of measures and interventions for caregiver adjustment to child autism diagnosis. *Autism,* 13623613251407305, https://doi.org/10.1177/13623613251407305. A copy of the published article is included in Appendix C. This article differs in some areas from Study 1 as reported in this thesis, as changes were made in response to reviewer feedback as part of the peer-review process, including conduct of an updated database search on October 03, 2025 following initial submission of this thesis. An earlier draft of this study was also submitted for the MCP/PhD systematic review requirement (PSYC6077). I designed the study, conducted the systematic review, analysed the data, and wrote the full drafts of the manuscript. Co-authors contributed to screening studies for inclusion in the systematic review, and to editing drafts. The systematic review search strategy was developed with support from University of Sydney academic liaison librarian, Thomas Goodfellow.

Study 2 has not yet been submitted for publication, but has been prepared for submission with input from co-authors. The citation for this work is: Clark-Whitney, E., Tully, L. A., Leonard, B. E., Moelle, E., & Dadds, M. (2025). Parent adjustment to autism diagnosis and parent-mediated intervention: A randomised controlled trial. [Manuscript in preparation].

This study was part of a randomised controlled trial (RCT), conducted in collaboration with all co-authors. Valsamma Eapen, Bruce Tonge, Jaimie Northam and Adrienne Turnell were also involved in the main RCT, as were lived experience consultants Grace Fava and Fiona Le Nepvue, however these collaborators were not involved in the component of the RCT that is reported in Study 2, and are therefore not involved as authors on the manuscript for Study 2. These co-authors and collaborators designed the main RCT, and I designed the specific components reported in Study 2, with input from supervisors Mark Dadds and Lucy Tully. Erika Moelle and Bridie Leonard assisted with data cleaning. I analysed the data for Study 2, and wrote the full drafts of the manuscript. Co-authors contributed to editing drafts. Data analysis was conducted with consultation with Chris Howden through University of Sydney Informatics Hub.

Study 3 has not yet been submitted for publication, but has been prepared for submission with input from co-authors. The citation for this work is: Clark-Whitney, E., Fotofili, J., Tully, L. A., Rabba, A. S., & Dadds, M. (2025). "My child is autistic. What the heck do I do next?": A qualitative study examining parent adjustment to autism diagnosis and experiences of parent-mediated intervention. [Manuscript in preparation]. I designed the study, conducted data collection and data analysis, and wrote the full drafts of the manuscript. Co-author Jasmine Fotofili contributed to data analysis, as described in Study 3, and also wrote the researcher positionality statement describing her contribution (page 93). Co-authors contributed to editing drafts. Lived experience advisory group members Grace Fava and Fiona Le Nepveu also contributed to editing drafts. Volunteer student research assistants (Alexandrea Tan, Caroline Clements, Jasmine Fotofili, and Ziqi "Gigi" Kuang) assisted with correcting and deidentifying interview transcripts.

I, Elysha Clark Whitney, attest to the accuracy of these authorship attribution statements.

[signature removed]

Elysha Clark Whitney, September 26 2025

Updated January 27, 2026

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

[signature removed]

Mark Dadds, September 26 2025

Updated January 27, 2026

Statement on use of Generative AI

Generative AI (Copilot and ChatGPT) was used 1) to generate and troubleshoot syntax to be used for data analysis in R Studio and SPSS, and 2) for the purpose of minor text enhancement. No information specific to the research project or that would be considered intellectual property or university property was shared with Generative AI.

1) The use of Generative AI to generate and troubleshoot syntax did not including sharing data or including data as part of any prompt to Generative AI. General prompts requesting for syntax for particular analyses were provided to Generative AI (e.g., "Please provide syntax to extract EMMs from pooled model"), with generated syntax then used to conduct analysis in R Studio or SPSS. Error messages were provided to Generative AI for assistance troubleshooting syntax errors, but no output of data analysis was provided to Generative AI.
2) Generative AI was also used for the purposes of minor text enhancement. This included assistance with individual word finding (e.g., "A word to describe taking a zoomed out view of something, like 'broadly'"). This did not include using Generative AI to write segments longer than an individual word or phrase. The Generative AI tool was not used to enhance or change text. Generative AI was not provided with any of the written content of this thesis.

I confirm that the content was reviewed for possible errors, inaccuracies, and bias. I take full responsibility for the submitted thesis, confirm that the work is my own, and have used generative AI in accordance with University guidelines and policies.

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List of Abbreviations

Abbreviation	Definition
AAC	Augmentative and Alternative Communication
ACT	Acceptance and commitment therapy
ADAQ	Adjustment to the Diagnosis of Autism Questionnaire
ADHD	Attention Deficit Hyperactivity Disorder
CALD	Culturally and linguistically diverse
CBT	Cognitive behaviour therapy
COSMIN	Consensus-based Standards for the Selection of Health Measurement Instruments
DISCAP-5	Diagnostic Interview Schedule for Children, Adolescents and Parents-5
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ECBI	Eyberg Child Behaviour Inventory
ICD-11	International Statistical Classification of Diseases and Related Health Problems, 11th Edition
MCAR	Missing completely at random
MMAT	Mixed Methods Appraisal Tool
NDBI	Naturalistic Developmental Behavioural Intervention
NDIS	National Disability Insurance Scheme
PMI	Parent-mediated intervention
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
PWS	ParentWorks Spectrum
RCT	Randomised controlled trial
RDI	Reaction to Diagnosis Interview
RRB	Restricted/repetitive behaviours and interests
SRS-2	Social Responsiveness Scale - 2
TAU	Treatment-as-usual
WL	Waitlist

Abstract

When a child is diagnosed with autism, their parent (used henceforth to refer to parents and other primary caregivers) goes through a process of working through the associated thoughts and feelings, known as adjustment to the diagnosis (Pianta & Marvin, 1993). With little research examining parents' adjustment support needs, our understanding of how to best support parents' adjustment to their child's autism diagnosis remains limited. In particular, research has yet to investigate whether there are benefits for adjustment from the interventions that parents of autistic children commonly engage in, such as parent-mediated intervention (PMI), an evidence-based category of interventions in which the parent is trained in strategies to deliver intervention to the child (Bearss et al., 2015). Accordingly, the relevant literature is reviewed and three empirical studies are reported here.

Study 1 reports a systematic review of measures and intervention for caregiver adjustment to child autism diagnosis. The review identified significant heterogeneity in how adjustment is defined and measured, finding 38 unique measures of adjustment across 69 included articles. Absent or limited reporting of psychometric properties was noted. The review identified six interventions for which caregiver adjustment was a measured outcome. Three of these interventions demonstrated statistically significant improvement in caregiver adjustment. Notably, all were 'targeted' interventions, in that they exclusively addressed parent outcomes. As Study 1 identified that no studies had examined the effect of a broad intervention such as PMI on adjustment, Study 2 and Study 3 addressed this gap.

Study 2 presents an evaluation of parent adjustment to child autism diagnosis during a randomised controlled trial of a PMI, ParentWorks Spectrum (PWS; Leonard et al., 2025) (*n* = 49) compared to waitlist control (*n* = 50). The trial prioritised father involvement, and about 75% of families had two participating caregivers. PWS did not significantly improve adjustment, for mothers or fathers, despite positive and significant intervention effects for child

behaviour, social communication, and parent mental health and self-efficacy (Dadds et al., 2025). Parents' baseline adjustment did not predict dropout, engagement, or child outcomes. Mothers reported higher scores on the self-blame subscale of the Adjustment to the Diagnosis of Autism Questionnaire (Da Paz et al., 2018) as compared to fathers. This study suggests that PMI may not be sufficient to facilitate adjustment to diagnosis. However, it is not clear whether the lack of significant effect of PMI on adjustment, or of adjustment on PMI, was because parents in Study 2 may not have been experiencing significant adjustment difficulties.

Study 3 used qualitative methodology to explore experiences of adjustment for a representative subsample of parents (*n* = 29) who had completed PWS. Three themes to capture parents' adjustment journey were developed using thematic analysis of semi-structured interviews - 'feeling out of control', 'becoming agents of change' and 'accepting that what will be will be'. Drawing across these themes, Study 3 proposes a conceptual model of adjustment to diagnosis: the Active Balance model of adjustment, which explains adjustment as the process of actively working to balance acceptance and change. The PMI was identified as one support that contributed to adjustment, and parents also identified a range of additional support needs.

The current research indicates a fundamental need to improve consistency and rigour in how adjustment is defined and measured. Based on this identified need, and on the results of Study 3, I propose a conceptual definition of parent adjustment to autism diagnosis as the process of balancing acceptance of the autism diagnosis with striving for change in the parent themselves, the child, and the world around them focused around autism. The Active Balance model proposed in Study 3 builds on prior theory to explain the process by which parents actively work on adjustment, and further research is required to validate this model. Finally, clinical considerations for supporting adjustment are discussed. Drawing across the results of Study 2 and Study 3 suggests that parents may benefit from a range of adjustment supports to facilitate a balance of acceptance and change. PMI may contribute to supporting adjustment, but may not be sufficient to facilitate significant changes in adjustment on its own. Nevertheless, further research is needed to understand how parents experiencing significant adjustment difficulties respond to PMI, and to improve researchers' and clinicians' capacity to determine which parents may be in need of additional adjustment support, and when.

INTRODUCTION

When a young child is diagnosed with autism, their parent (or other primary caregiver, henceforth referred to as ‘parent’) is expected to mobilise quickly to support the child’s learning and development (Carlsson et al., 2016; Mulligan et al., 2012). The parent must develop an understanding of what autism is, and how to support their child’s unique needs. This often includes accessing appropriate supports for the child, and may involve the parent themselves participating in intervention for their child (Bearss et al., 2015; Sandbank et al., 2023). The parent is expected to do this while working through their own emotional reaction to the child’s diagnosis, a process referred to as adjustment to diagnosis (Pianta & Marvin, 1993). Adjustment is also referred to in the literature as ‘resolution of diagnosis’ (see Naicker et al., 2023 for a review focusing specifically on resolution), however the term ‘adjustment’ is used here in recognition that this process may remain ongoing throughout the parent’s life rather than having a definite endpoint. Adjustment to diagnosis is associated with parents’ physical and mental health (Da Paz et al., 2018; Reed & Osborne, 2019), as well as their ability to engage in responsive interactions with their child (Dolev et al., 2016; Wachtel & Carter, 2008). Parent and family adjustment to diagnosis has recently been identified as a priority area for autism supports (Green et al., 2022). However, our understanding of how best to support parental adjustment, particularly in combination with existing autism interventions, remains limited. This thesis therefore aims to understand the process of parents’ adjustment to their child’s autism diagnosis, and to examine adjustment in the context of parent-mediated intervention (PMI), an evidence-based intervention modality in which the parent is trained in strategies to build child skills and/or reduce child challenging behaviour (Bearss et al., 2015).

The following Introduction provides background to the current research. It includes an introduction to autism and an overview of the process of autism diagnosis, as well as a brief review of evidence-based interventions for young autistic children and their families. These sections include research regarding diagnosis and support for autism specifically in the Australian context in which the current research was conducted. The Introduction then provides a review of research on the construct of adjustment to diagnosis, including relevant theoretical models, challenges in defining and measuring adjustment, the limited longitudinal research examining adjustment as a process, and factors that may influence adjustment. The Introduction then considers evidence-based supports for adjustment, and argues for the need to examine adjustment in the context of PMI. Information regarding the studies included in this thesis, and the aims of each study, will be included at the end of the Introduction. It should be noted that this thesis focuses on parents' adjustment to autism diagnosis for parents of toddlers and young children. Therefore, while the number of adolescent and adult autism diagnoses is increasing (Grosvener et al., 2024; Russell et al., 2022), research regarding diagnosis in adolescence or adulthood is not reviewed in this thesis.

Autism and the Process of Autism Diagnosis

Autism is a neurodevelopmental condition referred to in diagnostic systems as 'Autism Spectrum Disorder' (American Psychiatric Association, 2022; World Health Organisation, 2019). However, in this thesis, it is referred to as 'autism' to reflect the move away from pathologising terminology (e.g., Bottini et al., 2024). Identity-first language (e.g., 'autistic child') will generally be used in this thesis, as opposed to person-first language (e.g., 'child with autism') as recent research suggests that this reflects the preferences of many autistic people (Taboas et al., 2023). However, person-first language will be used within the reported research where this reflects the language choices of the research participants.

The reported global prevalence of autism is 1 in 121 people, although this is considered likely to be an underestimate (Santomauro et al., 2025). In Australia, a higher prevalence of about 1 in 90 people is reported (Australian Bureau of Statistics, 2024). Autism is characterised by differences in social communication and interaction, and patterns of restricted or repetitive behaviours, interests, or routines (RRB; American Psychiatric Association, 2022). These core features must be present for an individual to be diagnosed with autism, however there is notable variability in the way these features present (Lombardo & Mandelli, 2022; Wiggins et al., 2021). Autism is also associated with increased likelihood of a substantial number of co-occurring conditions, including intellectual disability, Attention Deficit Hyperactivity Disorder (ADHD), disruptive behaviour disorders, sleep disorders, and an array of mental and physical health diagnoses (Khachadourian et al., 2023; Lai et al., 2019; Mutluer et al., 2022). Variability in these co-occurring conditions, as well as in the intensity and presentation of core social and RRB features, contributes to notable heterogeneity between autistic people (Georgiades et al., 2013). Across the lifespan, most autistic adults continue to require some level of support for daily activities (Bishop-Fitzpatrick et al., 2016). However, the nature of these support needs can vary significantly between individuals and across time, again reflecting the heterogeneity among autistic individuals (Bishop-Fitzpatrick et al., 2016). Researchers have had some success in predicting adult adaptive behaviour and social outcomes based on early features such as verbal language skills and co-occurring intellectual disability (Magiati et al, 2014). However, the ability to forecast an autistic individual's likely functioning and support needs based on their presentation in childhood is limited (Magiati et al., 2014). On the whole, then, there is substantial variability among those with an autism diagnosis, in terms of their presentation and their support needs in the early years and beyond (Georgiades et al., 2013).

Autism is believed to be present from birth or to develop during early infancy (Dawson et al., 2023). Core social communication and RRB features are not yet evident in infants (Ozonoff et al., 2010). However, studies show differences in brain development between autistic and non-autistic infants from the first year of life (see Dawson et al., 2023 for a review). Early differences in motor skills and visual attention, as well as sleep difficulties, are present from as young as nine months in infants who are later diagnosed with autism, and these differences are believed to form part of a developmental cascade that leads to core autism features (Bradshaw et al., 2022). Nevertheless, the predictive validity of these early developmental differences is not sufficient to allow for accurate diagnosis of autism before core behavioural features emerge (Dawson et al., 2023). Of note, the earliest concerns that parents report for children later diagnosed with autism are also non-specific features, such as delays in motor and language skills, passivity, sleep problems, and extreme emotional dysregulation (Guinchat et al., 2012).

Core autism features across social communication and RRB domains then begin to emerge between 12 and 24 months (Landa et al., 2013; Ozonoff et al., 2010), with reliable diagnosis of autism possible from the age of 18 months (Benedetto et al., 2021). However, the average age of diagnosis in Australia is not until 5 years (Gibbs et al., 2019). To understand the reasons for the delay that commonly occurs between the emergence of autistic traits and formal diagnosis, it is important to first outline the typical pathway to autism diagnosis.

Autism Diagnosis in Australia

In Australia, the pathway to an autism diagnosis typically starts with a parent speaking with a health practitioner - such as a general medical practitioner or maternal and child health nurse - about differences or concerns that they have noted in their child's development (Bent et al., 2020). Following this first consultation, families may then be referred to a specialist, such as a paediatrician, psychologist, or speech pathologist, for further assessment (Bent et al., 2020). Australian guidelines recommend that this assessment should include a medical evaluation, a structured diagnostic assessment considering autism and other possible diagnoses, as well as an assessment of functioning to determine strengths and support needs (Goodall et al., 2023). Regarding the structured diagnostic assessment specifically, Australian guidelines (Goodall et al., 2023) indicate that a diagnosis of autism should be made using the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR; American Psychiatric Association,

2022) or the International Statistical Classification of Diseases and Related Health Problems (ICD-11; World Health Organization, 2019), using clinical judgement as well as standardised assessment tools (Goodall et al., 2023). The assessment should include observation of the child as well as interviews with family and other important people in the child's life (Goodall et al., 2023). There are no recommendations for specific assessment tools beyond these general guidelines, and so the actual components of a diagnostic assessment for autism may vary widely. For example, use of gold-standard autism assessment tools such as observation with the Autism Diagnostic Observation Schedule (Lord et al., 2012) and parent interview with the Autism Diagnostic Interview - Revised (Rutter et al., 2003) may comprise part of the diagnostic assessment, but is not required under the guidelines (Goodall et al., 2023). Research has yet to evaluate Australian parents' experiences of autism diagnosis since the most recent guidelines were published in 2023 (Goodall et al., 2023). However, previous Australian research has highlighted limited uptake of autism diagnostic guidelines by health practitioners (Randall et al., 2016; Taylor et al., 2016).

Delays in Autism Diagnosis in Australia

Research has also indicated that diagnosis of autism in Australia is delayed, in that the average autism diagnosis is given significantly later than parents first notice differences in their child's development (Bent et al., 2020; Gibbs et al., 2019). Some of this delay is accounted for by delays in the parent bringing the developmental differences they have noted to the attention of a health practitioner. Parents in an Australian sample retrospectively reported first having concerns regarding their child's development, on average, just before the child turned two years old. However, from the point of initial concern, an average of eight months elapsed before parents consulted a health practitioner (Gibbs et al., 2019). With the exception of rural families, this delay was not accounted for by a lack of access to healthcare practitioners (Gibbs et al., 2019). Otherwise, the reasons for parents' latency in first raising concerns with a health provider are not well understood, although low parental knowledge about early autism features, as well as stigma associated with an autism diagnosis, may contribute to delays (Locke et al., 2020).

Longer delays often occur between the time that the parent first raises concerns about their child's development with a health practitioner and the child's eventual autism diagnosis (Bent et al., 2020; Gibbs et al., 2019). The diagnostic process, from when parental concerns were first discussed with a health practitioner to the diagnosis, was found to take Australian families an average of 8 appointments (Bent et al., 2020). One study found the diagnostic process to take an average of 12 months (Bent et al., 2020), with another finding an average duration of 28 months (Gibbs et al., 2019). Long waitlists for specialist services were found to contribute to diagnostic delays; however, in many cases, diagnosis was delayed because health practitioners did not recommend that the child receive further assessment for autism (Gibbs et al., 2019). In fact, in a sample of children who ultimately received an autism diagnosis, only 27% were recommended to seek assessment for possible autism when parents first raised concerns with a health practitioner (Gibbs et al., 2019). Practitioners may choose not to recommend further assessment because they assess the child's development as being generally within the normal range, despite the parent raising concerns (Bent et al., 2020). In other cases, the health practitioner may note that the child is showing autistic traits and/or differences in development, but recommend the "wait and see" approach to monitor whether these differences fade or persist over time before referring for further assessment (Bent et al., 2020).

There are a number of brief parent-report screening tools available for practitioners to empirically assess whether further assessment for possible autism is indicated, such as the Modified Checklist for Autism in Toddlers (Robins et al., 2001) and the Social Attention and Communication Surveillance-Revised (Barbaro et al., 2022). Use of such screening tools has been associated with more timely diagnosis in the US context (Martinez et al., 2018). However, research has found low levels of use of these tools in Australian community settings, which likely contributes to diagnostic delays (Barbaro et al., 2023; Bent et al., 2020; Randall et al., 2016; Taylor et al., 2016). Delays in diagnosis are greatest in children with more subtle autism features or with any co-occurring diagnosis (Gibbs et al., 2019). This suggests that health practitioners may be confident referring for further assessment when children clearly present with specific autistic traits, but they may be more hesitant to suggest assessment where the presentation is less obvious or more complex. This is logical, but also problematic in that referral for further assessment is precisely what would allow for diagnostic clarification in these less clear or more complex cases. Professional hesitancy to refer for evaluation of autism, as well as limited use of the available screening tools that could support referral decisions, therefore appear to be major roadblocks to a timely diagnosis in Australia (Barbaro et al., 2023).

The research reviewed here focuses on the process of autism diagnosis in the Australian context in which the research for this thesis was conducted. However similar limitations of the diagnostic process have been reported around the world (Makino et al., 2021). Diagnosis of autism should by no means be rushed, and thorough evaluation to allow for accurate diagnosis is imperative (Reed et al., 2019). However, unnecessary delays, including hesitancy to even assess for potential autism, are problematic. Such delays add to parent stress and decrease satisfaction with the diagnostic process (Crane et al., 2018; Jashar et al., 2019; Moh and Magiati, 2012). Diagnostic delays also delay access to support, which is concerning given that earlier diagnosis of autism and access to relevant support is generally associated with better long-term prognosis (Daniolou et al., 2022; Elder et al., 2017; Franz et al., 2022; Fuller & Kaiser, 2020; Mandy et al., 2022).

Supports for Autistic Children and their Families

For many families, one of the key benefits of a formal autism diagnosis is that it allows access to targeted intervention and support (at least on paper, although parents do report ongoing difficulties accessing appropriate supports; Bent et al., 2020). Broadly, it has been recommended that early intervention should focus on improving the child's quality of life, reducing harmful behaviours, and supporting the parent and other key caregivers (Waddington et al., 2024), as well as building child and parent skills to set a foundation for positive long-term development (Hyman et al., 2020). Notably, the field is moving away from a focus on "curing" autism or reducing autistic traits, though building social communication skills and reducing the interference of autism features may be beneficial in improving quality of life (Dawson et al., 2022; Schuck et al., 2022). Within these broad recommendations, the significant heterogeneity in autism necessitates individualised goals that can guide treatment decisions, rather than a one-sized-fits-all approach (Zwaigenbaum et al., 2015). The nature of supports for autism that parents can and do access therefore vary significantly.

A recent meta-analysis, an update to Project AIM (Sandbank et al., 2020; Sandbank et al., 2023), found that the evidence base for many common supports and interventions for autism in childhood is limited to low quality studies. Amid this limited evidence base, stronger quality of evidence was found for a category of interventions known as Naturalistic Developmental Behavioural Interventions (NDBI), which embed strategies from both developmental and behavioural interventions within real-life contexts and routines (Sandbank et al., 2023; Schreibman et al., 2015). Though Project AIM did not examine whether parent involvement moderated the effectiveness of NDBI, the authors recommend that support for young autistic children should involve increasing parents' capacity to effectively support their child (Sandbank et al., 2023). In fact, research has consistently demonstrated the benefits of parent involvement in intervention for young autistic children (see Cheng et al., 2023; Klinger et al., 2021 for reviews). In considering the strength of this evidence, it is important to note that much of the research evaluating programs that involve parents in intervention for their autistic child rely on parent-reported outcome measures, which are likely to be influenced by expectancy effects and therefore may overestimate intervention benefits (Crank et al., 2021; Sandbank et al., 2023). There is a need for more robust intervention research which utilises masked, independent outcome assessment, such as observational data and multi-informant report. Nevertheless, on the basis of extant evidence, recent recommendations for supporting autistic children have consistently stated that intervention should actively involve the parent or other primary caregiver (Green et al., 2022; Maglione et al., 2012; Zwaigenbaum et al., 2015).

Involving the parent in intervention can be done through parent support programs that target parent outcomes such as parent mental health or knowledge about autism, as well as parent-mediated intervention (PMI) that targets child outcomes (Bearss et al., 2015). In PMI, the practitioner trains the parent in intervention strategies such that the child receives intervention through the parent instead of, or in addition to, directly from the practitioner (Schultz et al., 2011). The parent therefore acts as an agent of change in building the child's skills or reducing challenging behaviours (Bearss et al., 2015). This allows for the child to receive intervention throughout the day and in their everyday settings and routines (Zwaigenbaum et al., 2015). PMI can therefore support greater generalisation of parent and child skills to a wider variety of contexts (Sandbank et al., 2023; Zwaigenbaum et al., 2015), and stronger maintenance of gains (Green et al., 2022), as compared to interventions in which the practitioner works with the child only. Furthermore, PMI reduces the financial and time costs of intervention, as fewer therapist hours are required (Lord & Bishop, 2010).

Beyond improvements to child outcomes, PMI may also have some benefit to the parent themselves (Kulasinghe et al., 2023). While PMI can place additional burden on parents to learn and implement intervention strategies (Jurek et al., 2023), a recent meta-analysis showed that PMI can reduce parent stress (Kulasinghe et al., 2023). This meta-analysis found no significant benefit of PMI for parent depression or general mental health, however (Kulasinghe et al., 2023). Research has also found that PMI improves parent self-efficacy, as parents feel more capable of effectively supporting their child (Fante et al., 2024; Hohlfeld et al., 2018; Kurzrok et al., 2021). Overall, the available research suggests that actively involving parents in intervention for their autistic child through PMI can provide benefits to both parent and child.

Support for Autistic Children in Australia

Despite research demonstrating positive child and parent outcomes from PMI (Cheng et al, 2023; Kulasinghe et al., 2023), and recommendations for parent involvement in childhood autism supports (Green et al., 2022; Klinger et al., 2021; Maglione et al., 2012; Zwaigenbaum et al., 2015), most supports for autistic children in the Australian community context do not routinely include parents (Mazzucchelli et al., 2023; Pye et al., 2024). Notably, efforts to improve the standard of care for autistic children (that is, the support that is typically available and accessed in the community) based on research as well as stakeholder input are ongoing (Commonwealth of Australia Department of Social Services, 2024). At present, support for autistic children is predominantly funded through the National Disability Insurance Scheme (NDIS), particularly through the Early Childhood Early Intervention program for children under 9 years (National Disability Insurance Agency, 2025). The NDIS is commonly used to fund predominantly allied health supports, such as speech therapy and occupational therapy, for young autistic children (Pye et al., 2024). While these supports are vital as part of a broader early support program, the NDIS's focus on individual therapy provided directly to the child, with limited scope for family-centred supports, has been called into question (Gavidia-Payne et al., 2024; Gerhard & Grant, 2025; Mazzucchelli et al., 2023). Focusing on the child as the recipient of support means that parents are typically not able to access programs that may enhance their ability to care for their child or support their own well-being, such as mental health support, respite care, or even psychoeducation to help parents better understand autism (Gerhard & Grant, 2025). Significantly, guidelines are unclear as to whether parent support and PMI can be funded by the NDIS, meaning that most families are not reliably getting this gold standard evidence-based support (Mazzucchelli et al., 2023). By prioritising practitioner delivery of intervention directly to the child, the NDIS has moved away from the significant body of research emphasising the benefits of PMI and the importance of building parents' knowledge and skills so as to empower them to support their child's wellbeing and development (e.g., Zwaigenbaum et al., 2015).

Beyond the lack of family-centred support, additional concerns have been raised that the NDIS – developed primarily to meet the needs of adults with disability – may not be optimal for supporting young autistic children (Moore et al., 2019). Limitations of the NDIS for this population include long wait times for services (which detracts from the potential for early intervention), a focus on deficits, lack of regulation of providers, and minimal opportunities for multidisciplinary collaboration between service providers (Gavidia-Payne et al., 2024; Gerhard & Grant, 2025). The NDIS also requires parents to advocate for their child to receive funding, and to make decisions regarding which services to use their limited funding for, which places significant administrative burden on parents (Carey et al., 2021). While choice and control is identified as a key goal of the NDIS, parents generally feel that they do not have access to the information needed to enact this control with confidence (Gavidia-Payne, 2020; Gavidia-Payne et al., 2024). With these challenges in mind, researchers have suggested that the NDIS not only provides inadequate parent- and family-focused support, but may actually increase stress for parents of autistic children (Clark & Dissanayake, 2024; Gavidia-Payne, 2020).

Parent Adjustment to the Diagnosis of Autism for their Child

The process of diagnosis, as well as the provision of early supports, provide the backdrop to parents' adjustment to their child's autism diagnosis. Adjustment to diagnosis refers to parents' psychological response to their child's autism diagnosis, at the time of diagnosis and ongoing (Pianta & Marvin, 1993). Parents report a range of initial reactions to their child's autism diagnosis, including shock, grief at the perceived loss of the future they had envisioned for their child, worry about what the child's future will now be, and relief at having an explanation that helps them better understand the child (Fernández-Alcántara et al., 2016; Mansell & Morris, 2004; Mulligan et al., 2012). Parents may experience a mix of these emotions, leading to them simultaneously view the child's autism diagnosis as both a positive and negative (Anderberg & South, 2021). As noted below, the definition of adjustment to autism diagnosis varies across the literature. For the purposes of the current research, parental adjustment is defined as the process of working through these initial thoughts and feelings, and ongoing thoughts and feelings about the child's autism diagnosis, to work towards a realistic perception of what autism means for the child and family. Adjustment is considered to be an ongoing process that occurs over time (Negri & Castorina, 2014). The term 'level of adjustment' will be used in this thesis to refer to adjustment as measured at a single timepoint within this process. The term 'higher adjustment' will be used to refer to more optimal adjustment at a given point within this process, and 'lower adjustment' to less optimal adjustment at a given point within this process. Higher adjustment includes having a realistic perception of autism, which recognises the challenges and strengths associated with the child's autism as well as the child beyond the diagnosis, and balances hope with an awareness of current and potential future difficulties (Oppenheim et al., 2007; Pianta & Marvin, 1993). Lower adjustment includes (but is not limited to) parents experiencing denial or not believing that the child is autistic, blaming themselves or the child's other parent for the child's autism diagnosis, believing that the child's future is hopeless because they are autistic, or fixating on attempts to "cure" autism (Da Paz et al., 2018; Mire et al., 2018; Pianta & Marvin, 1993).

Understanding parent adjustment to their child's autism diagnosis is important because research suggests adjustment may contribute to other aspects of parent, child and family well-being. Parents with higher adjustment report better physical health (Reed & Osborne, 2019), and better mental health, including lower psychological distress, depression, anxiety and caregiving-related stress (Da Paz et al., 2018; Dolev et al., 2016; Jones et al., 2014; Vitale et al., 2023). Improvements in adjustment over time have also been associated with reductions in depressive symptoms, parenting stress and burden, and increased life satisfaction (Da Paz et al., 2018). Beyond the parent's own well-being, higher adjustment is believed to enhance the parent-child relationship (Oppenheim et al., 2009), and is associated with more positive and attuned interactions with children (Di Renzo et al., 2020; Dolev et al., 2016; Oppenheim et al., 2024). In fact, one study found increased stress to mediate the relation of lower adjustment to lower parental warmth and higher hostility towards the child (Chan et al., 2023). Wachtel and Carter (2008) showed adjustment to predict interaction quality while controlling for other factors that may influence parent-child interactions, such as child functioning and parental depression. This suggests that adjustment may play a specific role in parents' capacity to engage sensitively with their autistic child. This association of adjustment with sensitive parenting has been found across cultural contexts (Di Renzo et al., 2020; Dolev et al., 2016; Wachtel & Carter, 2008). Across the family system, higher parent adjustment has been associated with higher scores on family-level measures of well-being and quality of life (Papadopoulos et al., 2024). Taken together, these findings underscore the importance of facilitating parents' adjustment to their child's autism diagnosis.

Theoretical Models of Adjustment to Diagnosis

Several theoretical models have been proposed to explain the process of adjustment to diagnosis (Negri & Castorina, 2014). Broadly, researchers have drawn from cognitive models of coping, and from models of grief. Researchers have applied models of coping by conceptualising the child's autism diagnosis as a stressor which parents must cope with (e.g., McGrew & Keyes, 2014; Siman-Tov & Kaniel, 2011). Lazarus and Folkman's stress and coping model (1984) explains that responding to a major change first includes a preliminary appraisal of whether the change is good, bad, or neutral. In the context of adjustment to autism diagnosis, preliminary appraisal refers to parents' initial thoughts about the child's diagnosis. This is followed by secondary appraisal, which involves determining what to do about the change. Secondary appraisal can include problem-focused coping using strategies to resolve the stressor itself, as well as emotion-focused coping using strategies to shift one's emotional response to the stressor. Problem-focused coping in the context of autism diagnosis could involve practical steps such as seeking out services. Emotion-focused coping may include prayer or attempting to find a sense of meaning associated with the diagnosis (Negri & Castorina, 2014). Coping also includes ongoing reappraisal, since the use of coping strategies may in turn shift the parent's evaluation of the diagnosis. In this way, the stress and coping model conceptualises adjustment as a dynamic process in which cognitive appraisal (i.e., beliefs about the child's autism diagnosis) and coping strategies inform one another on an ongoing basis.

It has also been proposed that adjustment to diagnosis can be understood as a process of grief (see Bhaskaran et al., 2024 for a review). While parents do not experience an actual loss of their child, researchers suggest that receiving an autism diagnosis leads parents to grieve their idea of a neurotypical child and the life they had imagined for them (Bravo-Benítez et al., 2019; Corcoran et al., 2015; Gentles et al., 2020; Negri & Castorina, 2014). Research has therefore applied models of grief to understanding adjustment. This research has identified that the original staged models of grief are likely insufficient to explain adjustment to diagnosis (Negri & Castorina, 2014). Kübler-Ross' (1969) original staged model of grief in the context of bereavement, explained grief as the process of moving through the stages of denial, anger, bargaining, and depression, before eventually reaching the fifth stage of acceptance. Bowlby (1980) then developed the theory of loss and mourning, which considered grief specifically in the context of attachment relationships. In line with this, early research on parents' adjustment to their child's diagnosis of autism (e.g., Milshtein et al., 2010; Oppenheim et al., 2009) drew on literature on adjustment to other developmental conditions such as cerebral palsy, which conceptualised the diagnosis as a trauma to the parent-child attachment relationship (Marvin & Pianta, 1996). The theory of loss and mourning (Bowlby, 1980) was therefore applied to understand how parents adjust to the diagnosis. Bowlby (1980) defined adjustment to occur through the stages of numbing, yearning and searching for the lost figure, disorganisation and despair, and finally reorganisation. Reorganisation was conceptualised as the final stage, in which the parent's understanding of the situation shifts to accurately reflect reality so that the child's diagnosis is fully integrated into the parent's understanding of the child and their relationship with the child (Bowlby, 1980). Reorganisation has also been referred to as resolution of the diagnosis (Marvin & Pianta, 1996).

However, efforts to apply grief models have led to recognition that the process of adjustment to autism diagnosis is likely more complex than can be captured through a simple stage model (Negri & Castorina, 2014). Unlike experiences of bereavement, parents adjusting to their child's autism diagnosis do not experience a finite loss or change. Rather, they are adjusting to a situation that continues to change as they adjust, in that the child continues to change. The models of chronic sorrow (Copley & Bodensteiner, 1987; Olshansky, 1962) and ambiguous loss (Boss, 1999) have been applied to better capture adjustment to diagnosis as an ongoing process. The model of chronic sorrow (Copley & Bodensteiner, 1987; Olshansky, 1962) applies Kübler-Ross' (1969) five stages, but suggests that most parents are not able to reach the final stage of acceptance because the grief response starts anew at major milestones. According to the model, major life events such as the child starting high school or turning 18 can act as reminders that the child's life is different than the parent had expected it would be (Bravo-Benítez et al., 2019). The parent must therefore repeatedly adjust to the diagnosis as the situation they are adjusting to changes over time. While the chronic sorrow model suggests that parents are unlikely to reach a state of acceptance, the model does suggest an optimal outcome known as 'focusing outwards.' This ability to focus outwards involves the parent integrating the child and their role as a parent into their broader lives, rather than their life being focused solely on the parenting role (Copley & Bodensteiner, 1987).

Adjustment is increasingly understood to be a non-linear process – parents might move through stages in a variable order, or might oscillate between stages (Rabba et al., 2019). O'Brien (2007) therefore suggested that the theory of ambiguous loss (Boss, 1999) may better explain parent adjustment to autism diagnosis as a complex, iterative process, in comparison to other grief models. Ambiguous loss theory explains that the most challenging losses or stressors to adapt to are those which are ambiguous or uncertain (Boss, 1999). Boss identified five aspects that make a stressor ambiguous, all of which O'Brien (2007) discussed as being relevant to autism. First is limited certainty in the diagnosis itself – the fact that autism is diagnosed through clinical decision-making without an objective biomarker may lead parents to question the validity of the diagnosis (Gentles et al., 2020; O'Brien, 2007). Second is the lack of clarity for parents regarding what they are adjusting to – autism is a spectrum, and so the diagnostic label provides little certainty regarding what to expect in terms of the child's level of functioning or support needs (Lombardo & Mandelli, 2022; Wiggins et al., 2021). Predicting what the child's life will look like into adulthood is particularly challenging (Magiati et al., 2014). Third, most autistic children have notable variation in their functioning across domains, and day-to-day (O'Brien, 2007). For instance, a child may present with strong verbal language but may struggle notably with self-care activities, or may become unable to use their verbal language when distressed. Fourth, autism being an 'invisible disability', in that it does not have an obvious physical phenotype, can lead others to questioning or downplaying the diagnosis, creating confusion for parents and making it harder to get support (Broomhead, 2019). Fifth, given that social communication differences are core to autism, the parent may fear that the diagnosis will interfere with emotional relationships (O'Brien, 2007). This can include parent worries about their own relationship with the child (Keenan et al., 2016), as well as about judgement and exclusion from others because of the child's diagnosis (Kinnear et al., 2016; Woodgate et al., 2018). Taking into account these sources of ambiguity in autism, ambiguous loss theory explains that adjusting to this unclear future can engender additional confusion and distress above and beyond typical grief (O'Brien, 2007).

Adjustment to ambiguous loss is seen to involve normalising and accepting the ambiguity, reconstructing identity and revising attachment so that parents can build a relationship with the child they do have rather than fixating on the child they had imagined, and adjusting mastery and developing new hope such that the parent sets goals that are realistic for their own child (Boss, 2006). Notably, these are not seen as stages the parent moves through, but rather a set of goals for adjustment to ambiguous loss (Boss, 2007). Some researchers have explained reaching these goals to be a gradual process in which the parent oscillates between adjustment and barriers to adjustment (Alimohamadi et al., 2024; Fernández-Alcántara et al., 2016). Beyond this, there has been limited research to explain the process by which parents work towards adjustment to ambiguous loss.

Ambiguous loss theory is utilised as the theoretical perspective underpinning the qualitative component of this thesis. This theory was selected because, in comparison to staged models of grief, it better reflects recent research which suggests that adjustment is a non-linear process (e.g., Poslawsky et al., 2014; Rabba et al., 2019; Yirmiya et al., 2015). Ambiguous loss theory also better captures the fact that many parents do adjust well to their child's autism diagnosis (Poslawsky et al., 2014), which is not consistent with the model of chronic sorrow.

Looking across the theoretical models of adjustment to diagnosis presented here highlights inconsistencies in how adjustment is understood within the literature. Coping models explain the cognitive processes through which parents adjust, but provide less insight into the overall process of adjustment over time. Grief models, on the other hand, describe this overarching process of adjustment, but do not discuss the actual mechanisms of this process. These diverging theoretical perspectives appear to underpin inconsistencies in how adjustment is defined and measured across the literature.

Challenges in Defining and Measuring Adjustment to Diagnosis

Stemming from varying theoretical perspectives, a number of differing constructs (e.g., attitudes towards autism, grief, coping) are discussed in the literature as 'adjustment to diagnosis'. Researchers in the field are yet to acknowledge this inconsistency or define what does and does not fall under the construct of adjustment to diagnosis. In turn, inconsistencies in the definition beget measurement issues. Without a clear conceptual definition of adjustment, it is not clear whether adjustment studies are actually measuring the same construct.

Confusion in the definition is compounded by the fact that the term 'adjustment to diagnosis' is used in the literature to refer both to the overall process as well as the point of that process that a parent is at, at a given time. Accordingly, some measures will ask parents to rate only their current attitudes towards their child's diagnosis (e.g., Caregiver Grief Scale; Meichsner et al., 2016) whereas other measures will ask parents to reflect on changes in their attitudes towards the diagnosis over time (e.g., Reaction to Diagnosis Interview; Pianta &

Marvin, 1993). Some include items assessing both current attitudes and changes in attitudes over time within the same measure, confusing the concepts of adjustment as a process and an outcome.

Variability in the definition and measurement of adjustment to autism diagnosis is problematic, in that it makes it difficult to compare results across studies. However the extent of variability in definition and measures is not yet known. The first aim of this research is therefore to systematically identify how adjustment to autism diagnosis has been defined and measured in research to date.

Limitations of Longitudinal Adjustment Research and Understanding Adjustment as a Process

Researchers' understanding of the process by which parents adjust to their child's autism diagnosis is notably limited by the lack of longitudinal research in this area. In particular, the small number of studies that have looked at changes in adjustment over time have included only two timepoints (Da Paz et al., 2018; Papadopoulos et al., 2024; Poslawsky et al., 2014; Yirmiya et al., 2015), precluding an understanding of the process by which parents adjustment or of the longer-term trajectory of parent adjustment to autism diagnosis.

The small number of studies exploring naturally-occurring changes in adjustment to autism diagnosis over time have found parents' adjustment to mostly remain stable–- that is, parents with higher adjustment typically maintained higher adjustment, whereas parents who were struggling with adjustment continued to show lower adjustment at follow-up ranging from seven months to three years later (Papadopoulos et al., 2024; Poslawsky et al., 2014; Yirmiya et al., 2015). Poslawsky and colleagues (2014) found that 83% of parents remained stable in their adjustment 7 months after the initial measurement, while Yirmiya and colleagues (2015) found 67% of mothers and 74% of fathers to remain stable even 3 years after initial measurement. Less than half of the mothers with low adjustment at the first timepoint, and less than a third of fathers with initial low adjustment, reported high adjustment three years later (Yirmiya et al., 2015). There were as many fathers who shifted from high to low adjustment as who shifted from low to high, and for mothers, a smaller 15% of those who initially reported high adjustment shifted to low adjustment three years later. These studies suggest a relative stability in adjustment for most parents, which may conflict with theoretical models proposing adjustment as a dynamic process that evolves over time. In line with this, research consistently shows that time since diagnosis is not a reliable predictor of level of adjustment (e.g., Dolev et al., 2016; Grogan et al., 2023; Naicker et al., 2024; Zhang et al., 2023). However, with limited longitudinal research on adjustment to autism diagnosis, the process by which adjustment does (or does not) evolve over time, and the barriers and facilitators to this process, are not well understood. The apparent stability of low adjustment may also suggest a need for further support when parents experience difficulties with adjusting to their child's diagnosis.

Insights into the trajectory of adjustment over time can also be gained from qualitative research. Studies have shown that parents describe their adjustment to fluctuate over time (Fernández-Alcántara et al., 2016; Rabba et al., 2019), rather than either remaining stable or changing in a linear fashion. This non-linear progression of adjustment appears to align with the ambiguous loss model. However, further research is needed to better understand parent perspectives on the process of adjustment to autism diagnosis. As such, one aim of the current research is to examine parent perspectives on their adjustment 'journey', or their experience of adjustment to diagnosis over time.

Factors Influencing Adjustment to Autism Diagnosis

Research examining predictors of parent adjustment to autism diagnosis–- including parent and child factors–- has had notably inconsistent findings. This variability is likely to some extent accounted for by the discrepancies in definition and measurement of adjustment noted above. With regards to child autism features, a number of studies found that parents had higher adjustment when the child had lower autism features (e.g., Dolev et al., 2016; Ferenc et al., 2023; Rosenbrock et al., 2021b), while others did not find a significant association (e.g., Grogan et al., 2023; Oppenheim et al., 2024; Reed et al., 2019). Da Paz and colleagues (2018) looked at the relation of autism features to three subscales of adjustment, finding that higher child autism features were related to greater despair but also greater acceptance of the diagnosis (Da Paz et al., 2018). Again, this suggests that inconsistencies in the association found between child autism features and parent adjustment may reflect differences in the facet of adjustment being measured or the way adjustment is defined between studies. Other child features such as child externalizing behaviour, IQ, and chronological age, have also shown inconsistent associations with parent adjustment (e.g., Dolev et al., 2016; Ferenc et al., 2023; Mohammad et al., 2022; Rosenbrock et al., 2021b; Wayment & Brookshire, 2018). Of note, child adaptive behaviour has been found across multiple studies to have no significant association with parent adjustment (e.g., Dolev et al., 2016; Leccisco et al., 2013; Milshtein et al., 2010; Poslawsky et al., 2014).

The role of parent factors in adjustment to autism diagnosis has also been explored. Adjustment does not seem to be influenced by parent demographic factors such as age, education, or marital status (e.g., Dolev et al., 2016; Mohammad et al., 2022; Sher-Censor et al., 2017). Several studies conducted in China have identified greater adjustment difficulties in families with lower household income (Feng et al., 2023; Su et al., 2013; Wang et al., 2024; Zhang et al., 2023). However, studies in other cultural groups have generally found no significant relationship between household income and adjustment to autism diagnosis (e.g., Dolev et al., 2016; Ekas et al., 2016; Montoya et al., 2024), with the exception of Wayment and Brookshir"s (2018) findings that lower household income was associated with higher adjustment (i.e., the opposite direction of effect than was reported in the Chinese samples described above) in a sample of US mothers. Taken together, these studies suggest that sociodemographic factors may interact with cultural attitudes towards autism, as discussed below.

Adjustment is more consistently associated with aspects of parents' broader mental health and wellbeing. Parents who report experiencing previous mental health challenges have lower adjustment (Wayment & Brookshire, 2018), as do parents experiencing physical illness (Abd Latif et al., 2023). Studies have also found that parents who are unemployed or employed part time report higher adjustment as compared to parents who are employed full-time (Qin et al,. 2021; Samios et al., 2008; Vitale et al., 2023). Parental employment may be conceptualised as a stressor. Employment also likely decreases the time that parents have available to care for and engage with their child, which is in itself a predictor of higher adjustment (Qin et al., 2021). However, Feng and colleagues (2022) found no relationship between parent employment and adjustment. Parents' general approach to coping with stressors also appears to play a role in adjustment, with parents who employ more problem-focused coping strategies (such as making plans to manage the stressor or reframing the stressor in a more positive light) reporting higher adjustment than parents who use mostly emotion-focused coping strategies (such as denial or focusing on the emotions associated with the stressor; Abbeduto et al., 2004). Access to informal supports such as social support (Alon, 2019; Wayment & Brookshire, 2018) and religious affiliation (Alon, 2019; Samios et al., 2008; Wayment & Brookshire, 2018; White, 2009) also appears to bolster adjustment.

Experiences of adjustment may also differ between mothers and fathers. In a longitudinal study, the number of mothers with high adjustment increased significantly after three years, whereas the number of fathers with high adjustment remained stable over this period (Yirmiya et al., 2015). In fact, while adjustment improved for 13% of fathers, another 13% seemed to get worse in that their adjustment shifted from high to low across the three years (Yirmiya et al., 2015). Several studies have also found that fathers perceive fewer benefits of parenting an autistic child as compared to mothers (Ekas et al., 2015; Samios et al., 2009; Vitale et al., 2023). It is important to note that fathers of autistic children are more likely to be employed outside of the home as compared to mothers, with mothers more likely to take on primary caring responsibilities (Blackwell, 2025; Hartley et al., 2014). These gendered differences in the division of labour may impact fathers' experiences of adjustment to diagnosis, given that research has identified higher adjustment in parents who work fewer hours outside the home (Qin et al., 2021; Vitale et al., 2023), and spend more time caring for their autistic child (Qin et al., 2021).

Taken together, these findings suggest that the journey of adjustment to autism diagnosis may be different for fathers as compared with mothers. Our understanding of the nature of this difference, and of how fathers adjust to their child's autism diagnosis, remains limited because the majority of research looking at parent adjustment has either exclusively or predominantly included mothers (Braunstein et al., 2013). In fact, a recent systematic review of fathers' experiences of their child's autism diagnosis found that only nine studies on the topic had been conducted (Brown et al., 2021a). Fathers are similarly underrepresented in autism research more broadly, and so the field lacks an adequate understanding of fathers' perceptions, preferences, and needs (Factor et al., 2019; Rankin et al., 2019). As a result, fathers may feel excluded from services, or feel that the available services do not meet their needs (Paynter et al., 2018; Seymour et al., 2020). Lower engagement with services can be detrimental to fathers' own mental health and well-being (Seymour et al., 2020), and can also perpetuate stress and burden for mothers (Courcy & de Rivières, 2017; Flippin & Crais, 2011). Father-inclusive research is an important step towards understanding how services can best support both mothers and fathers of autistic children (Flippin & Crais, 2011). As such, the current research aims to improve understanding of adjustment to autism diagnosis for fathers by including them in the measurement process and examining differences in adjustment between mothers and fathers.

Given the heritability of autism (Tick et al., 2016), parents of autistic children are more likely than parents of neurotypical children to be autistic or to display sub-clinical autistic traits (El-Bouhali-Abdellaoui et al., 2025; Sasson et al., 2013). However, only one study to date has considered whether parents' own neurodivergence may impact their adjustment to their child's autism diagnosis, finding that it did not (Milshtein et al., 2010). Parents' knowledge and beliefs about autism, though, do appear to play a role in adjustment. Many parents report having inaccurate beliefs about autism (Nissenbaum et al., 2002), which can hinder adjustment (Gentles et al., 2020; Wayment & Brookshire, 2018). Accordingly, parents who have had more experience with autism prior to the child's diagnosis may be able to more readily adjust, especially if these prior experiences have been positive (Gentles et al., 2020).

Beyond parents' own knowledge and beliefs about autism, others' attitudes and broader cultural beliefs can play a role in parents' adjustment. Parents describe disclosing their child's autism diagnosis to important people in their life, such as extended family, as an important part of their adjustment process (Rabba et al., 2019); however, negative reactions from others such as denial or blaming the parent can make it harder to adjust (Blanche et al., 2015; Li et al., 2025; Neely-Barnes et al., 2011; Rabba et al., 2019). Parents' experiences of stigma are likely to be particularly detrimental to adjustment to their child's autism diagnosis because they can lead to social isolation and undermine social support (Blanche et al., 2015), which is, in itself, an important predictor of adjustment (Alon, 2019; Wayment & Brookshire, 2018). Cultural values and beliefs about autism can inform parents' experiences of negative reactions or stigma from others (Blanche et al., 2015; Naicker et al., 2023). For example, parents from cultural groups that perceive autism to be caused by supernatural forces, or that deny the legitimacy of autism and blame the child's challenges on poor parenting, may experience greater stigma (see de Leeuw et al., 2020 for a review of cultural and contextual factors). Cross-cultural differences in attitudes towards autism may therefore underpin the differences seen in adjustment between different cultural groups (Abd Latif et al., 2023; Ekas et al., 2019; Poslawsky et al., 2014; Wachtel & Carter, 2008). Furthermore, findings that factors such as parent education and household income impact experiences of adjustment in some cultural groups but not others (e.g., Feng et al., 2023; Montoya et al., 2024; Poslawsky et al., 2014; Su et al., 2013) suggests a possible interaction of cultural and sociodemographic factors. It may be that these sociodemographic factors influence the extent to which parents, as well as their broader community, endorse more traditional values and culturally-bound beliefs about autism (Wang et al., 2023; Yu et al., 2020), although research is needed to explore these relations in a broader range of cultural groups.

Overall, our understanding of barriers, facilitators and predictors of adjustment remains somewhat limited by inconsistent findings. On the whole, there is not compelling evidence that child factors such as autism features or adaptive functioning consistently impact parents' adjustment. Parent factors, including coping styles and broader mental health, may be stronger predictors of adjustment, with possible differences in adjustment between mothers and fathers. Cultural attitudes and stigma towards autism may also shape parents' experience of adjustment by influencing parents' own knowledge and beliefs about autism, as well as their ability to access social support. With such inconsistent findings regarding the barriers and facilitators of adjustment, our understanding of how best to support parents' adjustment is limited. Thus, one aim of the current research is to examine parent perspectives on their adjustment support needs.

Intervention to Support Adjustment to Diagnosis

At present, support for parental adjustment is not part of standard post-diagnosis care. Yet, parents report needing more support to adjust to their child's autism diagnosis than they typically receive (Makino et al., 2021). As such, a recent article proposing a pathway of supports for young autistic children identified that supports for parent and family adjustment are the key need around the time of diagnosis (Green et al., 2022). To meet this need, researchers need to identify how best to deliver support for parent adjustment. Broadly, there are two main approaches that warrant consideration for supporting parent adjustment: targeted interventions, which focus specifically on facilitating adjustment; or broad interventions, which may improve adjustment as secondary to a wider set of outcomes such as child behaviour and development.

Evidence that targeted interventions can facilitate parent adjustment to autism diagnosis is emerging. Several targeted interventions have recently been developed or adapted, drawing on models of support for complicated grief (Bravo-Benítez et al., 2024) or modalities including Acceptance and Commitment Therapy (ACT; Hayes et al., 2012; Leadbitter et al., 2025) and mindfulness-based cognitive therapy (Lodder et al., 2020; Lunsky et al., 2021; Segal et al., 2013). Most targeted interventions for adjustment have also included psychoeducation to build parents' understanding of autism or of the adjustment process (Anthony et al., 2020; Leadbitter et al., 2025; Lodder et al., 2020; Yang et al., 2024). Several of these targeted interventions have demonstrated effectiveness in supporting parent adjustment (Bravo-Benítez et al., 2024; Leadbitter et al., 2025; Lodder et al., 2020). Of note, however, this research suggests that targeted intervention for parent adjustment is not sufficient to improve child outcomes (Leadbitter et al., 2025). It is unclear, however, whether the converse is true; broader evidence-based interventions, may support improvements in parental adjustment without the need to target it specifically in the intervention.

A broad intervention may be able to facilitate adjustment to diagnosis alongside other outcomes, such as improvements in child behaviour or social communication. If sufficient to support adjustment, a broad intervention would allow for greater parsimony, and likely improved intervention reach, as compared to a targeted adjustment intervention. Parsimony in intervention is important for dissemination, and for feasibility and acceptability to parents. From the research and clinical perspective, there are significant time and financial costs associated with evaluating, scaling and disseminating new programs (Dingfelder & Mandell, 2011). Researchers therefore need to understand whether existing widely-available interventions are sufficient to support adjustment to diagnosis, before investing in novel approaches. With a goal of supporting parents, it is also important to recognise that parents of autistic children tend to participate in or coordinate a large number of supports for their child, and can experience stress and burnout due to these demands (Gentles et al., 2019; Picardi et al., 2018; Vohra et al., 2013). Many parents may therefore find it less feasible or desirable to participate in targeted support for their own adjustment (Chen et al., 2023). It may be the case that less is more in supporting adjustment for these parents.

Broad interventions may therefore also allow for greater access to adjustment support as compared to targeted, parent-focused interventions. With limited financial and time resources, parents of autistic children may prioritise broad interventions which can directly support their child over parent-focused supports. Fathers in particular are less likely to engage with parent-focused supports (Paynter et al., 2018). Furthermore, we have limited knowledge of how to identify when a parent is in need of support for adjustment. Parents, and indeed health practitioners, may therefore be less likely to recognise when support is necessary. In our Australian context specifically, most parents would in fact likely be unable to access targeted adjustment support without significant out-of-pocket costs, given that NDIS funding focuses on supports for the child (Gerhard & Grant, 2025). If effective, supporting adjustment through a broad, child-focused intervention may be a means of overcoming these potential barriers to targeted adjustment support.

There is a clear need to better understand how to most effectively support parents' adjustment to their child's autism diagnosis. However, prior to the current research, a systematic review of the available interventions for adjustment and their effectiveness has not been conducted. The state of the evidence across targeted and broad interventions therefore remains unknown. Bringing together the available evidence across interventions is an important first step towards clinical recommendations for post-diagnosis support. The current research therefore presents a systematic review to identify the available interventions for parent adjustment and their effectiveness.

Adjustment and Parent-Mediated Intervention

Given that PMI is recommended as a core early support for autistic children and their families, it warrants consideration as a broad evidence-based intervention that may also benefit adjustment. In fact, there are several components of PMI that may make it conducive to supporting adjustment, including parent skill-building, psychoeducation, and parent-focused strategies. As such, the potential for PMI to improve parent adjustment warrants further consideration. However, a potential barrier to supporting adjustment through a broad intervention such as PMI is that parents' adjustment may actually influence their involvement in the intervention. There may therefore be a more complex interaction of adjustment and PMI engagement, completion, or outcomes. The potential effect of PMI on adjustment, of adjustment on PMI, and the interaction of the two are reviewed here.

PMI may facilitate adjustment by building parents' skills in supporting their child's development and reducing challenging child behaviours (Bearss et al., 2015). The resulting improvements in their child may reduce parents' stress (Kulasinghe et al., 2023), and help them to see their child and their diagnosis more positively, thus facilitating adjustment to diagnosis. Externalising behaviours, in particular, are one of the strongest contributors to stress and caregiver burden for parents of autistic children (Bradshaw et al., 2021; Olson et al., 2022). Parents also report child externalising behaviours to be a key precipitant for negative reactions from others, which can hinder adjustment (Blanche et al., 2015; Neely-Barnes et al., 2011).

Child social and communication challenges can also contribute to parent stress and strain (Bradshaw et al., 2021; Olson et al., 2022; Stuart & McGrew, 2009). As such, equipping parents with strategies to reduce externalising behaviour and improve child social communication through PMI may reduce stress and facilitate adjustment (Kulashinge et al., 2023). It is important to note that child autism features and challenging behaviours are not reliable predictors of parent adjustment specifically (e.g., Dolev et al., 2016; Ferenc et al., 2023). However, parents' adjustment may depend less on the child's actual level of functioning, and more on how this functioning changes over time. Seeing improvements in the child may be particularly conducive to the parent feeling more positive about the child's prognosis. In line with this, parents have described taking practical steps to support their child, such as engaging in intervention, to facilitate their adjustment (Downes et al., 2020; Rabba et al., 2019). Considering the theory of adjustment to ambiguous loss, improvement in parent skills and child functioning through PMI may facilitate adjustment by reducing uncertainty.

Although PMI focuses on parent skill development, it can often include foundational psychoeducation about autism (Bearss et al., 2015), which may also contribute to adjustment. Notably, psychoeducation is the most common component across targeted adjustment interventions (Anthony et al., 2020; Leadbitter et al., 2025; Lodder et al., 2020; Yang et al., 2024). Psychoeducation can dispel inaccurate beliefs about autism that hinder adjustment (Gentles et al., 2020). Accordingly, parents describe that improving their knowledge about autism supports adjustment (Legg & Tickle, 2019). Psychoeducation as a component of PMI may therefore facilitate adjustment to diagnosis.

Beyond the potential benefit for adjustment from parent skill development and psychoeducation, there is also the potential for PMI to improve adjustment through parent-focused strategies. There is increasing recognition in the field that support for parent wellbeing should be built into PMI (Rosenbrock et al., 2021a; Wainer et al., 2017). Recommendations for addressing parent wellbeing (without overburdening parents and providers with significant additional content) suggest that providers may incorporate strategies from evidence-based treatments such as Cognitive Behaviour Therapy (CBT; Beck, 2011) or Acceptance and Commitment Therapy (ACT; Hayes et al., 2012) into PMI (Lushin & O'Brien, 2016; Rosenbrock et al., 2021a). Preliminary research suggests that incorporating ACT strategies into PMI can be feasible and effective in improving parent mental health outcomes as well as child behaviour (Andrews et al., 2022; Pennefather et al., 2018). The effects on adjustment are yet to be evaluated. However, CBT and ACT are included in many of the targeted adjustment interventions (Leadbitter et al., 2025; Lodder et al., 2020; Lunsky et al., 2021). It is therefore feasible that integrating components of these treatments into PMI may in itself support adjustment, without the need for a standalone targeted intervention. For instance, clinicians may use cognitive reframing strategies to shift a parent belief such as 'my child's autism diagnosis means that they will never make progress in learning skills', and can draw on examples of the child's progress during the intervention as evidence against the belief. In short, PMI may facilitate adjustment through parent skills development, psychoeducation about autism, and integration of parent-focused strategies.

The relationship of PMI and adjustment is likely more complicated than a simple positive intervention effect, however. Parents' adjustment to their child's diagnosis is part of the wider context that may influence their decision to access an intervention such as PMI and shape their engagement when they do so (Gentles et al., 2019). In qualitative work, parents have described that struggling with adjustment to their child's diagnosis can be overwhelming (Abbott et al., 2012; Rabba et al., 2019), which may make it hard to engage in and complete (as opposed to drop out of) programs such as PMI. However, research has yet to assess the relation of adjustment to PMI engagement or completion. The role of adjustment warrants consideration, in light of research showing that other parent factors such as stress and depression can undermine parent engagement in intervention for autism (Ingersoll & Berger, 2015; Rovane et al., 2020). On top of this, parents with low adjustment to their child's autism diagnosis may hold maladaptive beliefs about autism that interfere with accessing, actively engaging in, and completing PMI (Morrissey-Kane & Prinz, 1999; Nock & Kazdin, 2001; Rovane et al., 2020). For example, parents who believe that autism means their child cannot develop reciprocal social relationships may be less motivated to access or engage in PMI focused on building social communication skills, or may drop out before completing the intervention.

Looking across the extant research therefore suggests a need to consider a complex, reciprocal influence of adjustment and PMI. From the outset, adjustment may play a role in whether parents decide to access a PMI. The transtheoretical model of behaviour change (Prochaska & Veliser, 1997) identified that recognising a need and potential for change (contemplation) is the necessary precursor to planning for change, such as enrolling in intervention. Gentles and colleagues (2019) looked more specifically at the processes underlying readiness for intervention in parents of autistic children. They identified 'coming to understand the child has autism' to be the necessary first step before parents are able to access autism-related supports (Gentles et al., 2019, p. 14). If a parent is struggling to come to terms with the fact that their child is autistic (i.e., experiencing denial of the diagnosis), they are unlikely to see an autism-focused PMI as necessary or appropriate for their child (Gentles et al., 2019). Alternatively, parents with low adjustment may recognise that the child is autistic, but remain stuck in their emotional reaction to the diagnosis, too overwhelmed to find and access a PMI (Gentles et al., 2019; Rabba et al., 2019). On the other hand, parents who recognise that their child is autistic but have low adjustment to the diagnosis may be eager to access an evidence-based intervention that they believe will "fix" the child (Gentles et al., 2019). From the outset, adjustment may play a complex role in readiness for intervention, and therefore in parents' decision and capacity to access a PMI.

Then, when parents begin a PMI, they bring the emotions and cognitions of adjustment into the program with them. Again, these may either hinder or help the parent's engagement and capacity to complete (rather than drop out from) PMI, and in turn the outcomes of the PMI for their child (Gulsrud et al, 2016; Kazdin, 1996). Overwhelming negative emotions and maladaptive cognitions may become barriers to regular session attendance, skill acquisition, or between-session practice of skills with the child. These barriers may also lead parents to drop out prior to completing the PMI (Kazdin, 1996). Conversely, low adjustment may create motivation for change, which can drive parents to engage with PMI (Gentles et al., 2019). Parents with high adjustment may also have beliefs that could interfere with PMI engagement, such as being content for the child to develop at their own pace without perceiving a need for intervention. PMI engagement impacts the success of the intervention with regards to child outcomes (Gulsrud et al., 2016). As such, if parents' adjustment impacts their engagement in PMI, it may also influence child outcomes from PMI.

The complexity of how adjustment and PMI may influence one another increases as the parent progresses through the intervention. When the parent sees improvement in the child as a result of the PMI, this may support their adjustment (Gentles et al., 2019). For some parents, this may create a positive feedback loop: positive adjustment may support engagement in the PMI and therefore improvement in the child, which in turn supports further adjustment, and so on. However, if adjustment is important for engagement in a PMI, parents who are struggling to adjust may be less likely to see the child make progress. Parents with low adjustment may therefore remain stuck, experiencing limited benefit of PMI for child functioning or adjustment. Parents struggling with adjustment may also be more likely to drop out early from the PMI, and therefore not get the full benefit of the program with regards to parent skill acquisition or child outcomes (Kazdin, 1996). Alternatively, progress may confuse parents and hinder adjustment – for example, if the parent initially sought an autism evaluation because their child was not communicating verbally, and the child then starts to speak as a result of PMI, parents may question the child's autism diagnosis. This may also lead to lower engagement or premature dropout, if the parent perceives that the program is no longer necessary after seeing initial benefit (Kazdin, 1996).

Considering these alternatives highlights the complexity of adjustment in the context of PMI. That is, by participating in PMI, parents may be adjusting to the child's diagnosis at the same time as actively changing the child's functioning and therefore the situation that they are adjusting to. However, research examining adjustment in the context of PMI is limited to one study (Grogan et al., 2023). This study identified no effect of pre-treatment adjustment on PMI strategy use, but did not assess its effect on PMI engagement or outcomes, nor the effect of the PMI on adjustment. Therefore, there has been no research to date looking at both possible directions of influence (i.e., effects of PMI on adjustment and effects of adjustment on PMI) in the same study. To address this gap, this thesis aims to evaluate adjustment in the context of PMI. Specific aims are to evaluate whether PMI leads to improvements in parent adjustment to autism diagnosis relative to a waitlist control condition, and whether parents' pre-treatment adjustment to their child's autism diagnosis predicts treatment dropout, engagement or outcomes.

Parent perspectives on adjustment in the context of PMI add important nuance beyond what can be gleaned from quantitative evaluation of adjustment and PMI outcomes. Situating PMI within parents' larger journey of adjustment can also provide more general insights into how to support adjustment to diagnosis. However, there has, as yet, been no qualitative research exploring experiences of adjustment specifically for parents who have completed a PMI. As such, the final aim of the current research is to use qualitative methodology to develop a deeper understanding of parents' experiences of adjustment to autism diagnosis. This includes examining parent perceptions of whether and how PMI contributed to their overall journey of adjustment to autism diagnosis as well as identifying additional adjustment support needs.

It is important to note that PMI is a diverse category of interventions, and so each PMI may include different components that may support adjustment. The specific PMI utilised in this research is ParentWorks Spectrum (PWS; Leonard et al., 2025). PWS is a 12-15 session therapist-assisted telehealth intervention. It is comprised of three modules focusing on: 1) managing challenging behaviour; 2) teaching child social communication and other skills; and 3) improving parent mental health and well-being. The modules were adapted from existing PMI for externalising behaviour problems (Dadds & Hawes, 2006) and autism (Green et al., 2010). Psychoeducation about autism is also integrated throughout the modules. The intervention is delivered by a therapist to one or both parents, with father inclusivity strategies used to support the involvement of both parents where possible (Lechowicz et al., 2019). Most sessions are parent-only, though parents can opt for the child to attend the session(s) focusing on child-led play. The intervention also includes homework to support skill practice and generalisation between sessions. PWS has been implemented with fidelity, and has demonstrated significant improvements in parent and clinician reports of child externalizing behaviour and parent reports of autism features, as well as parent reports of their anxiety, stress and sense of competence, relative to a waitlist control condition (Dadds et al., 2025). The synergistic approach targeting child and parent outcomes within the one intervention (Leonard et al., 2025) may make PWS particularly well placed to support parent adjustment to autism diagnosis without requiring targeted adjustment support.

Overview of Studies Reported in this Thesis

The thesis reported here presents three studies, which were written as articles for publication in a peer-reviewed journal. Because the three studies have each been written as for publication, there may be some general repetition in the background provided within each study. The research reported in each study is unique, and the studies together form a cohesive body of work. Together, these studies address an overall aim to improve understanding of how to support parents' adjustment to their child's diagnosis of autism. This work directly addresses key gaps in the literature identified throughout this Introduction.

Our current understanding of adjustment to autism diagnosis, and how to effectively support it, is limited by inconsistencies in the definition and measurement of adjustment across studies. Therefore, Study 1 reports on a systematic review of measures of caregiver adjustment to child autism diagnosis. Note that in Study 1, the broader term 'caregiver' was used to encompass research on adjustment for parents and other primary caregivers. Specific aims of Study 1 are to identify measures of caregiver adjustment to autism diagnosis (Aim 1.1a), to document the constructs each claims to measure (Aim 1.1b) and to identify the reported psychometric properties of the measures (Aim 1.1c).

Study 1 also addresses gaps in our knowledge of supports for adjustment. The review aims to identify interventions for which caregiver adjustment has been evaluated as an outcome (Aim 1.2a) and the effect of these interventions on caregiver adjustment to autism diagnosis (Aim 1.2b). Building on the gap identified in Study 1 – that research has yet to examine the effectiveness of PMIs on parent adjustment - Study 2 and 3 present a mixed-methods approach to understanding adjustment in the context of PMI.

Study 2 aims to examine whether a PMI results in improvements in parent adjustment relative to waitlist control (Aim 2.1), and also to examine whether parents' pre-treatment adjustment to their child's autism diagnosis predicts dropout from PMI, engagement in PMI, or child outcomes from PMI (Aim 2.2). The lack of father representation in adjustment to diagnosis research was also identified as a key research gap. This gap was addressed directly in Study 2, which aims to examine whether there are differences in parent adjustment to child autism diagnosis between mothers and fathers, both in terms of adjustment at a single timepoint (Aim 2.3), and in terms of the effect of PMI on adjustment (Aim 2.4a) and of adjustment on PMI (Aim 2.4b).

Study 3 aims to provide deeper insight into parent adjustment, with a qualitative study using reflexive thematic analysis to understand the perceptions of a representative subset of parents from Study 2 who completed the PMI. This Study aimed to understand parents' broader adjustment journey (Aim 3.1), as well as their perspectives on how PMI fit into this journey (Aim 3.2) and their additional adjustment support needs (Aim 3.3). Father involvement in Study 3 was also prioritised as a further means of addressing the lack of father representation in research on adjustment.

STUDY 1 - Systematic review: Measures and interventions for caregiver adjustment to child autism diagnosis

Abstract

Caregivers' adjustment to their child's autism diagnosis has important implications for child and caregiver outcomes. However, there has been substantial variability in definitions and measurement of caregiver adjustment to autism diagnosis. This study reports a systematic review of measures of caregivers' adjustment to their child's autism diagnosis, and the effectiveness of intervention for caregiver adjustment. A systematic review (PROSPERO CRD42023463196) was conducted according to PRISMA guidelines (Liberati et al., 2009). Adjustment was defined as caregivers' psychological response to their child's autism diagnosis. Database searches yielded 5770 unique articles, which were title and abstract screened. Full text screening was completed for 370 articles. Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018) was used to assess study quality. The review identified 69 articles, which included 38 measures of adjustment and six interventions targeting adjustment, three of which produced statistically significant improvement in adjustment. Study quality was mostly adequate. The review identified a need for consensus on defining and measuring caregiver adjustment. The review also identified the need for fathers, caregivers who are autistic, caregivers of adults to be more included in adjustment research. There is preliminary evidence for targeted interventions to support adjustment, but further research is needed.

Systematic review: Measures and interventions for caregiver adjustment to child autism diagnosis

Introduction

Worldwide prevalence estimates of autism range from 1-3% (Bradshaw et al., 2023; Nielsen et al., 2023; Wallis et al., 2023; Yang et al., 2023). While autism can be reliably diagnosed from 18 months in children with high levels of autistic traits (Benedetto et al., 2021), the global mean age of diagnosis is five years (van't Hof et al., 2020). The journey from caregivers' first concerns regarding their child's development to receiving an official autism diagnosis takes an average of 12 to 26 months, which can delay access to services and lead to confusion and stress for caregivers (Bent et al., 2020; Rivard et al., 2021). In the period immediately after their child's diagnosis, caregivers report experiencing a complex range of emotions such as shock, grief at the loss of the future they had envisioned for their child, and worry about what the child's future will hold (Fernández-Alcántara et al., 2016; Mansell & Morris, 2004). Some caregivers also report more positive emotions such as a sense of relief at the increased understanding of the child that can come with diagnosis (Mulligan et al., 2012).

Over time, caregivers then go through a process known as adjustment to the diagnosis. Across the relevant research, definitions of caregiver adjustment span a range of constructs, including more practical adjustments such as managing daily hassles and changes to daily routines (e.g., Dai & Carter, 2023), as well as psychological aspects of adjustment. Even within research focusing on psychological adjustment, definitions of adjustment range from more general caregiver mental health outcomes such as stress and mood (e.g., Benson, 2012; Gau et al., 2012), to those which look more specifically at caregivers' attitudes and emotions regarding their child's autism diagnosis (e.g., Da Paz et al., 2018; Dolev et al., 2016). In an effort to make the current review as focused as possible, adjustment was defined here as caregivers' psychological response to their child's diagnosis of autism. Adjustment is discussed interchangeably in the literature as both a process and an outcome – while theoretical discussions frame adjustment as an ongoing psychological process (Negri & Castorina, 2014), measurement typically captures a snapshot of adjustment outcomes at a particular timepoint. Within the current review, the term 'higher adjustment' will be used to refer to more optimal adjustment outcomes (operationalised in quantitative research as higher scores on measures of adjustment) as compared to 'lower adjustment', though it is important to note that adjustment does not necessarily fall on a linear scale. Higher adjustment appears to be positively associated with caregivers' own mental health and well-being (Da Paz et al., 2018; Dolev et al., 2016; Jones et al., 2014; Vitale et al., 2022), as well as their ability to engage sensitively with the child (Di Renzo et al., 2020; Oppenheim et al., 2007; Oppenheim et al., 2024; Wachtel & Carter, 2008). However, our ability to develop a thorough understanding of adjustment and its relation to other aspects of family functioning has been hampered by inconsistencies in how adjustment has been defined and measured.

This diffuse definition of adjustment is likely underscored by the range of theoretical models that have been applied to the concept. Broadly, researchers have applied process models of trauma and grief, as well as cognitive models of coping. Some research has conceptualised the child's diagnosis as a traumatic event (Casey et al., 2012; Zhang et al., 2015) and associated research has therefore utilised post-traumatic outcome measures to measure caregiver adjustment on a continuum from post-traumatic stress or post-traumatic growth. Alternatively, Kübler-Ross' (1969) staged model of grief has been applied to conceptualise the process of adjusting as that of grieving the life parents had expected for their child. Researchers have therefore used measures which capture some, or all, of the stages of grief, such as denial, despair, and acceptance (e.g., Da Paz et al., 2018; Wayment & Brookshire, 2018). However, more recent research has emphasised that adjustment is generally non-linear and does not have a finite endpoint, as caregivers continue to adjust throughout the child's life (Negri &

Castorina, 2014). In this sense, adjustment to child autism diagnosis is seen as distinct from post-traumatic or grief responses to a specific event, because the situation that parents are adjusting to – the experience of parenting an autistic child - is ongoing and frequently changing. Researchers have also applied the theory of *ambiguous loss*, noting that the process of adjustment is complicated by the fact that autistic individuals can have a vast range of outcomes, which means that the future that caregivers are adjusting to is more unclear as compared to a finite loss such as bereavement (Boss, 1999; Bravo-Benitez et al., 2019; O'Brien, 2007). Additionally, caregivers' adjustment may fluctuate as they experience intermittent reminders of their child's difficulties, for example during major life transitions such as the child starting school or reaching adolescence; thus, caregiver adjustment to child autism diagnosis has also been conceptualised as a process of *chronic sorrow* (Copley & Bodensteiner, 1987; Olshansky, 1962).

Distinct from these more process-oriented models, another body of research has focused on adjustment from the perspective of caregivers' cognitive appraisal of their child's autism diagnosis (Lazarus & Folkman, 1984; Rasmussen et al., 2020). Researchers have therefore measured various aspects of parental cognitions such as self-blame (Lodder et al., 2020; Mak & Kwok, 2010), perceived injustice (Wayment & Brookshire, 2018), use of coping strategies (Ayyash et al., 2023), and rumination (Wayment et al., 2019). This cognitive approach can also include understanding caregiver attitudes and beliefs. For instance, caregivers' stigmatising beliefs about autism and towards themselves as a parent of an autistic child, have been measured as a facet of adjustment to diagnosis (Anthony et al., 2020; Chan & Lam, 2018). However, longitudinal research exploring processes of change in these cognitive aspects of adjustment has been notably limited.

Given that adjustment has been understood through many different definitions and conceptual frameworks, it is challenging to compare findings across studies of adjustment. This limits researchers' ability to clearly identify factors that benefit or hinder adjustment, as well as adjustment's caregiver- and child-level sequelae. Accordingly, the first aim of the current systematic review was 1a) to identify measures of caregiver adjustment to autism diagnosis, including 1b) documenting the constructs these claim to measure as well as 1c) the reported psychometric properties of the measures.

Secondly, while higher adjustment appears to contribute to positive caregiver mental health and caregiver-child relationship outcomes (Di Renzo et al., 2020; Dolev et al., 2016; Vitale et al., 2022), our understanding of how best to support caregivers' adjustment is limited. There is an increasing emphasis on the involvement of caregivers in intervention for autistic individuals, especially early intervention for young children (Maglione et al., 2012). Through this caregiver involvement in intervention, the caregiver learns strategies to develop their child's skills and/or manage the child's challenges, such as externalizing behaviour (Schreibman & Anderson, 2001; Schultz et al., 2011; Swain et al., 2025). While some studies suggest that improvements in child functioning can have flow-on benefits for caregivers, the research examining caregiver outcomes in autism intervention remains in its early stages; several reviews have failed to find a consistent effect on caregiver outcomes and have highlighted limitations of the evidence base (Conrad et al., 2021; Factor et al., 2019; Schultz et al., 2011). Augmenting caregiver training with components focused more directly on the caregiver themselves, such as training in mindfulness or acceptance-based strategies, may improve caregiver outcomes (Li et al., 2024). However, prior reviews have focused only on other aspects of caregiver mental health and well-being such as stress and quality of life. No review has examined the effect of intervention on adjustment to diagnosis specifically. For researchers and clinicians to best support families along their journey of adjustment, it is important to understand what interventions are already being provided aimed at supporting caregiver adjustment, and their effects. The second aim of the current review was therefore 2a) to identify interventions for which caregiver adjustment has been evaluated as an outcome, and 2b) their effects on caregiver adjustment.

Method

The current study was conducted as a systematic review, using PRISMA guidelines (Liberati et al., 2009). See Appendix 1 for PRISMA checklist. The protocol (Appendix 2) for this systematic review was registered on PROSPERO (CRD42023463196).

Search Strategy

An electronic search was conducted by the first author on August 30, 2023, of the following databases: PsycINFO, Medline, Scopus, Web of Science, and the Cochrane Central Register of Controlled Trials. The keywords used were (adjust* OR accept* OR resol* OR grief OR "respon* to diagnosis" OR "react* to diagnosis") AND (parent* OR caregiver*) AND (autis* OR asperg* OR ASD); see Appendix 3 for full search terms and parameters for each database. A subsequent search was conducted on November 15, 2024, to capture articles published since the initial search date. The searches were limited to peer reviewed articles published in English and to papers classified as using quantitative methods; not all databases allowed for automatic limiting by these criteria, so some articles outside of these limits were excluded manually through later screening. No limits on publication date were applied, given that the review aimed to capture how adjustment to autism diagnosis has been measured across a changing theoretical landscape.

The current review focused on peer reviewed articles; the review therefore did not include grey literature searching and did not allow for inclusion of unpublished manuscripts, dissertations or study protocols. The review did not include citation searching of article reference lists. While citation searching is recommended where the review topic is difficult to search for using a database search (e.g., topics with a lack of clear keywords), the primary aim of the current review was to identify articles that claimed to measure adjustment to autism diagnosis, which required inclusion of articles only where one of the adjustment keywords above was used. Therefore, citation searching was not indicated (Hirt et al., 2024; Horsley et al., 2011). Articles identified through the database search were uploaded into Covidence, a web-based collaboration software platform that streamlines the production of systematic and other literature reviews (Covidence, 2023). Duplicates were automatically removed by Covidence.

Screening

Covidence software was used to screen identified articles according to the following eligibility criteria. Inclusion criteria: 1) Study sample is primary or secondary caregivers of a child or adolescent/adult offspring with a confirmed diagnosis of autism spectrum disorder according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013), or diagnosis of pervasive developmental disorder-not otherwise specified or Asperger's syndrome if the study was conducted prior to the publication of the DSM-5 in 2013. Includes permanent full-time primary or secondary caregivers (e.g., biological parents, adoptive parents, step-parents, other relatives acting in the primary or secondary caregiver role); 2) Study includes quantitative measurement of caregivers' psychological response to their child’s autism diagnosis. See Figure 1 below for a full list of included and excluded outcomes; and 3) Original research articles published in peer reviewed journals in English. Exclusion criteria: 1) Not published in English; 2) Grey literature (i.e., studies from non-peer reviewed sources, conference proceedings, dissertation papers, study protocols or treatment manuals); 3) Not target population as per above inclusion criteria. Studies including caregivers of children with “features of autism”, “suspected autism” or “increased likelihood of autism” were not considered suitable for inclusion in the current study, given the focus on studying adjustment to confirmed autism diagnosis; 4) Not targeting key study outcomes. Studies were excluded if they only included measurement of the following constructs (without measurement of psychological response to autism diagnosis): other aspects of the caregiving experience (e.g., stress, burden); measures of caregiver response to features associated with autism (e.g., challenging behaviour) rather than the concept of autism itself; measures of practical aspects of adjustment (e.g., changes to daily routine) that did not involve thought, emotions or beliefs; measures of other aspects of adjustment that did not pertain to perception of autism diagnosis (e.g., broader family adjustment measures). See Figure 1 below for a full list of included and excluded outcomes; 5) Qualitative research without quantitative measurement.

Figure 1 - Included and excluded outcome variables.

Included	**Excluded**
Acceptance of autism	Enjoyment of parenting/of child
Beliefs about ASD/perceptions of autism	Experience of parenting an autistic child
Beliefs about reasons for child's diagnosis (e.g., perceived locus of control regarding diagnosis)	Impact of the child on the family/ impact of autism on the family
Beliefs about the future of the child with autism: includes hope for the child's future, pessimism about the child's future	Perceived parenting competence
Benefit finding	Practical changes/accommodations
Coping with autism diagnosis	Coping with caregiving; trait coping skills
Emotional burden	Caregiver burden (more broadly to emotional burden)
Grief	Quality of life
Guilt regarding child's diagnosis	Satisfaction
Perceived loss associated with autism diagnosis	Satisfaction with the disclosure of the diagnosis
Post-traumatic growth	Self-efficacy
Reaction to autism diagnosis	Stress; parenting stress; stress due to autism features
Resolution of autism diagnosis	
Self-stigma/affiliate stigma	

At each stage of screening, the first author screened 100% of articles. Four other authors completed secondary screening, resulting in a total of 30% of articles double screened at each stage. Agreement for inclusion/exclusion at the title and abstract screening stage was 94%, and for full text inclusion/exclusion was 80%. For disagreements on inclusion at title and abstract screening, the article was included through to full text screening to allow for thorough evaluation. Disagreements at full text review were resolved through discussion between the two reviewers. While an agreement target of 85% was originally set during PROSPERO registration, the slightly lower 80% agreement level was accepted because the majority of discrepancies occurred early in the screening process, and agreement then improved following discussion of initial disagreements. Where the information provided in the article was insufficient to determine inclusion at full text screening (e.g., description of outcome measure was unclear), the corresponding author was contacted via email once with the request for the relevant information. Studies were subsequently excluded if no response was received within one month. Any duplicates that had not been automatically removed by Covidence were manually marked as duplicates and removed during screening.

Data Extraction and Quality Appraisal

Data extraction was completed by the first author. Extracted data was organised into the following sections: Demographics; Measure information and psychometric properties (Aim 1); and Intervention design and results (Aim 2). Multiple measures of adjustment included in the same study were extracted separately where relevant.

Article quality was assessed by the first author using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). Articles were classified as quantitative randomised controlled trials, quantitative non-randomized studies or quantitative descriptive studies and assessed for the five criteria for the relevant study type. For each criterion, a response of “Yes”, “No”, or “Can’t tell” was selected, with the percentage of “Yes” responses calculated to determine the overall article quality out of 100%.

Results

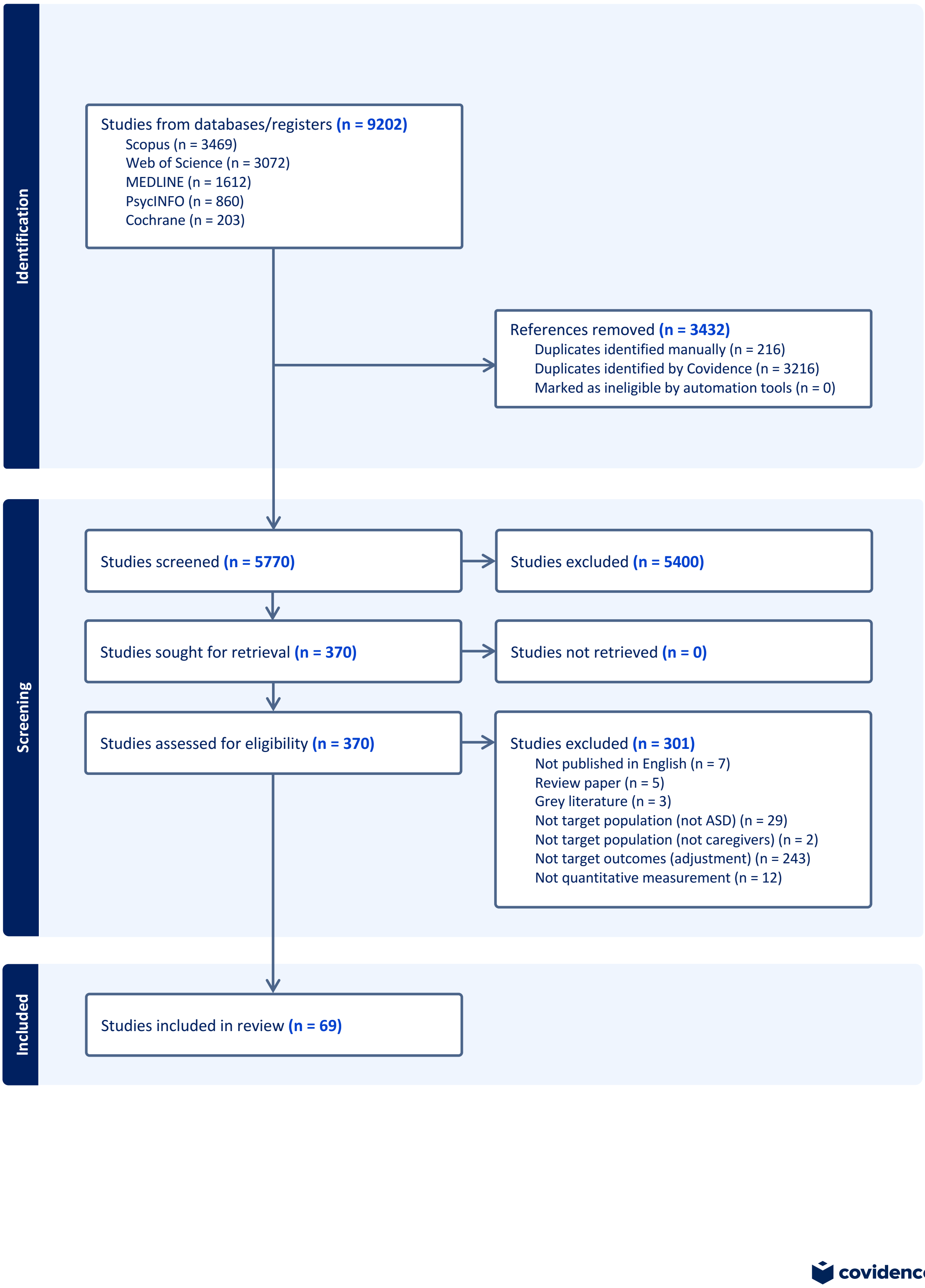
Study Selection

See Figure 2 for PRISMA flowchart. A total of 3189 articles from the initial search were screened after removal of duplicates; a further 2615 were screened following the updated search in November 2024. Following title and abstract screening, the full text of 370 studies was reviewed. During full text review, the authors of five articles were contacted to request for a copy of the full outcome measure to assess eligibility. One author provided a copy of the outcome measure, which was determined not to meet inclusion criteria upon review; the remaining authors did not respond and so the relevant articles were excluded due to the outcome measure as described in the article not meeting inclusion criteria. See Appendix B1 for a list of articles excluded at full text review, and reasons for exclusion. The most common reason for exclusion at full text review was that the outcome measure did not measure caregiver adjustment to the child's autism diagnosis (*n* = 243 articles). A final sample of 69 articles was included to address Aim 1, with a subsample of six articles with an intervention component included to address Aim 2. All articles included to address Aim 2 were also included in the sample of studies addressing Aim 1. Articles were published between 2004 and 2024. See Appendix B2 for a list of all included articles, also marked with an asterisk in References.

Study Quality

Study quality according to the MMAT ranged from 0% to 100%, with an average study quality of 74.86%. Study quality for each included article is reported in Appendix B2. The most common reason for lower study quality was that the sample was not representative of the target population or representativeness could not be determined; this was due to articles failing to report study inclusion and exclusion criteria or providing insufficient information regarding how a diagnosis of autism spectrum disorder was confirmed in their study.

Figure 2 -PRISMA Flowchart



Participant Characteristics

Participant characteristics, where reported in included articles or supplementary materials, are reported in Appendix B2. Studies were conducted across 24 countries, with the highest number of studies conducted in the United States (33%). The overall sample size across 69 studies was 12,237 caregivers; however, it is important to note that articles using the same sample as another article were not excluded, and some articles utilised large autism research databases such as the Simons Simplex Collection (Fischbach & Lord, 2010). Thus, it is likely that the articles do not include 12,237 unique participants. The sample size per article ranged from 17 to 424. Overall, 82.44% of caregivers were mothers, with 22 studies including only mothers. Seven studies included mother-father dyads of the same child. In no studies did fathers comprise the majority of the sample. None of the included studies reported assessing whether caregivers were themselves autistic, though one study assessed caregivers' level of autistic traits using a continuous measure (Milshtein et al., 2010).

Children of caregivers included in the extracted articles were 80.53% male and ranged in age from 1 to 43 years. About 40% of the included articles (n = 28) had a mean child age within the school age range (ages 6–12 years). No articles exclusively included adult offspring, though two studies (Lunsky et al., 2021; Montoya et al., 2024) focused on older adolescents and adults. The average child age at diagnosis across the 14 articles that reported this was 4.03 years, and the mean interval between diagnosis and completion of the measure of adjustment across the 23 articles that reported this was 41.88 months. About half of the included articles (n = 32, 46.38%) failed to report information about the race or ethnicity of children or parents. Twenty-four articles included information characterising the autism traits of the sample (such as diagnosis level or mean scores on a measure of autism traits), and 37 articles included other clinical information about the children such as intellectual function or medical conditions.

Aim 1 - Measures of Adjustment

Across the 69 studies included, 38 unique measures of adjustment were used (Aim 1a). See Appendix 4 for full information regarding the included measures. All measures were questionnaires except the Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1993), which is a semi-structured interview with a coding scheme that allows for the classification of caregivers' reaction to the child's diagnosis as resolved or unresolved. The RDI was the most commonly used measure of adjustment, used in 13 studies. The most commonly used questionnaire measures were the Affiliate Stigma Scale (Mak & Cheung, 2008) and the Post-Traumatic Growth Scale (Tedeschi & Calhoun, 2004). There were 28 measures each used only in one included study. Regarding Aim 1b), the included measures spanned 22 constructs, the most common of which was perceived positive contributions of autism to the caregiver's life. The construct assessed by each measure is listed in Table 7 (Appendix 4). Mapping onto the broad theoretical approaches to understanding adjustment, most of these constructs focused either on the process of adjustment, or on caregivers' cognitive appraisal of autism. Process focused measures included measures of resolution (e.g., Reaction to the Diagnosis Questionnaire; Sher-Censor et al., 2020), grief (e.g., Caregiver Grief Scale; Meischner et al., 2016), and post-traumatic growth (e.g., Post-Traumatic Growth Scale; Tedeschi & Calhoun, 2004). Measures assessing appraisal of autism included measures of initial reaction to diagnosis (e.g., Anderberg & South, 2001), beliefs about or perceptions of autism (e.g., Attitudes Towards Autism Questionnaire; Ferenc et al., 2023), and measures of caregivers' self-perception as a caregiver of an autistic child (e.g., Affiliate Stigma Scale; Mak & Cheung, 2008; Self-Blame & Responsibility Scale; Mak & Kwok, 2008).

Psychometric properties of included measures (Aim 1c) are included in Table 7 (Appendix 4). The majority of measures had acceptable internal consistency (Cronbach's $\alpha >$ .70), however this was not reported for nine measures. Factor analysis was conducted for eight of the measures. Only four measures were assessed for validity and four for test-retest reliability, with one of these four demonstrating non-significant correlations between Time 1 and 2 scores (Samios et al., 2009). Thirteen measures were used to evaluate change in adjustment over time, with 10 of these demonstrating significant changes over time.

Aim 2 - Interventions

Six identified articles included an intervention targeting caregivers' adjustment to their child's autism diagnosis (Aim 2a). See Table 8 (Appendix 5) for information regarding interventions and outcomes. Two intervention studies (Bravo-Benítez et al., 2024; Lodder et al., 2020) used a randomised controlled trial design, while other studies used a single group design without a control group. Interventions were delivered to caregivers only (i.e., without any involvement of the child), aside from the picture book intervention (Yang et al,. 2024), which briefly included children at the end of the session and required caregivers to engage children in home practice. All interventions were 'targeted', in that they focused specifically on caregiver adjustment and other caregiver mental health and well-being outcomes; none of the interventions were 'broad', in that none evaluated caregiver adjustment alongside child outcomes. Most interventions were delivered in group format. The majority of interventions included psychoeducation about autism and/or the adjustment process. Other intervention content included cognitive therapy strategies (Bravo-Benítez et al., 2024; Lunsky et al., 2021), mindfulness and acceptance-based strategies (Lodder et al., 2020; Lunsky et al., 2021) and problem-solving training (Nguyen et al., 2016). Regarding Aim 2b), the SOLACE (Lodder et al., 2020), Problem-Solving Skills Training (Nguyen et al., 2016) and caregiver grief (Bravo-Benítez et al., 2024) interventions evidenced statistically significant improvements in caregiver adjustment, which were maintained in those studies which included a follow-up timepoint. Medium to large effect sizes were reported for the complicated grief intervention (Bravo-Benítez et al., 2024), however the SOLACE and Problem-Solving Skills Training interventions did not report effect sizes. It was not possible to calculate average effect sizes, as intervention effect size was reported only in two articles. None of the studies reported clinical significance of change.

Discussion

This systematic review identified measures of caregivers' adjustment to their child's diagnosis of autism. The review identified 38 measures of caregiver adjustment used across 69 studies. The review's second aim involved identifying interventions for caregiver adjustment and examining their effectiveness. The review identified six interventions, two of which were compared to a control condition, and three of which demonstrated statistically significant changes in caregiver adjustment.

Measurement

The included measures spanned several conceptualisations of adjustment, such as acceptance, positive contributions of the diagnosis to the caregiver's life, and post-traumatic growth. This substantial variability in how adjustment has been defined and measured was present despite this review's specific focus on caregivers' psychological response to their child's autism diagnosis, excluding measures of practical adjustment or broader caregiver well-being. Amid the shifting theoretical conceptualisation of caregiver adjustment (Negri & Castorina, 2014), it is clear that the field has yet to agree on a clear definition of adjustment. This is a core limitation of the research in this area; it is not possible to validate whether a measure is accurately capturing a construct without first having a clear definition of what the construct is (Wacker, 2004). Further, without clear consensus regarding what *does* and *does not* fall into a construct, researchers may fall into concept stretching, whereby related but distinct constructs blur together (Wacker, 2004). Indeed, the number of constructs assessed by the measures identified here suggests that concept stretching has likely occurred in the absence of a clear definition of adjustment to diagnosis. Inadequate definition of a construct, and concept stretching, can in turn, confound researchers' ability to identify consistent effects and draw clear conclusions, as studies that appear to measure the same construct may not be. It is therefore imperative that the next step in research investigating caregiver adjustment to child autism diagnosis is the development of a clear definition. Research to validate proposed theoretical models of adjustment, and ideally to identify a model that best explains adjustment to diagnosis, should guide definition development. A consensus definition can then be co-produced with autistic people and parents of autistic people, including autistic parents, and using Delphi methodology to seek expert consensus among those who work with parents of autistic children (Dalkey & Helmer, 1963). Once adjustment is more clearly defined, further research will be needed to validate the proposed theoretical models of adjustment, and ideally to identify a model that best explains adjustment to diagnosis. While it was beyond the scope of the current study to formally identify the theoretical underpinning of each included study, a range of theoretical constructs were present, which likely contributed to variability in how adjustment was defined and measured across studies. Defining a clear theoretical model which accurately explains adjustment will support greater consistency in how adjustment is conceptualised.

The current study identified a range of measures of adjustment. In fact, over half the measures identified were only used in a single study, making it difficult to compare the results of those studies. It is important to note that these novel measures were often developed for studies conducted in countries that are typically underrepresented in autism research, such as Kuwait (Al-Kandari et al., 2017) and Qatar (Kheir et al., 2012). Such measures were likely developed with a goal of culturally sensitive measurement, which may indicate a need for cross-cultural validation of more commonly used measures of adjustment.

Overall, the available information regarding the psychometric properties of adjustment measures was lacking. Very few studies reported psychometric properties beyond internal consistency. It is therefore unclear whether existing measures of adjustment have adequate test-retest reliability or can be used to identify changes in adjustment over time, including intervention responsiveness. This limits the utility of these measures for longitudinal or intervention research, which is particularly problematic given that adjustment is conceptualised as a dynamic construct. Additionally, very few studies examined measures' construct validity, either by comparing them to existing adjustment measures or using divergent validity to confirm that the measure is not tapping into a construct other than adjustment. This limited validation of adjustment measures likely follows from the lack of a clear definition, as discussed above. Following agreement on a definition of adjustment, further research evaluating the measurement properties of relevant measures would then allow for the recommendation of gold-standard measurement tools through rigorous assessment using a system such as PRISMA-COSMIN (Elsman et al., 2024).

While a clear conceptual definition of adjustment is clearly needed, the current review nevertheless offers some insight into currently available measures of adjustment. The most commonly used measure of adjustment was the Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1993). It is important to note that this measure was originally developed and validated with parents reacting to their child's diagnosis of cerebral palsy. Despite its extensive use in autism research, the RDI is yet to be formally validated in caregivers of autistic children, though some studies in this group have demonstrated associations of RDI resolution status with conceptually-related variables such as quality of caregivers' interactions with the child (e.g., Dolev et al., 2016; Wachtel & Carter, 2008). The RDI has been shown to be suitable for use soon after diagnosis, as well as months to years after, and has demonstrated sensitivity to change over time with caregivers of autistic children (Poslawsky et al., 2014). It is, however, notable that the RDI asks about caregivers' reaction to the child's 'diagnosed condition' without focusing specifically on the diagnosis of autism; therefore caregivers' responses may confound adjustment to autism diagnosis with adjustment to co-occurring conditions such as intellectual disability or Attention-Deficit Hyperactivity Disorder. It is also important to note that use of the RDI requires training of interviewers and coders. There is also an additional time burden for caregivers associated with completing an interview as compared to a questionnaire. As such, the RDI may not be suitable for use in larger-scale studies. The Reaction to Diagnosis Questionnaire (Sher-Censor et al., 2020) was developed based on the RDI to address the limitations of an interview format, however the measure has yet to be formally validated with caregivers of autistic people.

Of the two most commonly used questionnaire measures, the Affiliate Stigma Questionnaire (Mak & Cheung, 2008) demonstrated sensitivity to intervention impact (Lodder et al., 2020). While the Affiliate Stigma Questionnaire may therefore be recommended for use in future studies, it is important to note that it only captures one aspect of adjustment—the extent to which caregivers feel stigmatised as a result of their child's autism diagnosis. Other studies have suggested that adjustment may have multiple facets, each with unique relations to other aspects of caregiver and child functioning. For example, the Adjustment to the Diagnosis of Autism Questionnaire (ADAQ; Da Paz et al., 2018) contains three subscales – despair, self-blame, and acceptance – which were identified using factor analysis. These subscales demonstrated different concurrent and longitudinal associations with other aspects of caregiver mental health and well-being (Da Paz et al., 2018). Use of a more nuanced measure such as the ADAQ may therefore be recommended for studies aiming to measure adjustment. However, it is important to note that the ADAQ has, to date, only been used in two studies and has only been formally validated with mothers. Further research demonstrating replicable psychometric properties of the ADAQ, especially in fathers, would therefore be warranted before this, or another measure, can be recommended for widespread use in research and clinical practice.

While the quality of the included studies was generally acceptable, there are notable gaps in the identified research. Firstly, many studies failed to report on the criteria used to confirm the child's autism diagnosis. This limits the conclusions that can be drawn about the similarity of samples across studies. The current review also identified that research into caregiver adjustment is lacking for caregivers of autistic adults. In caregivers of adults who were diagnosed with autism as children, investigating adjustment many years after diagnosis could enrich our understanding of the long-term trajectories of adjustment. This is particularly important to understand in the context of the significant variability in outcomes for adults with autism (Simonoff et al., 2020). It is also important to recognise that the lack of research into adjustment among caregivers of autistic adults is positioned within a context in which research about autism in adults is more limited overall as compared to that in children. In fact, research focusing on adults has been identified by stakeholders as a priority for ongoing autism research (Frazier et al., 2018). There is also increasing interest in understanding autistic adults' own adjustment to their diagnosis (de Broize et al., 2022), however, this was outside the scope of the current review. None of the included studies assessed whether caregivers themselves were autistic. Given that autism is a highly heritable condition, many caregivers of autistic children are autistic themselves (Tick et al., 2016). Research is yet to examine how parents who are diagnosed autistic, or who may be questioning whether they are autistic but not yet diagnosed, adjust to their child's autism diagnosis, which represents a notable gap in this body of research.

Fathers were also notably underrepresented across articles identified in the current review. In fact, about a third of the included articles focused exclusively on mothers. This same lack of father inclusion is evident across research with caregivers of autistic children (Brown et al., 2021a) and parenting research more generally (Parent et al., 2017). Fathers may experience challenges with distinct aspects of caring for an autistic child (Ornstein Davis & Carter, 2008; Vernhet et al., 2022). It would therefore be misguided to assume that research focusing predominantly on mothers' adjustment to their child's autism diagnosis can be applied to fathers. This necessitates validation of adjustment measures specifically with fathers and a focus on prioritising father inclusion in subsequent research.

Intervention

The current review identified a small number of interventions targeting caregiver adjustment to their child's autism diagnosis, which demonstrated mixed effectiveness. There is insufficient evidence on the basis of the included interventions to recommend any specific intervention modality. Some, but not all, of the cognitive therapy and mindfulness-acceptance based programs showed significant benefits. This finding aligns with a recent review showing promise for mindfulness-acceptance based programs to support other mental health outcomes in caregivers of autistic people (Li et al., 2024). The problem-solving skills training intervention (Nguyen et al., 2016) also demonstrated significant change in adjustment, however there was no control group for comparison. It is also important to note that the problem-solving skills training was the only individually-administered (as opposed to group) intervention, and so it is not clear whether providing caregivers with one-on-one clinician support may have facilitated improvements regardless of the program content (Baier et al., 2020). Overall, it is promising that the small body of interventions included here suggest that caregiver adjustment challenges may be amenable to change through a relatively brief targeted intervention. Further research is needed to better understand which intervention modalities or components reliably support adjustment, and to more rigorously evaluate intervention effects.

Importantly, though, evaluating the effectiveness of any intervention requires the use of an outcome measure that is appropriately validated with this population, reliable, and sensitive to change over time. Given the limitations of current measurement identified through Aim 1, it is clear that validation of a gold-standard measure of caregiver adjustment to autism diagnosis is required before interventions can be appropriately evaluated.

It is important to note that the included intervention studies all specifically targeted caregiver adjustment or other aspects of caregiver mental health. There were no studies identified which evaluated changes to caregiver adjustment through a broad intervention, such as caregiver-mediated intervention focused on child behaviour or skills. The potential for caregiver-mediated intervention to support adjustment should be viewed cautiously given limited evidence of benefits for other aspects of caregiver mental health (Conrad et al., 2021; Factor et al., 2019; Schultz et al., 2011). Nevertheless, it may be premature to develop targeted adjustment interventions without first exploring whether there are benefits to adjustment from the broad interventions that many caregivers of autistic individuals already engage in. In such interventions, caregivers are provided with psychoeducation about autism and are trained in skills that can help them manage day-to-day challenges such as their child's tantrums and non-compliance, and to build their child's skills (Schreibman et al., 2015). It is therefore possible that engaging in such interventions may facilitate caregivers' adjustment by way of increasing caregivers' knowledge and skills in relating effectively to their child, and reducing daily stressors (Dawson-Squibb et al., 2019). In line with this, caregivers engaged in qualitative research have described taking practical steps to support their child's development, such as engaging in intervention, to have benefits for their adjustment to their child's diagnosis (Downes et al., 2020; Rabba et al., 2019). By exploring how broad interventions might already be supporting caregiver adjustment, researchers can better understand whether there is a remaining need to augment such programs with targeted content or to develop standalone interventions for caregiver adjustment.

In line with this, it is important to recognise many caregivers do successfully adjust to their child's autism diagnosis (Gentles et al., 2020; Poslawsky et al., 2014). This points to the potential appropriateness of a stepped-care approach (Bower & Gilbody, 2005) whereby basic support for caregiver adjustment could be integrated within existing diagnostic and early support services, with caregivers showing greater adjustment challenges then stepped up to increasingly more intensive supports such as the interventions identified in this review. A stepped-care plan for adjustment support could be easily embedded within the broader stepped-care approach to autism support recommended by the Lancet Commission (Lord et al., 2022). It may also be important to identify predictors of adjustment challenges, to understand whether preventative support for adjustment can improve families' outcomes. Critically, applying a stepped approach to supporting adjustment requires use of a valid and reliable measure of adjustment to identify when caregivers need to be stepped up or down the levels of support, again highlighting the identification of a gold standard measure of caregiver adjustment as the necessary next step.

Conclusion

This systematic review identified a range of measures of caregiver adjustment to their child's diagnosis of autism, as well as a small number of novel interventions targeting caregiver adjustment. It is vital to note that there is also a substantial body of qualitative research examining caregiver adjustment to their child's autism diagnosis (e.g., Fernández-Alcántara et al., 2016; Rabba et al., 2019; Rasmussen et al., 2020). While outside the scope of the current review, this qualitative research has contributed significantly to our understanding of how caregivers experience adjustment and how to best support them. This provides important foundational knowledge that should be used to inform the ongoing work needed to more effectively define, measure, and support adjustment.

The current review has identified a series of next steps that are needed in this area of research. It is imperative that researchers first agree on a clear definition of adjustment, including what is and is not included in this construct. Without this first step, the development and validation of relevant measures is misguided, given that it is not yet clear what is being measured. The field may then benefit from validation of theoretical models of adjustment.

Consensus on key measures of adjustment is also needed, to increase consistency in measurement across studies. These measures would require validation, including in underrepresented groups such as fathers, autistic parents, and caregivers of autistic adults, and in a range of cultures. There is also a need to examine whether existing broad supports, such as caregiver-mediated interventions, are efficacious in improving adjustment. If broad interventions do not evidence sufficient benefit for caregiver adjustment, the small group of intervention studies identified in the current review reveal potential avenues for the development and dissemination of more targeted support. Learnings from these identified next steps would allow optimal support for caregiver adjustment to be integrated within personalised care pathways following autism diagnosis (Lord et al., 2022), moving towards the broader goal of improving the well-being of autistic people and their families.

STUDY 2 - Parent adjustment to autism diagnosis and parent-mediated intervention: A randomised controlled trial

Abstract

Background: Adjustment to autism diagnosis refers to parents' process of working through the thoughts and feelings associated with their child's autism diagnosis. Only one study (Grogan et al., 2023) has examined adjustment in the context of parent-mediated intervention (PMI), and did not evaluate intervention effects on adjustment. The current study examined whether PMI improved parent adjustment, and whether adjustment predicted parent dropout, engagement and outcomes from a PMI. The current study also addressed gaps in our understanding of fathers' adjustment to autism diagnosis.

Method: Parents (98 mothers, 76 fathers) of 99 autistic children ages 2-5 with externalising behaviour were recruited for a randomised controlled trial of a PMI - ParentWorks Spectrum (PWS) compared to Waitlist control – with main trial outcomes reported elsewhere (Dadds et al., 2025). Adjustment to diagnosis was assessed at pre- and post-treatment/waitlist using an abridged version of the Adjustment to the Diagnosis of Autism Questionnaire (Da Paz et al., 2018). Linear regression was used to assess the effect of treatment allocation on adjustment, and of pre-treatment adjustment on dropout, engagement, and child outcomes, with separate analyses of mother and father data.

Results: No significant effect of PMI on adjustment was found relative to waitlist control. No significant effect of pre-treatment adjustment was found on dropout, engagement, or child outcomes. Mothers reported significantly higher self-blame (one subscale of adjustment) as compared to fathers at pre-treatment, with no other differences found between mothers and fathers.

Conclusion: A PMI may not be sufficient to facilitate adjustment, and adjustment-specific modules or interventions may be needed. Also, parents may be able to engage in PMI

and achieve positive outcomes regardless of pre-treatment adjustment to diagnosis. However, further research is needed to understand how parents experiencing significant adjustment difficulties respond to PMI.

Parent adjustment to autism diagnosis and parent-mediated intervention: A randomised controlled trial

Introduction

Parent or caregiver involvement in intervention is considered an essential component of evidence-based support for young autistic children (Maglione et al., 2012; Zwaigenbaum et al., 2015). In particular, parent-mediated intervention (PMI) is a category of interventions in which the parent (hereafter used to refer to parents and other primary caregivers) is taught strategies to develop skills or improve behaviour in the child, in addition to or instead of the therapist working directly with the child (Bearss et al., 2015). There has been recent interest in understanding whether such interventions have flow-on effects on parent functioning. Research has found evidence of benefit for parent stress but not for other aspects of parent mental health (Kulasinghe et al., 2023). It is also not well understood how such aspects of parent functioning might influence their ability to engage in and benefit from PMI (Ingersoll & Berger, 2015; Shalev et al., 2020). One aspect of parent functioning that may be important to consider in the context of PMI is parents' adjustment to their child's autism diagnosis.

Adjustment to diagnosis refers to parents' psychological response to their child's autism diagnosis (Pianta & Marvin, 1993). Adjustment is understood as an ongoing process of working through the thoughts and feelings parents have about the child's autism diagnosis (Negri & Castorina, 2014). The extent to which parents are able to engage in this process effectively varies (Pianta & Marvin, 1993). As such, the terms 'high adjustment' and 'low adjustment' are used here to describe, respectively, more and less optimal adjustment at a given time within this process. Across studies, about a quarter to three quarters of parents are reported to experience difficulties with adjustment to diagnosis (Poslawsky et al., 2014; Yirmiya et al., 2015). Therefore, there may be a need for intervention to better facilitate parents' adjustment.

Intervention to Support Parent Adjustment

Despite findings that higher adjustment is positively associated with better parent and family functioning (Dolev et al., 2016; Oppenheim et al., 2009; Papadopoulos et al., 2024), research evaluating intervention to support adjustment has been limited. In fact, no research to date has examined the effect of PMI on adjustment. There is an emerging body of evidence supporting the effectiveness of novel, targeted interventions for improving adjustment. Three interventions, spanning Acceptance and Commitment Therapy (Leadbitter et al., 2025), cognitive and compassion-focused techniques (Lodder et al., 2020), and intervention for complicated grief (Bravo-Benítez et al., 2024) have demonstrated effectiveness in improving adjustment in randomised controlled trials. This provides initial evidence that parent adjustment to diagnosis is amenable to change through relatively brief (5-10 sessions) intervention. However, we do not yet know whether PMI is sufficient to support parent adjustment, without the need to target it more directly in a separate intervention.

Although PMI typically does not directly target parent adjustment to diagnosis, there are two key reasons why PMI may indirectly improve in adjustment. Firstly, PMI commonly includes psychoeducation, or teaching parents about autism (Bearss et al., 2015). Parents describe increasing their understanding of autism as a key means of improving adjustment to the diagnosis (Gentles et al., 2020; Legg & Tickle, 2019). In fact, psychoeducation is a core component of most targeted interventions for adjustment (Anthony et al., 2020; Leadbitter et al., 2025; Lodder et al., 2020; Yang et al., 2024). Secondly, PMI facilitates parents' development of specific parenting skills that they can use to support their child's social communication skills or adaptive behaviour, and to appropriately manage and reduce challenging behaviours (Bearss et al., 2015). It is therefore feasible that PMI could facilitate adjustment by giving parents skills that allow them to feel more capable of effectively supporting their autistic child (Fante et al., 2024). Seeing improvements in the child through PMI may also enhance parents' adjustment.

If effective, supporting adjustment through PMI could allow for greater parsimony and accessibility as compared to a targeted adjustment-specific intervention. Parsimony of interventions is an important consideration for parents of autistic children, who are typically already engaged in multiple interventions for their child, and are therefore at risk of burnout (Gentles et al., 2019; Picardi et al., 2018; Vohra et al., 2013). Considering the time and financial costs of interventions, parents may be less likely to opt in to a target adjustment intervention as compared to an intervention such as PMI which can support child outcomes (Chen et al., 2023). Parents who are particularly overwhelmed by struggling with adjusting to their child's diagnosis may be the least likely to access targeted support because of this overwhelm, although they may be in greatest need of support for adjustment. Given that PMI is recommended as a core component of early intervention for autism (Maglione et al., 2012), it may be a more feasible way of supporting parental adjustment to diagnosis at scale. Importantly, one study found that a targeted intervention for adjustment did not improve child outcomes (Leadbitter et al., 2025). Therefore, PMI may provide the best opportunity to change both parent and child outcomes in a single intervention. This is not to say that targeted intervention for adjustment is not needed – rather, that we do not yet know whether it is needed until research evaluates whether a broad support such as PMI is sufficient to facilitate adjustment.

Considering the Effect of Adjustment on PMI

It is also important to consider whether parents' adjustment may influence their experience of PMI – that is engagement, completion and outcomes from PMI. Only one study to date has examined the effect of adjustment on PMI. Grogan and colleagues (2023) found that pre-treatment adjustment did not predict parents' in-session use of intervention strategies.

The role of adjustment in parents' engagement in PMI, or whether parents complete (as opposed to drop out early from) PMI has yet to be explored. Identifying whether parent factors such as adjustment influence PMI engagement and completion is important because lower parent engagement or premature dropout can reduce the effectiveness of PMI for child outcomes (Gulsrud et al., 2016; Kazdin, 1996). Related aspects of parent functioning such as stress and depression can interfere with engagement and program completion, and therefore with PMI outcomes (Ingersoll & Berger, 2015; Rovane et al., 2020; Shalev et al., 2020). Research examining whether adjustment plays a similar role in PMI engagement and dropout is therefore needed. Research has also yet to identify whether parents' adjustment impacts the effect of PMI on child outcomes.

There are two reasons to expect that parents' adjustment to diagnosis may influence their dropout from or engagement in PMI, and therefore their PMI outcomes. First, qualitative research suggests that when parents feel overwhelmed by the adjustment process, this can interfere with their ability to take in and apply information and skills (Abbott et al., 2012; Jurek et al., 2023; Rabba et al., 2019). Parents who are overwhelmed by adjustment may therefore find it harder to engage in and complete a PMI. Second, parent cognitions about themselves, the child or the intervention can be a common barrier to intervention success (Morrissey-Kane & Prinz, 1999). Parents with lower adjustment may hold negative beliefs about their own ability to facilitate improvement in their child, which can in turn interfere with parental engagement and the success of the intervention (Jurek et al., 2023). On the other hand, parents with lower adjustment may perceive PMI as a means to "fix" their child, increasing engagement. With these two factors in mind, there is a need for further research to consider the role of adjustment to diagnosis during PMI.

Adjustment During Parent-Mediated Intervention: A Bidirectional Model

Taking together the potential for adjustment to diagnosis to influence engagement in PMI, and for PMI to influence adjustment, suggests a need to consider the bidirectional relationship of adjustment and PMI. In PMI, the parent facilitates improvement in their child's development (Conrad et al., 2021; Bearss et al., 2015), so they are not adjusting to a static situation, but to one which they are actively and iteratively changing. While the child's diagnosis does not change, parents' understanding of what autism means for their child and family likely shifts as they see changes in the child through PMI. For example, if adjustment influences parents' engagement with PMI, this may impact the benefits the parent sees from the PMI in terms of child outcomes, which may in turn shift their adjustment to diagnosis (Gentles et al., 2019). Conceptually, a dynamic, iterative interaction of adjustment and intervention appears likely. However, research has yet to directly examine how adjustment both impacts and is impacted by PMI. Examining these relationships may have implications for understanding both how best to support parent adjustment, and how to enhance the effectiveness of PMI.

The Need for Father-Inclusive Research

It is important to recognise that most research across adjustment to autism diagnosis, and PMI, has predominantly included mothers (Braunstein et al., 2013; Brown et al., 2021a; Factor et al., 2019; Rankin et al., 2019). The limited research that has been conducted suggests that the process of adjustment to diagnosis may differ between mothers and fathers, with fathers showing less consistent improvement in adjustment over time as compared to mothers (Yirmiya et al., 2015). Intervention for adjustment may therefore be particularly important for fathers. Yet, fathers are less likely to engage with parent-focused supports when compared to mothers (Seymour et al., 2020). Supporting adjustment through a broad PMI may therefore be particularly helpful in engaging fathers, who may be at greater need of, but less likely to engage with, more targeted supports. However, with low levels of father involvement in PMI research more broadly, the benefits of PMI for fathers are less clear than for mothers (Factor et al., 2019; Rankin et al., 2019). In fact, research has found that some fathers may not experience the same decrease in stress that mothers report following PMI for autism (Baker-Ericzén et al., 2005). It is therefore unclear whether the potential benefits of PMI for adjustment may differ between mothers and fathers. It also remains unclear whether there are differences in adjustment between mothers and fathers, and if so, how mothers' and fathers' adjustment may differentially influence PMI.

Current Study

The current study explored adjustment to child autism diagnosis in the context of ParentWorks Spectrum (PWS; Leonard et al., 2025), an evidence-based, father-inclusive PMI for parents of young autistic children that primarily aimed to improve child disruptive behaviour, child core autism features, parent mental health and the co-parenting relationship. The following research questions were addressed: (1) Do parents in the PWS intervention group show greater improvement in adjustment to their child's autism diagnosis as compared to a waitlist control group?; (2) Does parents' pre-treatment adjustment to their child's autism diagnosis predict intervention dropout, engagement, and child outcomes (child conduct problems, challenging behaviour, and core autism symptoms) at post-treatment?; 3) Does pre-treatment adjustment differ significantly between mothers and fathers?; and (4) Does the effect of PMI on adjustment (4a) and the effect of adjustment on PMI engagement or outcomes (4b) differ between mothers and fathers? It is important to note that, while we suggest a reciprocal relationship of adjustment and intervention throughout PMI, this was explored through research questions examining each proposed direction of effect (i.e., PMI on adjustment, and adjustment on PMI) individually. Given the lack of prior research on adjustment in the context of PMI for autism, these questions were considered exploratory, and specific hypotheses were not proposed.

Method

Study Design

The current study was part of a larger randomised controlled trial (RCT) evaluating the effectiveness of PWS (Dadds et al., 2025). Ethical approval for this research was provided by the University of Sydney (2020/854; see Appendix 6). Families were randomised to PWS or waitlist control (WL) on a 1:1 basis. Both the PWS and waitlist group were able to receive treatment as usual (TAU) during the study as long as it did not involve parenting support. The design for the trial was a 2 (group: PWS + TAU [PWS], WL + TAU [WL]) × 2 (time: pre-treatment, post-treatment) RCT. The aim of the current study was to explore adjustment to autism diagnosis in this trial. The larger trial was pre-registered (ACTRN12621000596808), however the outcomes measures addressing parent adjustment to diagnosis in the current study were added later and not included as part of this pre-registration.

Participants

Participants were parents (98 mothers, 76 fathers) of 99 children aged 2 years to 5 years 11 months. Three children had an alternative caregiver participate in addition to the mother (1 mother, 1 grandmother, 1 aunt), however these alternative caregivers were excluded from analysis in the current study, due to the focus on comparing results for mothers and fathers. Inclusion criteria for the study were: 1) child aged 2 years to 5 years 11 months with; 2) a prior DSM-5 diagnosis of Autism Spectrum Disorder Level 2 or 3; and 3) parent-reported externalizing behaviour problems. Participants were excluded if: 1) the parents were experiencing severe mental health challenges, domestic/family violence, substance use problems, legal or custody disputes; or 2) the child had a known genetic disorder (e.g., Fragile X), severe developmental delay (developmental quotient [DQ]<35), or another impairment and/or a major medical disorder that impacted participation in the program. See Table 1 for parent and child demographic information.

Table 1 - Pre-treatment demographic and clinical features for parents and children in the Intervention and Waitlist conditions.

	Intervention (PWS, *n* = 49)		Waitlist (WL, *n* = 50)	
	Mean	SD	Mean	SD
Parent/family features				
Mother participating	49 (100%)		49 (98.0%)	
Father participating	35 (71.4%)		41 (82.0%)	
Mother education	4.96	1.04	5.00	1.02
Father education	4.89	1.23	4.88	1.00
Mother age	36.27	5.03	38.12	5.17
Father age	38.83	4.34	40.12	5.20
Household income per year	3.49	1.86	3.31	2.11
Child features				
Age (years)	4.50	.97	4.46	1.10
Gender (male)	39 (79.6%)		43 (86.0%)	
Age at diagnosis (years)*	3.38	1.08	3.42	1.00
Time since diagnosis (years)*	1.11	0.93	1.03	0.86
Ethnicity				
Caucasian	20 (40.8%)		13 (26.0%)	
Asian	7 (14.3%)		9 (18.0%)	
Middle-Eastern	1 (2.0%)		1 (2.0%)	
African/African-American	0		1 (2.0%)	
Other	0		3 (6.0%)	
Multiple ethnicities	21 (42.9%)		23 (46.0%)	
ECBI Intensity raw score (Mother report)*	145.18	38.91	152.71	34.60
ECBI Intensity raw score (Father report)	144.60	38.02	139.75	36.21
ECBI Problem raw score (Mother report)*	17.96	8.47	20.32	7.67
ECBI Problem raw score (Father report)*	18.74	9.82	16.27	8.17
SRS-2 Total (Mother report)*	100.31	23.81	103.00	18.83
SRS-2 Total (Father report)*	94.26	24.87	98.59	21.26
DISCAP-5 Conduct problems	3.33	1.50	3.42	1.46
DISCAP-5 Anxiety/Depression	1.84	18.7	1.48	1.74
DISCAP-5 ADHD	2.53	1.60	2.72	1.98

Parent education: Parent highest level of education on 1–6 scale where 1 = primary school and 6 = postgraduate degree; Household income: Annual household income per year (before tax) on 0–6 scale where 5≧$150k per annum; ECBI = Eyberg Child Behavior Inventory; SRS-2 = Social Responsiveness Scale-2; DISCAP-5 = Diagnostic Interview for Children, Adolescents and Parents-5.

*Due to missing data - Age at diagnosis and time since diagnosis: PWS *n* = 47, WL *n* = 47; ECBI Intensity (Mother report): WL *n* = 49; ECBI Intensity (Father report): WL *n* = 40; ECBI Problem (Mother report): PWS *n* = 47, WL *n* = 47; ECBI Problem (Father report): PWS *n* = 31, WL *n* = 37; SRS-2 Total (Mother report): WL *n* = 48.

Procedure

The study was completed online, through the Child Behaviour Research Clinic at the University of Sydney, with recruitment Australia-wide. Recruitment was conducted by contacting services supporting young children and their families (e.g., daycares, paediatricians), including services likely to support autistic children (e.g., speech therapy, occupational therapy). A flyer with study information and contact information was distributed to these services. Interested parents seeking support to manage externalising behaviour in their young autistic child contacted the University of Sydney Child Behaviour Research Clinic via phone, email, or a webform, and then completed an intake phone call to assess for inclusion and exclusion criteria. Following confirmation of eligibility and parent interest, parents completed an online informed consent form. Parents who consented to participate in the trial completed pre-treatment questionnaires, clinical interview and a family observation assessment, and were then randomly allocated to immediate treatment (PWS; n = 49 children) or 12-week waitlist period (WL; n = 50 children). See Dadds and colleagues (2025) for further detail regarding random allocation and the CONSORT flow chart for recruitment to the trial. Parents in each group completed post-treatment/waitlist assessments after the final session for the PWS group and after 12 weeks for the WL group. The WL group received the PWS intervention after completing the post-waitlist assessment.

Intervention

ParentWorks Spectrum (Leonard et al., 2025) is a manualised PMI. The intervention includes three modules: Module 1 focuses on managing challenging child behaviour, Module 2 focuses on enhancing child social communication and the parent-child relationship, and Module 3 on improving parent well-being and the parenting team. Modules 1 and 3 were adapted from an existing parenting intervention targeting childhood disruptive behaviour (Dadds & Hawes, 2006), while Module 2 was adapted from the PACT parent-mediated autism intervention (Green et al., 2010). PWS does not include specific content addressing parents' adjustment to diagnosis. However, the program includes psychoeducation about autism and externalizing behaviour, parent skill building, and support for parent mental health and well-being, which may have flow-on benefits for parent adjustment. Further, while PWS is a manualised intervention, the program is tailored to the needs of each individual family. Therapists may therefore have included additional content aimed at addressing adjustment to diagnosis more directly, where clinically indicated. PWS was delivered individually to one or both parents, by a clinical psychologist or supervised provisional psychologist. Children generally did not attend sessions, though parents were given the option for their child to attend 1-2 sessions to allow the parent to receive feedback on child-directed play. The program comprised 12-15 weekly sessions of 60 to 90 minutes. Intervention fidelity was reported to be high (Dadds et al., 2025). In the main trial, a significant intervention effect for PWS relative to WL was shown for parent-reported and clinician-rated disruptive behaviour and conduct problems, and parent-reported core autism features, with medium to large effect sizes (Dadds et al., 2025). Significant benefits of the PWS relative to WL were also found for parent sense of competence, stress, and anxiety, with moderate effect sizes, although no significant effect was found for parent depression (Dadds et al., 2025). A prior pilot RCT of PWS also found significant benefits of PWS (n = 14) relative to WL (n = 12) for child behaviour and conduct problems and parent sense of competence, though significant effects for child core autism features or parent stress were not found in the pilot trial (Leonard et al., 2025).

Measures

Parent and child demographic information was collected from all participating parents at pre-treatment.

Adjustment to Autism Diagnosis

Adjustment was measured using a brief version of the Adjustment to the Diagnosis of Autism questionnaire (ADAQ; Da Paz et al., 2018). The original measure includes 30 items to assess adjustment on three subscales - despair, self-blame, and acceptance. For the current study, a brief version of the measure (see Appendix 7) was developed by selecting three out of the four highest loading items from each subscale according to the factor analysis reported by Da Paz and colleagues (2018). Parents reported their agreement with each item on a scale from 1 to 4, and subscale scores were calculated as the mean of items for that subscale. Lower scores on the despair and self-blame subscales, and higher scores on the acceptance subscale, are considered to represent more optimal adjustment. Cronbach's alpha for internal consistency for the brief subscale versions used in the current study (mother despair $\alpha = .67$, father despair $\alpha = .66$, mother self-blame $\alpha = .79$, father self-blame $\alpha = .85$, mother acceptance $\alpha = .45$, father acceptance $\alpha = .49$) were similar to the values reported in the validation of the full scale. For the brief version, given that each subscale comprises three items, mean inter-item correlation is considered a more appropriate measure of internal consistency as compared to Cronbach's alpha (Clark & Watson, 1995). Mean inter-item correlations were acceptable (mother despair .41, father despair .39, mother self-blame .56, father self-blame .65, mother acceptance .22, father acceptance .24), although values over .50 for self-blame may indicate redundancy of items in this subscale.

Child Outcomes

Child outcomes for the current study (Research Question 2) were also the primary outcomes used to evaluate the efficacy of the PWS intervention in the main trial (Dadds et al., 2025). Conduct problems were assessed through clinical interview with the Diagnostic Interview Schedule for Children, Adolescents and Parents-5 (DISCAP-5; Tissue et al., 2022). Based on parent report in the interview, clinicians provided a severity rating for Oppositional

Defiant Disorder and Conduct Disorder (range 1-6, scores >3 indicate that the child meets DSM-5 diagnostic criteria for the diagnosis; American Psychiatric Association, 2013). Ratings across these two diagnostic categories were averaged into an aggregate conduct problems score. DISCAP-5 ratings for anxiety/depression and ADHD are also included in Table 1 for the purposes of characterising the sample, but were not included in analyses given that these were not intervention targets. Child challenging behaviour was also measured using the Eyberg Child Behaviour Inventory (ECBI; Eyberg & Pincus, 1999). The ECBI asks parents to report on the intensity (frequency over the past week) of 36 challenging behaviours on a 1 to 7 scale (summed to ECBI Intensity score), as well as whether each of these behaviours has been a Problem for them ("Yes" responses summed to ECBI Problem score). Child autism features were assessed using the Social Responsiveness Scale-2 (SRS-2; Constantino & Gruber, 2012), a parent-report questionnaire which provides ratings for social communication, social interactions, and repetitive/stereotyped behaviours and interests. The SRS-2 total raw score was used in the current study.

Dropout

Dropout was considered a binary outcome – 'dropout' or 'completer'. Participating parents were classified as a 'dropout' if they discontinued participation after being allocated to the PWS group but before completing all intervention modules. This included participants who completed none or some intervention sessions. This binary outcome does not include a measure of number of sessions completed before dropout. Parents who completed the full PWS intervention were classified as a 'completer'.

Engagement

At the end of each PWS treatment session, each participating parent was asked to self-report their own engagement in that session from 1 (not at all engaged) to 10 (fully engaged).

Clinicians also provided a session rating of engagement from 1 to 10 across both parents. Session engagement ratings were averaged across the course of treatment.

Statistical Plan

Analyses were conducted using SPSS version 28.0 (IBM Corp, 2021), and R (R Core Team, 2025). Analysis first used independent-samples *t*-tests to confirm equivalence of PWS and WL groups for demographic, adjustment variables and child outcomes at pre-treatment. Preliminary analysis using Little's MCAR Test and logistic regression comparing pre-treatment adjustment scores between participants with and without post-treatment questionnaires were conducted to confirm whether missing data (either due to program dropout or questionnaire non-completion) was missing completely at random (MCAR). Given that prior research has shown inconsistent association between child demographic and clinical features and parent adjustment (e.g, Da Paz et al., 2018; Dolev et al., 2016; Poslawsky et al., 2014), preliminary analysis was also used to identify the relationship of pre-treatment adjustment to child factors (age, gender, DSM-5 autism diagnosis Level, and time since autism diagnosis) and pre-treatment scores on primary outcome measures, to identify necessary covariates for inclusion in subsequent analysis.

All analyses for Research Question 1 and 2 were completed separately for mothers and fathers. While conducting separate analyses reduced power as compared to including data from both parents in the one model, this was necessary given that data from parents of the same child are non-independent (Kenny, 2011). Analyses for Research Question 1 used linear regression models to analyse treatment allocation (PWS or WL) as a predictor of post-treatment adjustment, controlling for pre-treatment adjustment. Analyses for Research Question 2 used linear regression in the PWS group only, to examine pre-treatment adjustment as a predictor of average session engagement ratings (parent and clinician), and of post-treatment child outcomes controlling for the relevant pre-treatment score. Analyses for this research question also used independent samples *t*-tests to compare pre-treatment adjustment scores between dropouts and treatment completers, within the PWS group. Analyses for Research Question 3 used paired *t*-tests to compare pre-treatment adjustment scores for mothers and fathers of the same child (n = 75). Research Question 4a and 4b were addressed by rerunning the linear models used in Research Question 1 and 2 respectively, but with data from both parents included and analyses conducted as linear mixed models with the child's ID number included as a random effect to control for non-independence by nesting within each family. Parent gender was also included in the models, and the interaction of parent gender with each predictor was used to identify any moderation effects. These analyses were conducted only for outcomes assessment separately for mothers and fathers; moderator analyses were not conducted for dropout, clinician-rated engagement, or post-treatment DISCAP conduct problems because only one outcome score was available per child for each of these variables (i.e., mother and father outcome variables were identical because ratings were provided across both parents). Holm correction (Holm, 1979) was applied to all p values to account for multiple comparisons.

Post-hoc power calculations using G*Power (Faul et al., 2007) suggested that analyses would be able to detect a small to medium effect of intervention on adjustment (Research Question 1; required Cohen's f = 0.13 for mothers; f = 0.18 for fathers; Cohen, 1988). Small to medium effect sizes were considered feasible based on effect sizes for targeted adjustment interventions (Leadbitter et al., 2025). Analyses for Research Question 2 used the PWS group only, and so would require a medium to large effect size of Cohen's f = 0.38 for n = 49 mothers and a large effect size of Cohen's f = 0.56 for n = 35 fathers to detect an effect. Analyses with this smaller sample size may not have been sufficiently powered to detect a small to medium effect of adjustment on dropout, engagement or child outcomes.

Results

Post-treatment scores were missing for 13 mothers and 16 fathers, due to program dropout or questionnaire non-completion. All variables of interest were found to be normally distributed with appropriate skewness and kurtosis (See Appendix 8). Analysis of baseline equivalence (See Appendix 9) found no significant differences between PWS and WL. Missing data analysis using Little's MCAR test and logistic regression was non-significant across adjustment variables (See Appendix 8). However, given that post-treatment questionnaires were missing for 13% of mothers and 21% of fathers who had completed pre-treatment questionnaires, multiple imputation was used to impute missing post-treatment values for mothers and fathers who had completed pre-treatment questionnaires only. Regression models were calculated for each imputed dataset, with results pooled. Parent-rated and clinician-rated engagement values were not considered appropriate to impute because these were either missing because the clinician did not record session engagement, because the family dropped out of the program (and was classified as a 'dropout') or because an individual parent did not participate in sessions despite completing pre- and post-treatment questionnaires (i.e., the family completed PWS but only one of the parents attended sessions). Sample sizes for engagement analyses are therefore: Mother-rated engagement $n = 40$; father-rated engagement $n = 24$; clinician-rated engagement $n = 44$.

See Table 2 for pre-treatment and post-treatment adjustment scores. Preliminary analyses showed a significant correlation between pre-treatment father-reported child autism features (SRS-2 total) and father despair ($r = .30$, $p = .009$). Mothers of children with a Level 3 autism diagnosis also had significantly higher baseline despair ($M = 2.61$, SD = 0.90) as compared to mothers of children with a Level 2 autism diagnosis ($M = 2.20$, SD = 0.82), $t(96) = -2.23$, $p = .028$. No other child factors or pre-treatment clinical features showed significant associations with parent adjustment. Given that DSM-5 autism level and SRS-2 are both measures of autism features, only child autism level was included as a covariate in regression models.

Table 2 - Adjustment scores for parents in the Intervention and Waitlist conditions.

	Intervention (PWS)				Waitlist (WL)			
	Mothers		Fathers		Mothers		Fathers	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Pre-treatment - Despair	2.32	0.84	2.21	0.84	2.41	0.90	2.24	0.79
Post-treatment - Despair	2.11	0.93	2.17	0.83	2.43	0.87	2.19	0.69
Pre-treatment - Self-blame	2.36	0.98	2.05	0.94	2.46	0.91	2.05	0.92
Post-treatment - Self-blame	2.07	0.92	1.75	0.80	2.36	0.90	2.02	0.86
Pre-treatment - Acceptance	2.66	0.78	2.84	0.64	2.88	0.56	2.72	0.62
Post-treatment - Acceptance	2.85	0.66	2.73	0.73	2.80	0.66	2.73	0.61

Higher adjustment is indicated by lower scores for Despair and Self-Blame, and higher scores for Acceptance.

Sample sizes: PWS Mothers pre-treatment n = 49, post-treatment n = 43;

Fathers pre-treatment n = 35, post-treatment n = 28.

WL Mothers pre-treatment n = 49, post-treatment (post-waitlist) n = 42;

Fathers pre-treatment n = 41, post-treatment (post-waitlist) n = 32.

Research Question 1: Effects of PWS Intervention on Adjustment

Linear regression models with results pooled across imputed datasets showed that treatment allocation (PWS or WL) did not significantly predict post-treatment adjustment (despair, self-blame, or acceptance), in mothers or fathers, when controlling for pre-treatment adjustment as well as pre-treatment child autism severity, with $p > .05$ for all models. See Table 3 for summary of unstandardised coefficients for the effect of treatment allocation on post-treatment adjustment, Appendix 10 for full regression models, and Appendix 11 for figures showing adjustment scores across pre-treatment and post-treatment by group.

Table 3 - Pooled imputed models: Effect of treatment allocation on post-treatment adjustment*

Dependent variable	Mothers		Fathers	
	Unstandardised *B*	*p*	Unstandardised *B*	*p*
Despair	0.224	0.393	0.029	1.000
Self-blame	0.198	0.393	0.149	0.666
Acceptance	-0.165	0.393	-0.026	1.000

*Controlling for the relevant pre-treatment adjustment score, and for Level of autism diagnosis. See Appendix 9 for full pooled models. *p* values adjusted for multiple comparisons.

Research Question 2: Effects of Pre-Treatment Adjustment on Dropout, Engagement and Outcomes

There were no significant differences in pre-treatment adjustment between treatment completers (n = 44 mothers, 32 fathers) and dropouts (n = 5 mothers, 3 fathers). For mothers despair $t(47) = -.41$, $p = .683$; self-blame $t(47) = -.74$, $p = .465$; acceptance $t(47) = .16$, $p = .874$. For fathers despair $t(33) = 1.97$, $p = .058$; self-blame $t(33) = .09$, $p = .928$; acceptance $t(33) = .194$, $p = .848$. Linear regression models did not find mothers' or fathers' pre-treatment adjustment to significantly predict self-reported engagement or clinician-rated engagement, with $p > .05$. Linear regression models also did not find pre-treatment adjustment to significantly predict parent reports of externalising behaviour on EBCI Intensity and Problem scores or child autism features on the SRS-2, or clinician ratings of conduct problems on the DISCAP-5 at post-treatment when controlling for the relevant pre-treatment score, for mothers or fathers, *p*s > .05. See Table 4 for summary of unstandardized coefficients, Appendix 12 for full linear regression models and Appendix 13 for scatter plots showing relations of each adjustment variable to each outcome.

Table 4 - Linear regression models: Effect of pre-treatment adjustment on engagement and child outcomes

	Mothers Unstandardised *B*	*p*	Fathers Unstandardised B	*p*
Self-report engagement				
Despair	-0.095	1.000	0.283	1.000
Self-blame	0.016	1.000	-0.224	1.000
Acceptance	0.168	1.000	0.563	0.555
Clinician-report engagement				
Despair	-0.335	0.762	0.032	1.000
Self-blame	0.018	1.000	-0.229	1.000
Acceptance	0.212	1.000	0.448	0.856
ECBI Intensity				
Despair	6.060	1.000	12.800	0.720
Self-blame	-6.837	1.000	-7.698	1.000
Acceptance	-4.287	1.000	-9.552	1.000
ECBI Problem				
Despair	0.710	1.000	-1.279	1.000
Self-blame	-1.480	1.000	1.160	1.000
Acceptance	0.839	1.000	-1.578	1.000
SRS-2 Total				
Despair	-1.369	1.000	1.798	1.000
Self-blame	-4.454	1.000	1.977	1.000
Acceptance	1.960	1.000	-2.616	1.000
DISCAP Conduct Problems				
Despair	0.346	1.000	0.041	1.000
Self-blame	-0.291	1.000	0.211	1.000
Acceptance	-0.679	0.054	-0.828	0.402

Controlling for Level of autism diagnosis (except for in models for SRS-2), and for the relevant pre-treatment score (except in models for engagement). See Appendix 12 for full linear regression models. *p* values adjusted for multiple comparisons.

Research Question 3: Pre-Treatment Comparison Between Mothers and Fathers

Analyses comparing pre-treatment adjustment scores for mothers and fathers from the same family revealed significantly higher self-blame scores for mothers ($M = 2.41$, SD = 0.96) compared to fathers ($M = 2.06$, SD = 0.92), $t(74) = 2.64$, $p = .030$. No significant differences were found between mothers' and fathers' despair, $t(74) = 1.58$, $p = .256$, or acceptance, $t(74) = 0.31$, $p = .581$.

Research Question 4: Comparison of Effects Across Treatment Between Mothers and Fathers

Moderator analyses revealed no differences in the effect of intervention on adjustment (Research Question 4a) or the effect of pre-treatment adjustment on treatment outcomes (Research Question 4b) between mothers and fathers, $p > .05$ for all interaction terms. Analyses showed a significant interaction effect of self-blame with parent gender, $F(1, 29.78) = 7.95$, adjusted $p = 0.032$, and of acceptance with parent gender, $F(1, 26.73) = 7.29$, adjusted $p = 0.048$. The direction of these effects suggested a strong relationship between pre-treatment adjustment and self-report engagement for mothers. However, engagement data was available for 40 mothers but only 24 fathers, which was lower than the 35 fathers with questionnaire data available for other moderator analyses. Therefore, it was not clear whether the apparent stronger relationship between adjustment and engagement for mothers was an artifact of the larger sample size. Therefore, linear mixed models for engagement were also run only including participants where both parents had self-report engagement data available ($n = 23$). None of the interaction effects were significant in this subsequent analysis. The interaction of self-blame and parent gender showed $F(1, 21.64) = 6.65$, adjusted $p = 0.068$, and the interaction of acceptance and parent gender showed $F(1, 20.56) = 6.81$, adjusted $p = 0.068$. See Table 5 for summary of unstandardised coefficients for each moderator analysis and Appendix 14 (Research Question 4a) and 15 (Research Question 4b) for full linear mixed models.

Table 5 - Linear mixed models: Interaction of parent gender with effect of treatment allocation on adjustment (Research Question 4a) and adjustment on engagement and outcomes (Research Question 4b)

	Unstandardised *B*	*p*
Research Question 4a – Effect of PWS on adjustment		
Despair * Parent	-0.164	0.939
Self-blame * Parent	0.014	0.943
Acceptance * Parent	0.214	0.939
Research Question 4b – Effect of pre-treatment adjustment on outcomes		
Self-report engagement		
Despair * Parent	-0.459	0.152
Self-blame * Parent	0.592	0.032[#]
Acceptance * Parent	-0.627	0.048[#]
ECBI Intensity		
Despair * Parent	3.565	1.000
Self-blame * Parent	-1.232	1.000
Acceptance * Parent	-0.075	1.000
ECBI Problem		
Despair * Parent	-2.127	0.969
Self-blame * Parent	0.740	1.000
Acceptance * Parent	-0.465	1.000
SRS-2 Total		
Despair * Parent	0.377	1.000
Self-blame * Parent	2.465	1.000
Acceptance * Parent	-1.063	1.000

[#]$p < 0.05$

See Appendix 14 and 15 for full linear regression models. *p* values adjusted for multiple comparisons.

Discussion

The current study examined parents' adjustment to their child's autism diagnosis across a RCT of ParentWorks Spectrum (PWS; Leonard et al., 2025), a parent-mediated intervention (PMI) targeting child challenging behaviour, social communication, and parent well-being in families of young autistic children. Research Question 1 evaluated the effect of PWS on parents' adjustment, relative to a waitlist control condition. Despite the main trial finding significant benefits of the intervention for child behaviour, conduct problems, and autism features, and parent mental health and self-efficacy (Dadds et al., 2025), PWS did not improve parents' adjustment to their child's autism diagnosis, relative to the waitlist condition. Analyses for Research Question 2 examining the effects of pre-treatment parent adjustment on the PMI found that parents' adjustment prior to the intervention did not significantly impact dropout, engagement, or intervention outcomes. Research Questions 3 and 4 investigated differences in adjustment and its relation to PMI between mothers and fathers. Mothers reported significantly higher self-blame compared to fathers, with no significant differences in mothers' and fathers' despair or acceptance. The effects of the PMI on adjustment, or of adjustment on PMI, outcomes, did not differ across mothers and fathers. Moderator analyses identified a stronger relation of pre-treatment self-blame and acceptance to self-reported engagement for mothers as compared to fathers. However, the absence of a significant effect of self-blame or acceptance on self-reported engagement in Research Question 2 analyses for mothers only, as well as non-significant follow-up interaction analyses including only participants with self-report engagement available for both parents, suggests that the apparent moderator effect of parent gender may be attributable to the greater number of mothers with self-report engagement data available.

Adjustment in the Context of PMI

The current study was, to our knowledge, the first to investigate whether a PMI for autism improves parents' adjustment to their child's autism diagnosis. It was also the first to examine the effect of adjustment on dropout, engagement, and child outcomes from a PMI. One prior study looked at the effect of adjustment on parents' use of intervention strategies during a PMI and, similar to the current study, found no significant effect (Grogan et al., 2023). Considering the current findings in combination with this past research, it is possible that PMI is not a relevant support for adjustment, and that targeted programs are needed when support for adjustment is required. It is also possible, however, that the current sample were not experiencing adjustment difficulties, because adjustment may impact whether parents access PMI in the first place.

First, it is possible that adjustment is not a relevant construct in the context of PMI. That is, parents' thoughts and feelings about their child's autism diagnosis may have no bearing on their ability to engage in an autism-focused intervention, and seeing their child improve through this intervention may have no significant impact on how parents feel about their child's diagnosis. Indeed, it is possible that parents engaged in PMI may be focused specifically on goals such as reducing challenging behaviour and improving social communication, with no consideration to their thoughts and feelings about the child's autism diagnosis more generally. PMI may therefore not be sufficient to facilitate significant improvements in adjustment to diagnosis, and parents may be able to engage effectively in a PMI regardless of their pre-treatment adjustment. However, concluding that parent adjustment is not an important construct to consider in the context of PMI does not align with parent perspectives in past qualitative research. In a study by Rabba and colleagues (2019), parents described that taking steps to support their child (which could include PMI) was important for their adjustment, but also noted that being overwhelmed by difficulties with adjustment could make it harder to take in information relevant to supporting the child. It is important to note that Rabba and colleagues (2019) explored parents' experiences of adjustment more generally, rather than specifically in relation to PMI. Nevertheless, it appears premature to conclude that adjustment to diagnosis is not relevant to PMI.

An alternative explanation is that adjustment may impact PMI in ways that were not measured in the current study. In particular, adjustment may affect whether parents access PMI in the first place. Parents whose adjustment is particularly low may deny or struggle to believe that their child is autistic (Naicker et al., 2023), and may therefore be less likely to access an autism-focused treatment such as PMI (Gentles et al., 2019). As discussed above, parents who are overwhelmed with difficulties adjusting may also have limited capacity to search for and enrol in a PMI (Rabba et al., 2019). It was outside of the scope of the current study to identify whether adjustment impacted parents' choice to access PMI. This warrants further consideration, however, both as an explanation for the current findings, and as a potential means of improving access to PMI. The current sample may not have included parents who were experiencing adjustment difficulties at a level that would interfere with PMI engagement, completion or outcomes, because parents experiencing adjustment difficulties at this level may not have accessed the PMI in the first place. If adjustment was already relatively high in the current sample at pre-treatment, there may have also been limited scope for the PMI to improve adjustment, thus accounting for the lack of a significant effect of PMI on adjustment. The role that potential sampling bias may have played in the current findings is discussed as a limitation below. Beyond the current study, though, it is important that researchers understand if adjustment impacts whether parents access PMI. PMI is a key evidence-based early support which can provide significant benefit to autistic children and their parents (Conrad et al., 2021; Maglione et al., 2012). It is therefore important to identify whether adjustment may be acting as a barrier to accessing PMI, so that researchers can then identify how to address this barrier.

The current study aimed to identify whether PMI is sufficient to support adjustment, and whether adjustment impacts on PMI. However, on the basis of the current research, we may not be able to determine how parents who are struggling with adjustment respond to PMI. Additional research examining the feasibility, acceptability and effectiveness of PMI for parents experiencing significant adjustment challenges will be important to understand how to address the needs of such parents.

Implications for Supporting Adjustment

Understanding the implications that the current study has for supporting adjustment in clinical practice requires consideration of the current findings in combination with prior research on interventions for adjustment. The current study did not find evidence that PMI can facilitate significant improvement in parents' adjustment to their child's autism diagnosis. This is in contrast to novel, targeted adjustment interventions - the Empower Autism (Leadbitter et al., 2025), SOLACE (Lodder et al., 2020) and complicated grief (Bravo-Benítez et al., 2024) programs – which have demonstrated efficacy for improving parent adjustment in RCTs. This may suggest that intervention to support adjustment needs to specifically target adjustment rather than addressing adjustment through a broad intervention.

However, it is important to consider that there may be important differences between parents who access a targeted adjustment intervention and those who enrolled in the current trial of a PMI for autism and externalising behaviour. Parents accessing a targeted adjustment intervention would presumably do so because they are experiencing more significant adjustment difficulties. In contrast, it is unclear whether parents in the current study were in need of support for adjustment, or whether they were already adjusting well to their child's diagnosis before they enrolled in the PMI. There may therefore have been more scope for the targeted interventions to significantly improve adjustment, if parents started the targeted interventions with lower adjustment in comparison to parents in the current study. It remains unclear whether PMI may be equally effective to a targeted intervention in improving adjustment for parents who have low adjustment at pre-treatment.

There is therefore a need for further research to better understand which parents need support for adjustment, and what the best way to support these parents is. It may be that a targeted intervention is necessary to improve adjustment for parents who are experiencing significant adjustment difficulties. Indeed, parents who are experiencing significant adjustment difficulties may require targeted support to improve adjustment prior to accessing a PMI. Nevertheless, the current findings should be considered preliminary, given the limitations discussed below. There remains a need to consider parsimony before completely abandoning consideration of facilitating adjustment through PMI. It may also be pertinent to consider how more targeted support for adjustment can be delivered in synergy with PMI. For example, augmenting an existing PMI with adjustment-focused components may balance the need for parsimony with the added benefit of targeted support. In the current study, measurement of intervention fidelity did not include recording whether adjustment-focused content was delivered, since such content was not a component of the manualised intervention. It is therefore not known whether and under what circumstances treating clinicians may have included content more directly addressing adjustment, and the effect of such content. Further research would need to address the feasibility, acceptability and efficacy of augmenting PMI with adjustment support, and to consider the ideal timing of adjustment support within a PMI program.

Unique Experiences of Adjustment for Mothers and Fathers

In terms of differences between mothers and fathers, this study found that mothers reported greater self-blame for their child's autism diagnosis as compared to fathers at pre-treatment, but no significant differences were found for despair or acceptance, nor was the effect of PMI on adjustment or adjustment on PMI significantly different between mothers and fathers. Moderator analyses for engagement were inconclusive; initial analyses showed that there was a stronger relation between pre-treatment self-blame/acceptance and self-report engagement for mothers, however subsequent analyses suggested that this result may be due to the much lower number of fathers with self-report engagement data available. The high rate of missing self-report engagement data for fathers suggests that about one third of fathers in the PWS group completed the pre-treatment questionnaires but did not self-report on their engagement, potentially indicated that these fathers did not attend treatment sessions. This may be because fathers of autistic children are more likely to be employed outside of the home as compared to mothers (Blackwell, 2025; Hartley et al., 2014), and therefore fewer fathers may have been able to regularly attend sessions due to other commitments. However, it may also be useful for further research to examine whether adjustment impacts fathers' capacity or choices to attend and participate in PMI sessions.

The limited prior research on fathers' adjustment has had mixed findings regarding differences in adjustment between mothers and fathers. Oppenheim and colleagues (2024) found no significant differences in adjustment between mothers and fathers of the same child. Yirmiya and colleagues (2015), in contrast, found that a higher percentage of fathers reported high adjustment at a first timepoint compared to mothers, but that fathers showed less clear improvement over time as compared to mothers, with some fathers reporting worse adjustment after 3 years. The current study is the first to identify that differences between mothers' and fathers' adjustment may vary depending on the facet of adjustment measured. With limited research including fathers' experiences of adjustment, there is a need to better understand unique – and shared – adjustment experiences and support needs between mothers and fathers.

The finding that mothers reported significantly higher self-blame can be understood within a historical context of researchers, clinicians, and wider society blaming mothers for their child's autism (Courcy & de Rivières, 2017). A leading theory early after autism was defined in the 1940s was that autism was caused by mothers who were cold and uncaring towards their child, or the "refrigerator mother" theory (Cleary et al., 2023). Our knowledge has grown substantially, so that we are now able to understand autism as a neurodevelopmental difference that has a biological basis and is not caused by parenting (Dawson et al., 2023). However, the present findings that mothers reported feeling significantly more self-blame for their child's autism diagnosis as compared to fathers suggests a lingering legacy of the refrigerator mother theory, that mothers may have internalised. Indeed, while we have moved away from blaming mothers for causing their child's autism, research suggests that mothers continue to feel that they are held responsible for their autistic child's behaviour and development, by professionals and members of the public, more so than fathers (Courcy & de

Rivières, 2017; Douglas & Klar, 2019). These experiences sit within the larger context of ongoing inequality in societal expectations for mothers and fathers (Roskam et al., 2022).

Inequality in expectations for mothers and fathers can present challenges not only for mothers, but also for fathers, who often feel excluded from autism-specific supports (Paynter et al., 2018). When fathers are left out of research and clinical intervention, this precludes our understanding of how best to support fathers, and perpetuates gendered expectations of parenting, doing a disservice to mothers, fathers, and children (Rankin et al., 2019). Thus, building in specific strategies to support father engagement and empower co-parents to work as a team (Lechowicz et al., 2019), as was done in PWS, is vital.

Strengths and Limitations of the Current Research

This study had several important strengths. First, about two thirds of participating families identified as culturally and linguistically diverse. This proportion is notably higher than many prior studies examining PMI for autism (Trembath et al., 2019), providing insights into experiences of PMI and adjustment to diagnosis for parents from a more diverse range of cultural backgrounds. Second, the rate of father participation was also notably higher than prior adjustment intervention research (e.g., Leadbitter et al., 2025; Lodder et al., 2020; Lunksy et al., 2021), and autism intervention research (Rankin et al., 2019). This allowed us to address important gaps in our understanding of differences in adjustment between mothers and fathers, with further research needed to identify how best to support adjustment for both mothers and fathers. Third, the use of an adjustment measure with three validated subscales (Da Paz et al., 2018) allowed for a nuanced assessment of adjustment. This highlighted that mothers may experience particular difficulties with self-blame for their child's autism diagnosis, which supports for adjustment should aim to address.

However, the results of the current study may have been impacted by three key methodological limitations. Firstly, the generalisability of the current findings may be limited due to sampling bias. In particular, we may have inadvertently recruited a sample of parents who were higher in adjustment. To be recruited into this trial parents had to self-refer to a university clinic, and be seeking support to manage challenging behaviour in their autistic children. Of note, the only other study that has evaluated adjustment in the context of PMI to date, which found no effect of adjustment on parent strategy use, also recruited through a specialised university clinic (Grogan et al., 2023). Parents experiencing more significant adjustment difficulties may not have had the capacity to find and enroll in such an intervention. As such, it is unclear whether our sample included parents who were experiencing significant adjustment difficulties. While adjustment scores across the three subscales had suitable range and were normally distributed, the lack of a clinical-cutoff for the ADAQ means that it was not possible to identify whether any parents in the sample were experiencing clinically-significant adjustment difficulties. It is also important to note that the majority of participating parents were tertiary educated. While past research has suggested that parent education does not impact adjustment to autism diagnosis (e.g., Dolev et al., 2016; Poslawksy et al., 2014; Zhang et al., 2023), parents' level of education and associated socioeconomic status may have impacted their capacity to enroll and engage in PWS. In addition, participants in the current study did not represent the full range of experiences of parenting an autistic child, because only parents of a child with a Level 2 or 3 autism diagnosis (i.e., requiring substantial or very substantial support) and externalising behaviour challenges were eligible to participate. Some past research has shown higher autism features (e.g., Dolev et al., 2016; Poslawsky et al., 2014; Vitale et al., 2023) and externalising behaviour (Cheung et al., 2019; Wayment & Brookshire, 2018) to be associated with lower adjustment. Indeed, in the current study, higher child autism features were associated with greater despair for both mothers and fathers. Thus, the findings of the present study are not generalizable to all autistic children and their families. This highlights a need to understand experiences of adjustment and PMI for parents of children with a Level 1 autism diagnosis and also parents without significant concerns regarding externalising behaviour in their child. Overall, research exploring adjustment to diagnosis in PMI for more representative samples in community settings, and including parents experiencing significant adjustment challenges, is needed before we can assume that adjustment has no bearing on intervention dropout, engagement or outcomes, or that PMI cannot facilitate adjustment.

Secondly, the ability to detect an effect of adjustment on PMI or vice versa in the current study may have been reduced by limitations of the measures used. While the measure of adjustment used in the current study, the ADAQ (Da Paz et al., 2018), has shown sensitivity to changes in adjustment after 18 months, it is unclear whether the ADAQ is sensitive to changes in adjustment that may occur over a 12-15 week intervention. In addition, an abbreviated version of the scale (9 out of 30 items) was used for the first time in the current study, which may have truncated the range of score and therefore reduced the ability to detect change on this measure. While the Cronbach's alpha values of the abbreviated subscales was equivalent to those Da Paz and colleagues (2018) reported for the full scale, the low alpha values for the despair and acceptance subscales suggest that measurement error may have reduce the estimated effects in the regression models (Cohen et al., 2003). Regarding measurement limitations, it is also important to consider that three of the four child intervention outcomes (challenging behaviour intensity and problem, and autism features) were parent rated. Given that parents could not be masked to intervention condition, these parent ratings may have been biased by intervention expectancy effects, which may have obscured a possible effect of pre-treatment adjustment on these child outcomes.

The measure of engagement used in the current study was not validated. Also, parents were asked by their treating clinician to self-report engagement at the end of each session, and may have rated their engagement more highly due to social desirability effects. While engagement variables demonstrated appropriate skewness and kurtosis, these measurement limitations may have reduced the range and therefore the ability to detect an effect. We attempted to address this by also including a more objective clinician rating of engagement, however this was limited to one single rating across the parent dyad rather than separate ratings for mothers and fathers. Furthermore, engagement was defined here as within-session engagement. We were therefore not able to examine the effect of adjustment on other aspects of parent engagement, such as regular attendance or between-session practice of skills. Future research may benefit from using a structured model of engagement such as the Connect, Attend, Participate, Enact model (Piotrowska et al., 2017). This model defines connecting, attending, participating, and enacting as components of engagement in a parenting intervention. Therefore, to more thoroughly understand whether adjustment impacts PMI at any stage, it may be helpful for research to use validated measures of engagement that specifically address each of these components. This would also allow for an understanding of whether adjustment influences parents' motivation or capacity to access a PMI.

Finally, post hoc power analyses suggest that the current study was likely underpowered to detect an effect for Research Question 2, given that this utilised the PWS group only and therefore had a reduced sample size. Power to detect an effect for engagement may also have been further reduced by the relatively large number of participants with missing engagement data, especially for fathers (about 18% of mothers and 31% of fathers in the treatment group). This missing data may have been due to one parent in the dyad not attending treatment sessions, or may have been due to clinicians not completing weekly engagement ratings. It will be important for future research using larger samples, with adequate power to further examine the relation of adjustment to PMI engagement and outcomes.

Conclusion

The current study was the first to evaluate whether a broad intervention for autism – PMI – has flow-on benefits for parents' adjustment to their child's autism diagnosis. This was also the first study to evaluate whether parents' adjustment influences engagement in or dropout from intervention, their ability to benefit from the intervention in terms of child outcomes. This study found no significant effect of the PWS intervention on parents' adjustment relative to a waitlist control condition, and no effect of pre-treatment adjustment on intervention dropout, engagement or outcomes. Finally, the study added to our limited understanding of adjustment to diagnosis for fathers, and found a need to support mothers with self-blame specifically. The current study suggests that a broad intervention may not be sufficient to facilitate adjustment. It may therefore be necessary to address significant adjustment difficulties by delivering more targeted intervention for adjustment or augmenting PMI with adjustment-focused support. However, parents who have capacity to access PMI may be less in need of support for adjustment as compared to other parents, and it remains unclear how parents experiencing significant adjustment difficulties respond to PMI. Given that supporting parental adjustment through a broad PMI approach may be parsimonious with time and cost benefits to families, there is a clear need for additional research, with more reliable and sensitive measures and in community settings – before we can conclude that PMI does not have a role to play in supporting adjustment to diagnosis.

STUDY 3 - "My child is autistic. What the heck do I do next?": A qualitative study examining parent adjustment to autism diagnosis and experiences of parent-mediated intervention

Abstract

Following a child's diagnosis of autism, parents undergo a process known as adjustment to diagnosis, which involves coming to understand what the child's diagnosis means for themselves and their child (Pianta & Marvin, 1993). Adjustment can be a complicated, ongoing process, which has implications for parent and child well-being. There is therefore a need to better understand parents' perceptions of this journey, their adjustment support needs, and how existing supports such as parent-mediated intervention (PMI) fit into this journey. The current study examined perceptions of adjustment in 29 parents (7 mother-father dyads, 14 individual mothers, 1 individual father) of autistic children aged 4-8 years with externalising behaviour problems who had completed a PMI, ParentWorks Spectrum. Participants completed semi-structured interviews about their adjustment journey, including the role of PMI in this journey, which were analysed using reflexive thematic analysis. Three key themes were identified: 1) Feeling out of control, 2) Becoming agents of change, and 3) Accepting that what will be will be. These themes informed the development of the Active Balance model of adjustment to diagnosis, which explains adjustment as a process of actively gaining a sense of control over uncertainty by balancing acceptance with change. This model identifies parents as empowered agents of their own adjustment, in contrast to previous models of adjustment as a passive process. Parents identified PMI as one of several possible supports for their adjustment, and emphasised the need to improve the process of diagnosis. Clinical implications for improving diagnostic processes and post-diagnosis support are discussed.

“My child is autistic. What the heck do I do next?”: A qualitative study examining parent adjustment to autism diagnosis and experiences of parent-mediated intervention

Introduction

When a child is diagnosed with autism, their parent (the term ‘parent’ is used here to refer to parents and other primary caregivers) often receives inadequate support to understand and make sense of this diagnosis (Crane et al., 2016; Eggleston et al., 2019; Makino et al., 2021). In particular, there is a need to better support parents’ adjustment to their child’s autism diagnosis (Green et al., 2022). Adjustment to diagnosis refers to the process by which parents come to an accurate understanding of what the autism diagnosis means for the child, parent and family (Pianta & Marvin, 1993). This process involves parents working through their initial emotional response to the diagnosis, which can range from shock, despair, grief, worry, relief, and hope (Fernandez-Alcántara et al., 2016; Mansell & Morris, 2004; Rabba et al., 2019), as well as ongoing thoughts and feelings about the diagnosis (Alimohamadi et al., 2024; Fernández-Alcántara et al., 2016 Pianta & Marvin, 1993). Better adjustment is associated with more positive parent mental health and well-being (Da Paz et al., 2018; Dolev et al., 2016; Jones et al., 2014; Vitale et al., 2023), and better overall functioning of the family system (Milshtein et al., 2010). Accordingly, understanding adjustment can provide insights into how best to support parents and families following an autism diagnosis. It is particularly important to understand how parents perceive that evidence-based supports influence their adjustment. Parent mediated interventions (PMI) are one such evidence-based support that are regularly provided to parents (Bearss et al., 2015). In PMI, parents are trained in strategies so that they can act as the “agent of change” (Bearss et al., 2015, p. 6), developing skills or reducing challenging behaviour in their child. Given parents’ active role in PMI, it is important to understand how PMI may contribute to parents’ process of adjustment.

Theoretical Assumptions: Adjustment as a Process of Responding to Ambiguous Change

Adjustment to diagnosis is understood as a process that occurs over time (Marvin & Pianta, 1996). Much previous research has used models of grief to understand the process of adjustment to autism diagnosis (see Negri & Castorina, 2014 for a review). While parents do not experience the actual loss of their child, grief models are considered relevant based on research showing that parents often respond to an autism diagnosis by grieving the future they had envisioned for their child, which may include culturally-based goals such as the child getting married and having children, or broader goals such as the child having a happy life (Bravo-Benítez et al., 2019; Gentles et al., 2019). O'Brien (2007) suggested that ambiguous loss (Boss, 1999) may be the most relevant grief-based theoretical model for understanding adjustment to autism diagnosis specifically. This theory explains that adjusting to a loss which is unclear can be more challenging and prolonged as compared to typical grief (Boss, 1999). Adjusting to an autism diagnosis is considered unclear due to factors such as the diagnosis of autism occurring through clinical decision-making (as opposed to biological testing), significant variability between autistic people, and difficulty predicting long-term outcomes (O'Brien, 2007). In other words, adjustment to autism diagnosis may be particularly complex because it is not clear to parents what exactly they are adjusting to.

However, defining autism as a loss is not consistent with the current neurodiversity-affirming conceptualisation of autism as a variation in development rather than a pathology (Kapp et al., 2013). Indeed, not all parents experience their child's autism diagnosis as a loss (Mansell & Morris, 2004). A revised conceptualisation of ambiguous loss as *ambiguous change* is therefore proposed to underpin adjustment to autism diagnosis. It is also important to note that, in the current study, we wanted to understand parents' own perspectives on autism without presupposing perspectives such as a medical (i.e., viewing autism as pathology) or neurodiversity (i.e., viewing autism as a natural variation in development; Kapp et al., 2013) model.

Evidence-based Support and Adjustment

To improve support for adjustment, it is important to examine how parents perceive that existing supports impact their adjustment, as well as exploring their perceptions of further support needs. Research has identified a lack of supports focused specifically on parent mental health and well-being in parents of autistic children (Kulasinghe et al., 2023). Novel interventions specifically targeting parent adjustment have demonstrated efficacy in randomised controlled trials (Bravo-Benítez et al., 2024; Leadbitter et al., 2025; Lodder et al., 2020), but are not widely available at present. Parents are more likely, though, to be engaged in intervention focused on outcomes for their child (Wainer et al., 2017). It's therefore important to understand how parents perceive involvement in intervention for their child to affect their adjustment to diagnosis.

In particular, parent-mediated intervention (PMI) is a common, evidence-based support delivered to young autistic children and their parents (Conrad et al., 2021). PMI is a category of interventions where the parent is taught strategies to deliver intervention to their child, usually focused on managing challenging behaviours or supporting their child's acquisition of specific skills (Bearss et al., 2015; Schultz et al., 2011). PMI has been found to lead to increases in parents' knowledge and skills (Liu & Schertz, 2022) as well as positive child outcomes such as improved social communication and reduced challenging behaviour (Conrad et al., 2021). It is feasible that these improvements in parent knowledge and skills, and in child functioning, may influence parents' thoughts and feelings about the diagnosis. In fact, some parents describe that taking practical steps to support their child – such as learning about autism - facilitates their adjustment (Downes et al., 2021; Rabba et al., 2019; Smith et al., 2023). At the same time, parents have also noted that challenges with adjustment can make it harder to engage with supports or learn information (Abbott et al., 2012; Rabba et al., 2019; Smith et al., 2023). Adjustment difficulties may therefore interfere with parents' capacity to engage in and benefit from PMI. However, research has not yet examined parent perceptions of whether and how PMI influences adjustment to diagnosis.

There is also a broader need to understand parent perceptions of their adjustment support needs, and perspectives on how services can better meet these needs. Reed and colleagues (2019) found that elements of the diagnostic process itself, such as the length of the process and perceived interpersonal skills of the diagnosing clinician, may impact parents' adjustment to the diagnosis. Rabba and colleagues (2019) identified additional adjustment support needs following the diagnosis, including information about autism, planning and guidance on available next steps, parent self-care, and recognition of the diagnosis by others such as family and friends. Together, this past research suggests that efforts to improve parent adjustment to diagnosis likely need to focus across the entire adjustment 'journey', including the process of assessment and diagnosis, immediately post-diagnosis, and ongoing. There is therefore a need to more comprehensively understand parent perspectives on their support needs throughout this adjustment journey.

Study Aims

The current study explored perceptions of adjustment to child autism diagnosis among a group of parents of autistic children aged 4 to 8 years, who had completed a PMI. To understand the role of PMI in parents' adjustment journey, it was important to develop a broader understanding of their overall journey of adjustment. Therefore, the study aimed to: 1) explore parents' perceptions of their overall journey of adjustment to their child's autism diagnosis; 2) explore parents' perceptions of how PMI fit within this overall journey; and 3) understand parents' additional adjustment support needs.

Methodology

Participants

Participants were drawn from a sample of 90 families who had completed a specific PMI, ParentWorks Spectrum (PWS; Leonard et al., 2025) when their child was aged 2-5 years. See Dadds and colleagues (2025) for a summary of inclusion criteria and participant demographics for the larger study. Given that an aim of the current study was to explore parents' perceptions of how the PMI fit within their overall adjustment journey, only parents who had completed the entire program were eligible to participate in the current study. Parents who had dropped out prior to completing PWS were not eligible because they would not have been able to comment on how the program as a whole fit within their adjustment journey.

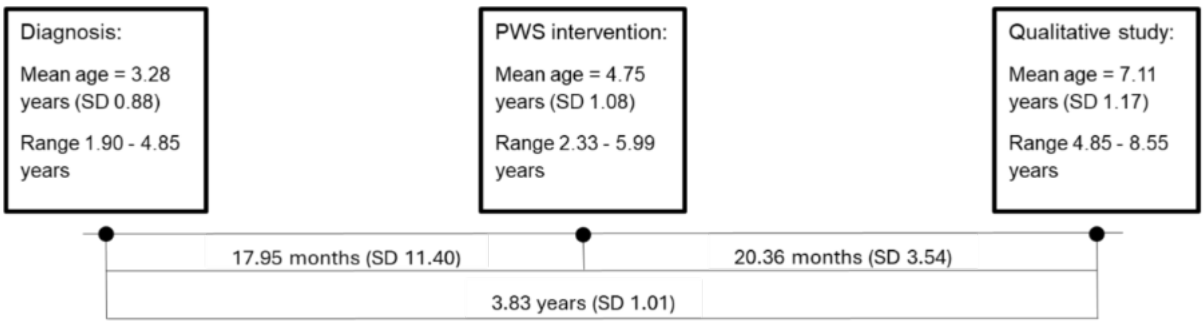
Information regarding participation in this qualitative study was sent to 43 families. A sample of 29 parents (7 mother-father dyads, 14 individual mothers, 1 individual father) from 22 families participated in this study, representing 51% participation rate among contacted families. See Table 6 for parent demographic information. One mother and one father self-identified as autistic. Children of participating parents were 18 boys and 4 girls. Children were aged 4-8 years, and had a prior diagnosis of autism Level 2 or 3. Children also had parent-reported externalising behaviour problems, at the time of participation in the larger study. See Figure 3 for a timeline of children's average age at autism diagnosis, intervention, and participation in the current study.

Parents who participated in the current study had a significantly longer time between the child's diagnosis and their commencement of participation in PWS (M = 17.95 months, SD = 11.40 months), as compared to parents who participated in the larger study only (M = 12.33 months, SD = 11.20 months), $t(100) = 2.01$, $p = 0.048$. No significant differences were found between the sample of parents in the current study and those in the larger study on other demographic or pre-treatment clinical variables (e.g., child age, household income, child autism features, parent- and clinician-rated behaviour and conduct problems, parent mental health; see Dadds et al., 2025 for information regarding measurement of clinical features in the larger study).

Table 6 - Parent self-reported demographic information.

	Mothers (*n* = 21)	Fathers (*n* = 8)
Age – Mean (SD)	38.38 (5.64)	39.50 (5.07)
Ethnicity		
Caucasian	7 (33%)	6 (75%)
East Asian	3 (14%)	1 (13%)
South Asian	2 (10%)	None
Middle-Eastern	2 (10%)	None
Turkish	1 (5%)	None
Greek-Cypriot	1 (5%)	1 (13%)
Multiple	5 (24%)	None
Education		
Secondary school	3 (14%)	1 (13%)
Undergraduate degree, diploma etc.	8 (38%)	4 (50%)
Postgraduate degree	10 (48%)	3 (38%)

Figure 3 - Timeline of diagnosis and study participation.



Intervention

ParentWorks Spectrum (PWS; Leonard et al., 2025) is a manualised 12-15 week PMI for parents of autistic children aged 2-5 years. Participating parents meet weekly one-on-one via Zoom with a psychologist to learn evidence-based strategies to manage challenging behaviours in their child, engage their child in reciprocal play interactions, and improve parents' well-being and ability to work as a caregiving team. The child was not involved in sessions, apart from one session where parents received feedback on a play interaction with the child. The intervention led to significant reductions in parent- and clinician-rated challenging behaviour and parent-rated autism features, along with improvements in parent mental health and perceived competence, relative to a waitlist control group (Dadds et al., 2025).

Procedure

The study was approved through The University of Sydney Human Research Ethics Committee (see Appendix 6). Participants who had previously completed PWS as part of the larger study were contacted via email with information regarding this study, up to three times. Further information was provided to interested parents by phone, and parents then provided informed consent online via REDCap. Participants were contacted in order of enrolment in the larger study, until saturation of meaning was reached. The interviewer kept a log documenting when new ideas relevant to the research aims were brought up in an interview, and saturation was defined as no new ideas logged in three consecutive interviews (Hennink et al., 2017).

Researcher Positionality and Community Involvement

The first author (ECW) conducted all interviews and led data coding. ECW was a female PhD candidate and psychologist; participants were informed of these qualifications and that the interviewer was involved with the research team that conducted PWS. ECW is neither autistic nor a parent/caregiver. At the time the interviews were conducted, ECW had seven years of experience interacting with autistic people and their parents across clinical and research settings, including work as part of a team conducting autism diagnostic assessments in young children. This research was completed as part of ECW's doctoral dissertation.

The research was conducted with an advisory group of three parents of neurodivergent children; two with adult children, and one with school-age children. The advisory group were engaged in the development and piloting of the interview protocol, coding of transcripts, discussion of themes, and editing of the manuscript. One parent (JF) was involved more extensively in the thematic analysis. JF approached this research as a psychology student and as a parent of neurodivergent children. Her lived experience not only shaped her academic interest in autism but also fostered a continuing connection to the topic. Having first-hand experience with the emotional process of receiving her child's diagnosis and navigating the adjustment process, she brings insight into the complexities of parental adjustment, and the importance of recognising the lived, relational, and social dimensions of parenting children with autism.

Dataset Generation

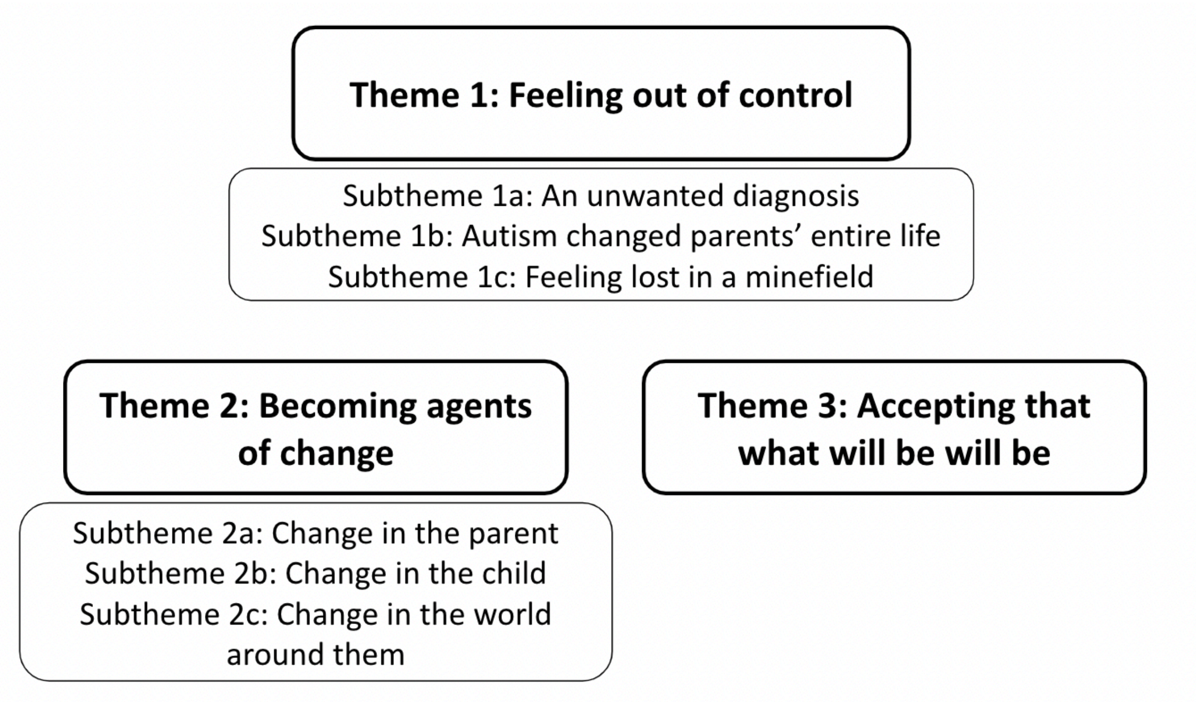
Participants completed a semi-structured interview with ECW via Zoom. Where both parents from a family participated, the two were interviewed together, and the interviewer attempted to elicit responses from each throughout. Interviews were an average duration of 76 minutes (range 58 to 97 minutes). Interviews were conducted in a semi-structured format, based on a protocol that included questions regarding the process of autism diagnosis, adjustment to diagnosis, PWS, and a debrief (See Appendix 16). The interviewer used the language of participants where possible - for example, individual preferences were followed for person-first (i.e., person with autism) or identity-first (i.e., autistic person) language (Taboas et al., 2023). The protocol was developed by ECW, in collaboration with other authors, and based on relevant recommendations (Cridland et al., 2015), and was piloted with two parents from the advisory group. Changes were made after each pilot based on their feedback, including adding questions and changing the order of sections.

Interviews were recorded and automatically transcribed through Zoom. Transcripts were then edited for accuracy by research assistants who viewed the video recording while correcting the transcript. De-identified transcripts were coded using reflexive thematic analysis (Braun & Clarke, 2006). We applied a contextualist theoretical perspective (Willig, 1999), recognising that parents' experiences of adjustment are informed by elements of their context including sociodemographic features, prior knowledge of autism, and facets of the diagnosis and available post-diagnosis support. Recognising that participating parents each had unique elements of context, as well as shared elements (e.g., participated in PWS, resided in Australia, child has received a formal diagnosis of autism Level 2 or 3), applying the contextualist perspective allowed us to recognise parents' unique, contextually-informed experiences of adjustment, but also to draw out concepts that may be central to the adjustment process through PMI. Coding was focused at the semantic level, and was inductive. Coding was predominantly completed independently by ECW; however early in the coding process, ECW and JF coded one full transcript together, engaging in discussion throughout to collaboratively decide on each code. Insights from these discussions were recorded and considered in ongoing coding. ECW completed coding by reading each transcript and assigning a code to each idea identified in the data. Following coding of all transcripts, ECW and JF worked collaboratively to cluster codes based on similarities in meaning, creating 39 clusters (See Appendix 17 for a list of clusters). Consideration of clusters and included codes was used to develop themes and subthemes. Themes were reviewed and revised, considering coded extracts in each theme as well as the overall scope of codes, clusters and themes. This process confirmed that themes were internally homogenous and externally heterogenous (Braun & Clarke, 2006). Following revision of themes, ECW and JF discussed and agreed on three themes, with Theme 1 and Theme 2 each having three subthemes (See Figure 4). Consideration of these themes in combination with relevant theory then led to the development of an overarching conceptual model of adjustment (See Figure 5).

Results

To address Aim 1, three themes were developed to explain parents' overall adjustment journey. See Figure 4 for a thematic map. Parents' initial adjustment to their child's autism diagnosis was characterised by 'feeling out of control' (Theme 1). Three subthemes - 'an unwanted diagnosis', 'autism changed parents' entire life', and 'feeling lost in a minefield' - explained the factors that contributed to this uncertainty and lack of control for parents. Theme 2 and Theme 3 captured the ways parents worked to gain a sense of control. Parents adjusted to their child's diagnosis by both 'becoming agents of change' (Theme 2) and 'accepting that what will be will be' (Theme 3). Becoming agents of change (Theme 2) included three subthemes - 'change in the parent', 'change in the child', and 'change in the world around them'. Regarding Aim 2, the PMI was identified as one of many ways parents worked towards change (Theme 2) and acceptance (Theme 3). Regarding Aim 3, supports which reduced uncertainty (Theme 1) and supported change (Theme 2) and acceptance (Theme 3) were identified as additional support needs.

Figure 4 - Thematic Map



Theme 1 – Feeling out of Control

Parents described experiences around the time of their child's autism diagnosis as feeling out of their control. The process of diagnosis was often long, confusing and "disjointed" (Father; son diagnosed age 2). Some parents came into this process with negative perceptions of autism, and so the child’s diagnosis felt “unfair” (Mother; son diagnosed age 3). One mother (son diagnosed age 3) described receiving the diagnosis as “stepping into the unknown”, because parents were given insufficient guidance or support. Another mother (son diagnosed age 2) stated that “it didn’t have to be that hard”.

Subtheme 1a: An Unwanted Diagnosis

Some parents reported entering their child’s autism assessment with “no knowledge of autism” (Mother; son diagnosed age 2). Parents who had previously heard about autism reported having a limited understanding based on stereotyped, negative representations in the media. For example, one mother (son diagnosed age 4) shared “When you were thinking autistic people, you say, ‘Oh, they don't make eye contact. They are not social at all’”. Some parents therefore regarded autism as an undesirable diagnosis, viewing alternatives such as speech delay or developmental delay more favourably.

Some parents described receiving their child’s autism diagnosis as “devastating”, and reported feeling “sad” or “frustrated”. Some parents reported experiencing denial - “I kept saying ‘maybe they misdiagnosed’” (Mother; son diagnosed age 3). For others, the diagnosis set off a period of “grieving what you thought [the] child’s life is going to be” (Mother; daughter diagnosed age 3) and “grieving the life I thought I would have” (Mother; son diagnosed age 3).

Some parents instead reported that they were “never upset” (Father; son diagnosed age 3) by the child’s diagnosis. Some saw the diagnosis as “a relief, because before I was getting blamed” (Mother; son diagnosed age 5). Others saw the diagnosis as helpful in allowing them to better understand the child and access support, with one father (daughter diagnosed age 2) noting “I think the only change [brought by the diagnosis] was basically: okay, you got the confirmation, so you can actually get some funding for [the child]”.

Subtheme 1b: Autism Changed Parents’ Entire Life

Parents described the child's autism diagnosis as a turning point at which "everything resets... everything changes, everything shifts" (Father, daughter diagnosed age 3). Some reported coming into parenting with ideas of what their child and their life as a parent would be like; one mother (son diagnosed age 3) therefore described that "I was sad for myself that raising him wasn't gonna be like what I might have imagined" (Mother, son diagnosed age 3). For some, supporting their child's additional needs meant that parenting was significantly more challenging than they had expected. Parents talked about being "in the trenches" (Mother; son diagnosed age 4) managing daily challenges including communication, sleep, sensory overwhelm, and physical health problems. One father (son diagnosed age 2) explained "it's kind of like we've been parenting an infant for eight years". Some parents reported making major life changes, such as giving up their career, or moving to Australia to access better supports for the child.

For some, parenting their child was different not only from what they had expected, but also from the experiences of people around them parenting neurotypical children. They discussed managing "layers that typical parents don't have to navigate" (Mother; daughter diagnosed age 3), including taking the child to therapies, understanding and planning for their sensory needs, and advocating for the child to receive suitable support at school. Parents also felt that they needed to plan more for the future than a parent of a neurotypical child - "There's a lot of worry around like what their life is going to look like, and when you're gone, who's gonna care for your child" (Mother; daughter diagnosed age 3).

Subtheme 1c: Feeling Lost in a Minefield, At Diagnosis and Beyond

Gaps in the diagnostic process, in post-diagnosis support, and in ongoing services were described to increase uncertainty. During the diagnostic process, parents were confused by "conflicting information" (Father; son diagnosed age 2) from different professionals. Parents were also confused when professionals dismissed their concerns about their child's development - “We took him to several hospitals to get him checked, and they kept saying, there's nothing wrong with him” (Mother; son diagnosed age 3). Parents reported that professionals gave alternative explanations such as boys being slower to develop, or the child’s behaviour being a phase. Some parents felt blamed for the difficulties they were seeking support with – one mother (son diagnosed age 4) recounted that paediatrician had told her “No, no, there's nothing wrong with your kid. It's you, if you gave them a better diet, and if you were more organized and had more routine, your kid wouldn't be like this”. Parents therefore felt that they had to push for the child to be assessed and diagnosed, which was challenging when the parent was unsure themselves.

Once the formal diagnosis of autism was given, parents reported experiencing further uncertainty because they received little information about what autism is, what to do next, or what the diagnosis would mean for the child’s future: “I didn't know anything about autism really, so it was a huge unknown. I think at the beginning all I wanted to know was what's he going to be like? What am I trying to get my head around here? And no one was able to tell me” (Mother; son diagnosed age 2). Parents felt like they had little to no help in navigating these unknowns – “You're not given a pathway at a paediatrician's office on what you should do next. That's solely up to the parent, and you go home and you Google” (Mother; daughter diagnosed age 3). Trying to navigate the “big minefield” (Mother; son diagnosed age 4) of available resources felt like a “full time job” (Mother; son diagnosed age 3) for many parents.

Even as parents came to understand their child’s support needs, finding services to meet these needs could be an ongoing challenge. Reported barriers to accessing appropriate services included long waitlists and concerns that “[many programs are] not evidence-based, or they're run by people that are just simply not qualified” (Mother; son diagnosed age 4). Parents described particular challenges finding services specialised in support needs such as managing self-injurious behaviour or using Augmentative and Alternative Communication (AAC) -

“When you have a child with complex needs that becomes less of a pool of people that you can actually work with” (Mother; daughter diagnosed age 3). These gaps led to an ongoing sense that things were out of parents’ control, making it more challenging to adjust to the child’s diagnosis.

Parents shared that their difficulties with adjustment could have been minimised by clear information about autism and the available next steps at the time of diagnosis - “When I first got his diagnosis, I wish I had someone to tell me what to do because we didn't know” (Mother; son diagnosed age 3). Some had wanted professionals to provide evidence-based resources or recommendations regarding support. Others would have preferred to be connected with other parents of autistic children who could provide not only information, but also social connection and hope for the future - “after they share some information to me, and how their kids look like now, I feel more comfortable” (Mother; son diagnosed age 4). Other parents were hesitant to put too much weight on others’ personal experiences and noted concerns about the potential spread of misinformation. One mother (son diagnosed age 4) cautioned that “autism is one of those diagnosis where there's a lot of information in the community that, sadly, is not correct, or may be harmful for your child”. She explained that support groups should therefore be “led by someone with experience and with knowledge in the evidence base” so that they don’t become “an unguided trainwreck” where inaccurate information could add to confusion and hinder adjustment. Some parents also felt excluded from spaces such as parent support groups where “their lived experience of autism was very different to mine” (Mother; son diagnosed age 1) given the notable variability in autism.

Theme 2 – Becoming Agents of Change

One way that parents gained a sense of control was by actively putting effort into supporting their child - “it's gotten better because we kept searching for how to help him”

(Mother; son diagnosed age 3). Through this effort, parents became agents of change in themselves, the child, and the wider community.

Subtheme 2a: Change in the Parent

Parents felt that “it kind of gets better as you learn more” (Mother; son diagnosed age 3), because learning helped parents to understand their child and to effectively manage their child’s challenges. Within this subtheme, parents described that PWS had empowered them with strategies that made their life “easier” (Mother; son diagnosed age 4) and made them feel “confident” (Mother; son diagnosed age 2) in parenting their child. One father (son diagnosed age 3) described the program as “very useful just for us to get a more well-rounded picture of how to deal with specific behaviours, and how to engage with him”, highlighting changes to his capacity to manage challenging behaviour and to connect with his child. With these skills, parents felt more in control - “Now I have the confidence... I don't let their behavior dictate my life where before, their behavior was dictating the way I react and parent them” (Mother; daughter diagnosed age 3). There was a recognition that parents’ active involvement in therapy through programs such as PWS was key to this change in the parents, and to their child’s success - “Most of the responsibility sits with us, to teach and to enforce and to practice the behaviours… that his therapists are teaching him” (Father; son diagnosed age 3). Beyond PWS, parents identified other sources of learning as important, such as reading online resources and learning from other parents of autistic children.

Recognition of their role as the agent of change driving improvements in their and their child’s life empowered parents, but also created an overwhelming sense of responsibility and “guilt when you're not doing something” (Mother; son diagnosed age 2). Parents noted ongoing mental health challenges, including stress, worry, and loneliness. Nevertheless, some parents also reflected that putting in work to support their own mental health and well-being was integral to being able to continue supporting their child, with one father (son diagnosed age 2) finding that “there's just no way you can regulate him unless you're regulated yourself”. PWS was identified to be instrumental in parents learning the importance of caring for their own mental health, and in “giving those strategies and tools to be the parent to self-regulate" (Mother; daughter diagnosed age 3). Parents noted that this support for themselves was typically not offered in supports for their child, and highlighted the combination of child-focused and parent-focused strategies as an important benefit of PWS - “it was excellent that it was focusing on parents as opposed to [just the] child, because we matter too” (Mother; son diagnosed age 3).

Subtheme 2b: Change in the Child

Putting in work allowed parents to see their child make progress, which in turn made them feel better about the child’s autism diagnosis and more in control of the situation - “Progress helps us feel good about it and assures us that he’ll probably be ok” (Father; son diagnosed age 3); "I see the improvements, and that brings me more confidence, and I think I'm not upset with his diagnosis anymore, I'm confident” (Mother; son diagnosed age 2). Parents defined progress by seeing their child happier, more settled, and/or developing new skills that supported their independence. Reflecting specifically on PWS, parents identified improvements in the child’s behaviour and emotion regulation, and specific changes such as the child becoming toilet trained and being able to sleep through the night as a result of strategies they learned through the program. One mother described “the way he communicates with us changed... his general acts became more relaxed. [He will] point out what he wants instead of the screams that he used to do” (Mother; son diagnosed age 3).

Some parents saw that their child “fitting in” (Mother; daughter diagnosed age 2) with neurotypical peers, or autistic traits becoming “less evident” (Father; son diagnosed age 3) was the main indicator of progress - “I would expect after I do all the things I can help him, he will get better or close to the normal kids” (Mother; son diagnosed age 4). Some parents described that they were more able to accept their child's autism diagnosis as the child appeared less autistic - "The more normal that he behaves, I guess it doesn't really make a difference, but the more satisfying it is" (Father; son diagnosed age 3). This suggests that, while parents were working to adjust to their child's autism diagnosis, some were also trying to adjust the child to meet their ideal of a neurotypical child.

Subtheme 2c: Change in the World Around Them

Parents also advocated for broader changes in their community. Advocating for the child's needs to be appropriately met at school was common, and included daily discussions with teachers as well as "[writing] to the Minister [for Education], ringing Department of Education every other day" (Mother; son diagnosed age 3). Parents also described broader efforts to increase understanding of autism among the public - "If we're out in the community and [child] behaves a certain way, then I will 100% educate that person on, this is my daughter, she has autism, she has every right to be here. I will always be her biggest advocate" (Mother; daughter diagnosed age 3). Some parents reported building their child's skills in self-advocacy, such as being able to advocate for their own needs at school. Being an agent of societal change through advocacy was described as "a very hard path to decide to take" (Mother; daughter diagnosed age 3).

Overall, this theme explains that parents may attempt to adjust by changing the situation they are adjusting to – including themselves, the child, and the world around them - rather than adjusting to the situation as it is.

Theme 3 – Accepting That What Will Be Will Be

Parents also gained a sense of control over their situation by accepting that some things are out of their control. Multiple parents shared a common reappraisal of their situation: "it is what it is". This captured parents' recognition that, no matter how much work they put in, there were some immutable aspects of their situation - "That's been a really long journey of acceptance to accept that [child] is always going to need a lot of support just to do the most basic things" (Mother; daughter diagnosed age 3). The potential for improvement was seen as constrained by the child's capacity, with progress sometimes facilitated by the passing of time rather than the parents' own efforts - "He'll do things when he's ready, if he will ever be ready" (Mother; son diagnosed age 1).

While PWS didn't directly target adjustment to diagnosis, some parents reflected that learning more about autism through the program helped them to understand and accept their child and the diagnosis. One mother (son diagnosed age 4) described that participating in PWS helped to "reframe some of my thinking around [child]'s challenging behaviours" allowing her to be more accepting of the diagnosis and of her child's autistic traits. Other parents reported speaking with their PWS therapist during the program more specifically about difficulties adjusting to the child's diagnosis. One mother (son diagnosed age 3) described that having space to talk about her adjustment challenges during PWS "felt like I got something out of my chest", but nevertheless noted ongoing difficulties adjusting to her son's diagnosis - "I'm still trying to convince myself that it's ok".

One father (son diagnosed age 3) also reported seeking individual therapy with a psychologist to address challenges adjusting to his son's diagnosis, but explained acceptance to come from a combination of targeted support, learning about autism, and the passing of time - "I need[ed] support, but also need[ed] to process all these things, and read and to have a better understanding of what it is, and to finally accept things". Social support, especially connecting with other parents of neurodivergent children who "[get] it straight away because [they've] been there" (Mother; son diagnosed age 3), was also seen as conducive to acceptance - "hearing [similar experiences] from other parents has a really affirming effect" (Mother; son diagnosed age 4).

A more empowered acceptance of autism was evident for some parents who identified clear benefits in parenting an autistic child - “[your child] being different is also an opportunity to learn more things” (Mother; son diagnosed age 3). However, other parents conveyed a more neutral acceptance - “I think he's always gonna stand out, and that's not a bad thing, and it's not a great thing, just it is what it is” (Mother; son diagnosed age 3).

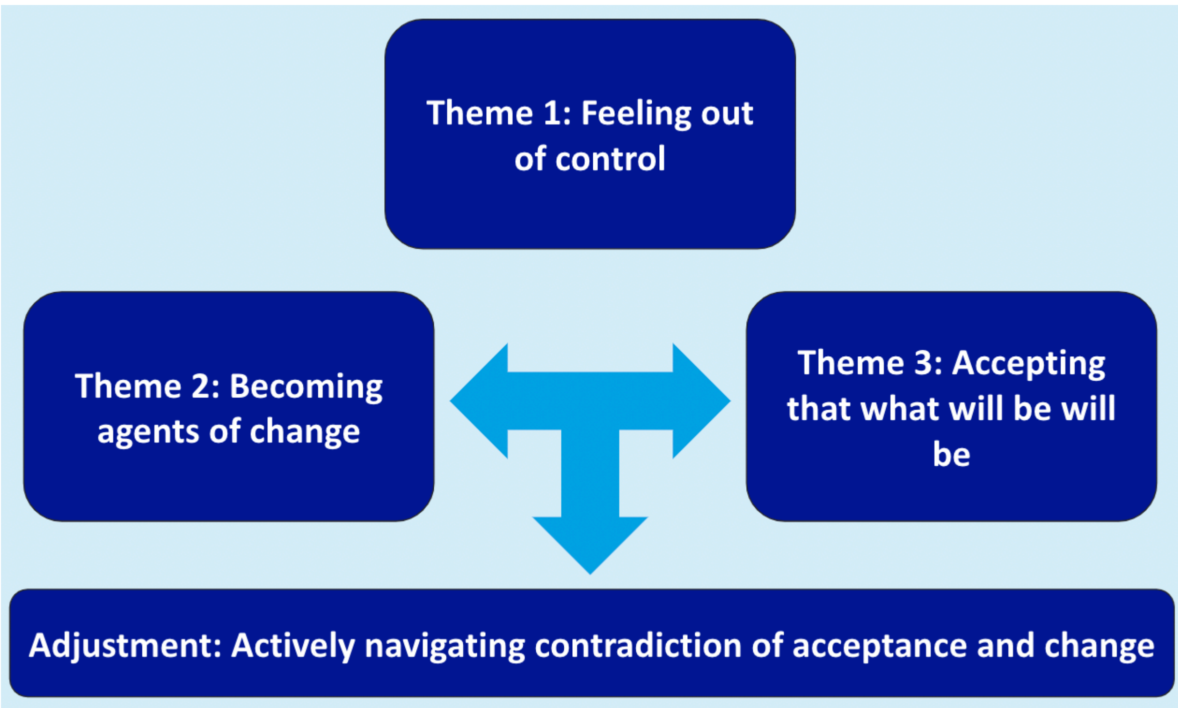
Adjustment as Acceptance and Change

Together, these themes depict adjustment as the process by which parents gain a sense of control over uncertainty following their child’s diagnosis of autism. Neither becoming agents of change nor accepting things as they are encompassed the full scope of adjustment. As agents of change, parents were not adjusting to their reality as it is, but rather attempting to change their child or other aspects of their situation. On the other hand, focusing only on acceptance brought a more passive sense of resignation which downplayed the capacity for progress. Notably, while these concepts of acceptance and change appear to be in opposition, parents discussed experiencing both. Parents were aware of contradictions in their own thoughts - “At the end of the day, as perfect as he is, and he’s perfect and I wouldn’t have him any other way, I still don’t understand why he has to go through life differently” (Mother; son diagnosed age 3). Parents also talked about “acceptance about the hopelessness of everything” (Mother; son diagnosed age 1) and of needing to accept a level of not accepting – “I think I’ll always be sad about [child]’s diagnosis, I think that it will never go away. I think that it’s just acceptance to be honest” (Mother; daughter diagnosed age 3). Others explained needing to accept things the way they are in order to support efforts to change - “Accepting, okay, my child has the issue, and we can't have a normal life until, you need to sacrifice something to get there” (Mother; daughter diagnosed age 3); “I'm more accepting of myself and more accepting of him, and I can see the massive improvements” (Mother; son diagnosed age 4). Importantly, adjustment was conceptualised as an ongoing and active process - "adjusting is an evolving thing that we are doing" (Mother; son diagnosed age 3).

Discussion

The current study explored parental perceptions of adjustment to their child's autism diagnosis for a group of parents who had completed a parent-mediated intervention (PMI), PWS. The first aim of the study was to explore parents' perceptions of the overall adjustment journey. By drawing across the identified themes, we present a conceptual model of adjustment as parents' process of gaining control over ambiguity by actively working to balance acceptance and change – the Active Balance model of adjustment to diagnosis (Figure 5). Parents actively work to accept the ways things are, at the same time as pushing for things to improve. The balance of acceptance and change appears to facilitate parents feeling more in control and more confident in their abilities to support their child now and into the future.

Figure 5 - Active Balance model of adjustment to diagnosis.



The second aim was to understand the role of PMI within the broader adjustment journey, in this group of parents who had all completed the same PMI. The PMI was described to support both change and acceptance, therefore contributing to parents' adjustment. Through the PMI, parents developed specific knowledge and skills to manage their child's behaviour, develop their child's skills, and support their own mental health (as also evidenced by significant intervention effects for these outcomes in Dadds et al., 2025). The resulting improvements they saw in their child and in the parent-child relationship supported confidence in their capacity to act as an agent of change (Jurek et al., 2023), allowing them to feel more in control of their life and therefore facilitating adjustment. Notably though, parents also felt that PWS supported acceptance of their child's diagnosis - by learning more about autism, parents were better able to recognise where it would be unrealistic or unfair to expect change.

However, while the PMI contributed to parents' capacity to balance acceptance and change, parents discussed it as one of many facilitators of adjustment. As an iterative process, adjustment occurred as parents learned what to accept and what to work on changing. This learning happened over time and with experience, as well as through specific facilitators such as PMI. As such, this work situates PMI not as a turning point for adjustment, but as one component of a complex adjustment journey.

In line with the third aim, the current study identified parents' support needs throughout the process of diagnosis and adjustment. Parents described the greatest unmet support needs during the process of assessment and immediately following diagnosis. Identified needs during this process included a more streamlined process of diagnosis, additional information about autism, and guidance in navigating the available resources and supports – needs which have also been highlighted across previous research (Makino et al., 2021; Rabba et al., 2019). The lack of these supports was seen to hinder parents' early adjustment by increasing uncertainty. Ongoing support needs included effective intervention to support improvements in the child, support for parent mental health and well-being, and social support. Accessing such supports helped parents to work towards both acceptance and change, thereby facilitating adjustment.

Active Adjustment to Ambiguous Change

Parents' reflections that their child's autism diagnosis brought profound uncertainty align with the model of ambiguous change (referred to elsewhere as ambiguous loss; Boss, 1999; O'Brien, 2007). However, the model presented here captures a more active and empowered adjustment to ambiguous change than that which has been discussed previously (O'Brien, 2007). While Boss (1999) highlighted that mixed emotions are central to ambiguous loss, this was conceptualised as a more passive ambivalence, in comparison to the active balancing of contrasting ideas seen in the current study. Similarly, past research has depicted parents oscillating between conflicting feelings (e.g., Alimohamadi et al., 2024; Fernańdez-Alcántara et al., 2016). However, the current study suggests that parents carry opposing perspectives on their child's diagnosis not in conflict, but in balance. As such, effectively navigating adjustment to an autism diagnosis appears to require parents to engage in a level of dialectical thinking (Peng & Nisbitt, 1999). Parents are, at some level, recognising that they can accept their child exactly as they are, at the same time as striving to make changes that support the child. The Active Balance model of adjustment presented here is preliminary, however, and further research is needed to gain a deeper understanding of the adjustment process, particularly across diverse groups of parents.

Addressing Adjustment Support Needs

With the active balance model of adjustment in mind, supports for adjustment should focus on reducing uncertainty, and/or facilitating a balance of acceptance and change. Specific recommendations for addressing support needs during the diagnostic process, at diagnosis and immediately post-diagnosis, and ongoing, are briefly discussed here, followed by overarching recommendations for adjustment support.

Firstly, the parent perspectives represented here highlight the need for a more streamlined process of autism assessment and diagnosis with clearer information for parents throughout. This work emphasised that the process of diagnosis set the foundation for parent adjustment (Reed et al., 2019), making this a key area where improvement is needed. Improving the diagnosis pathway begins with increasing uptake of autism screening tools in primary health settings, so that health practitioners are able to make evidence-based referral and assessment decisions (Eapen et al., 2022; Karlov et al., 2025; Vivanti et al., 2025). Then, receiving clear information that explains what autism is, what the diagnostic process involves, and what post-diagnosis pathways may look like, would likely reduce uncertainty and increase parents' sense of control throughout the diagnostic process (Osborne & Reed, 2008). Importantly, preparing parents for some ongoing ambiguity, such as clarifying that a diagnostic assessment will not allow the provider to make long-term predictions about the child's functioning, may reduce the distress associated with this uncertainty (Anderberg & South, 2021; Boss, 1999; Jacobs et al., 2020).

At the time of diagnosis, there is a need to provide parents with clear information about autism, including individualised feedback for their child. Building on the current findings, this information should support both acceptance and change. Practitioners should draw from neurodiversity-affirming approaches that promote acceptance of autism (Pritchard-Rowe & Gibson, 2024). At the same time, they should highlight potential areas of improvement for the child, so as to identify supports needs and intervention targets, and importantly inspire hope for parents (Anderberg & South, 2021).

Ongoing adjustment support needs included access to effective support for the child – such as PMI - as well as for the parents' own mental health. Promisingly, there is increasing evidence of effective supports for autistic children (Sandbank et al., 2023) and their parents (Li et al., 2024). However, parents may struggle to identify which supports are evidence-based and to decide between the multitude of available supports (Grant et al., 2016). Again, this emphasises the need for clear information and guidance, at diagnosis and beyond. Recommendations for parents should also emphasise the importance of social support (Alon, 2019; Rabba et al., 2019; Smith et al., 2023) and potential benefit of support groups (Lee et al., 2024).

Beyond broad supports such as PMI and social support, there has been recent interest in developing supports which specifically target parent adjustment (e.g., Bravo-Benítez et al., 2024; Leadbitter et al., 2025; Lodder et al., 2020). In the current study, parent perspectives on the need for such targeted support were mixed. For some parents, access to broad supports that did not directly target adjustment, such as PMI and social support, were considered sufficient. Other parents reported that they had sought more specific support for adjustment, either by talking to their PWS therapist or another psychologist. Therefore, there may not be a universal need to provide parents with targeted support for adjustment following their child's autism diagnosis, but targeted support programs may be of benefit for parents experiencing more severe adjustment difficulties. Further research is needed to better understand who may benefit from targeted support for adjustment.

Across this proposed pathway of adjustment supports, there is a need for professionals to engage parents as active collaborators in decision-making (Mulligan et al., 2012). As in previous research, parents in the current study described feeling overwhelmed and out of control when left to navigate the process on their own, but equally disempowered when decisions were made without their involvement (Fante et al., 2024; Gavidia-Payne, 2020; Keenan et al., 2010). Decisions regarding post-diagnosis support should therefore be facilitated through shared decision-making strategies (Angell et al., 2023; Charles et al., 1997). These strategies require the provider to make the parent aware of all relevant information - such as assessment findings and available service options - so that parent and provider can arrive at a decision based on this shared information. It is vital to also engage the autistic person themselves in shared decision-making where possible, though the nature of this engagement will differ depending on aspects of autistic person's functional capacity.

Fundamentally though, providers require additional training to develop knowledge of available supports, and skills to effectively support families through the diagnostic process, deliver diagnostic feedback, and engage parents in shared decision-making (Gore et al., 2024; Levy et al., 2016; Strauss et al., 2015). Minimising provider burden by developing relevant guidelines (Pattison et al., 2022) and evidence-based resources would likely be of benefit. There is a need for further research to better understand parent and provider preferences for resources, such as the ideal format, content, and timing of resource delivery. Parents also highlighted potential benefits of a peer navigator model, which may be a means of providing parents with both informational and social support, without additional burden for health practitioners. Peer navigator programs have demonstrated some efficacy for this population (Hock et al., 2022; Lee et al., 2024), though effects on adjustment specifically have not been investigated. Engaging practitioners, parents, and autistic perspectives in future research will help ensure that supports implemented are feasible and acceptable for all stakeholders.

Strengths, Limitations, and Recommendations for Future Research

There were a number of strengths of the current research, but also limitations that should be kept in mind when interpreting the results. The involvement of an advisory group throughout the research was a strength of the current study. Notably, the advisory group included two parents of autistic adults, who were able to offer a broader view of adjustment across time. The other advisory group member was a parent of young children whose experiences were more current and therefore aligned more closely with the participants' experiences of diagnosis and adjustment. We therefore captured some diversity of lived experience perspectives. However, not involving autistic individuals in the research is a notable limitation. Ongoing evaluation of the Active Balance model of adjustment must involve co-design with parents and autistic individuals, including autistic parents.

The inclusion of father perspectives was also a strength of the current research. Notably, much of the past research on adjustment to autism diagnosis has focused only on experiences of mothers (Brown et al., 2021a). Understanding fathers' experiences of adjustment to diagnosis is the first step in ensuring that resources and supports for adjustment meet fathers' needs.

Regarding limitations, several aspects of the research context may have influenced participants' responses. First, while the interviewer was not involved in delivering the intervention to participating parents, knowing that she was from the same research group may have led parents to evaluate PWS more positively due to social desirability effects (Bergen & Labonté, 2020). Alternatively, the interviewer's perceived association with the familiar program may have increased parents' comfort to openly share their experiences. Second, parents' recollection of the adjustment journey would have likely been influenced by the time lapsed since diagnosis (almost 4 years on average), and since participating in PWS (an average of 20 months). This allowed for a broader view of the overall adjustment journey, but may have made it harder for parents to recall the influence of specific components, such as the PMI, within their adjustment journey. Some parents explicitly reported difficulty remembering elements of the diagnostic process or of PWS.

Third, parents in the current study may differ in important ways from the wider community of parents of autistic children. Participation in the larger study was limited to parents of a child with a diagnosis of autism Level 2 or 3, and co-occurring externalising behaviour challenges. It would be pertinent to explore experiences of adjustment to diagnosis for parents of children with a diagnosis of autism Level 1 and without significant behavioural challenges, to understand whether the Active Balance model is relevant for these families.

Furthermore, the current sample may have been particularly motivated or well-resourced, given that they had the capacity to enrol in and complete a PMI through a university clinic. In fact, the majority of parents in the current study were tertiary educated, and nearly half had postgraduate degrees. Notably, research has found that parents' access to required supports for their child is lowest for parents who are less well-resourced (O'Flaherty et al., 2024). Beyond financial resources, factors such as parents' mental health literacy, knowledge of service systems, and parents' own disability or mental health challenges (potentially including significant difficulties with adjustment to diagnosis) likely play a role in parents' capacity to engage supports (Anderberg & South, 2021; Carey et al., 2021; Smith et al., 2023). When the onus is on parents to navigate support systems, as described by parents in the current study, the families who are struggling the most may be the least likely to receive appropriate support (Carey et al., 2021; O'Flaherty et al., 2024). We therefore see a problematic paradox whereby difficulties with adjustment may make it harder for parents to access the very supports that could facilitate their adjustment. In a similar vein, it is important to recognise that the current study recruited only participants who had completed the entire PWS program, and therefore the views of participants who dropped out of the program were not represented here. Understanding the adjustment journey of parents who commence PMI but are unable to complete the program or choose to discontinue would allow for a more nuanced understanding of how PMI fits into parents' journey of adjustment. It remains unclear how the Active Balance model of adjustment may apply to parents with significant adjustment difficulties or other barriers which may limit their capacity for acceptance and/or change. More research is therefore needed to understand the experiences of parents who struggle significantly to adjust to their child's autism diagnosis. This work can inform the development of universal supports for adjustment in parents of autistic children, as well as more targeted support for those with more significant adjustment difficulties.

Conclusion

The current study highlights the strength and resourcefulness in parents as they actively work on adjustment to their child's diagnosis through an iterative process of acceptance and change. Evidence-based support such as PMI may be one part of this complex, ongoing process. Improving diagnosis and support systems remains integral to creating more positive experiences for families, particularly given the high rates of stress and physical and mental health difficulties observed in parents of autistic children (Kulashinge et al., 2021; Vasilopolou & Nisbet, 2016). Use of co-design processes across research and policy can ensure that stakeholder perspectives genuinely inform practical solutions to the challenges that parents are identifying. In this way, we can work towards service systems that bolster, rather than hinder, parents' active efforts to adjust to their child's autism diagnosis.

GENERAL DISCUSSION

This thesis reported on research examining parents' adjustment to their child's diagnosis of autism, investigating measurement of adjustment as well as adjustment in the context of parent-mediated intervention (PMI). A mixed methods approach was used across three studies: Study 1 reported a systematic review of measures and interventions for parent adjustment to diagnosis; Study 2 evaluated parent adjustment within a randomised controlled trial (RCT) of a PMI; and Study 3 utilised qualitative methodology to understand PMI in the context of parents' overall adjustment journey.

In Study 1, Aim 1.1 was to systematically review how adjustment has been defined and measured in the literature. There is a notable lack of consensus regarding what is and is not included within the construct of adjustment to diagnosis. Specifically, this review found considerable variability in the measures used to assess adjustment (Aim 1.1a), as well as in the constructs measured and the conceptual definition of adjustment used across studies (Aim 1.1b). Aim 1.1c was to identify the reported psychometric properties of adjustment measures, and found that reporting of these properties was inadequate, especially with regards to test-retest reliability and intervention responsiveness. Aim 1.2a was to identify interventions that have evaluated parent adjustment to diagnosis as either a primary or secondary outcome. The review identified six studies of novel interventions targeting adjustment to diagnosis. Regarding their effectiveness (Aim 1.2b), three studies found statistically significant improvements in adjustment following intervention, though only two of these included comparison to a control group. The remaining three did not find significant improvements in parents' adjustment to diagnosis, in single group designs. However, it is important to note that, in the time since the review reported in Study 1 was completed in November 2024, results of an additional randomised controlled trial demonstrating a significant effect of targeted intervention on adjustment have also been published (Leadbitter et al., 2025). Because of the variability across the effective interventions, it was not possible to recommend a specific intervention modality. This systematic review identified that adjustment to diagnosis has, to date, only been researched as an outcome of targeted interventions. That is, research had not explored whether there are changes in parents' adjustment as a result of broad interventions that do not directly target adjustment, such as parent-mediated intervention (PMI). This was identified as an important gap in our understanding of how to support parent adjustment - many families of autistic children are already participating in some form of intervention for their child (Bearss et al., 2015; Sandbank et al., 2023), warranting consideration of whether a broad intervention may be sufficient to support parental adjustment without the need for a specific, and additional, intervention.

This research gap was therefore addressed by Study 2 and 3, by investigating adjustment in the context of an RCT of a PMI, ParentWorks Spectrum (PWS). In Study 2, Aim 2.1 was to evaluate whether the PMI resulted in significant changes in parent adjustment to diagnosis relative to a waitlist control condition, and found no significant differences in adjustment outcomes between the PWS and waitlist groups. Aim 2.2 examined whether parents' treatment adjustment predicted intervention dropout, engagement or child outcomes, and found no significant relationships.

Aims 2.3 and 2.4 were to compare adjustment for mothers and fathers in Study 2, given the lack of father involvement in extant adjustment research (Brown et al., 2021a; and as identified in Study 1). This research examined pre-treatment adjustment differences in adjustment between mothers and fathers (Aim 2.3). Significant differences in self-blame - one measured facet of adjustment - were found between mothers and fathers of the same child, indicating that fathers may feel lower levels of self-blame about their child's autism diagnosis than mothers. Additional Aims to identify differences between mothers and fathers regarding intervention effects on adjustment (Aim 2.4a) and effects of pre-treatment adjustment on intervention engagement and outcomes (Aim 2.4b) found that parent gender did not act as a significant moderator of any effects. The qualitative work reported in Study 3 did not explore differences between mothers' and fathers' perspectives, but included both mothers and fathers where possible. However, only 36% of the interviews conducted for Study 3 included fathers, which was notably lower than the father participation rate of 77% in Study 2.

Qualitative research in Study 3 aimed to understand parents' adjustment journey (Aim 3.1) and their experiences of PMI as part of this journey (Aim 3.2), as well as their additional adjustment support needs (Aim 3.3). Thematic analysis of semi-structured interview transcripts identified themes of 'feeling out of control', 'becoming agents of change', and 'accepting that what will be will be'. Drawing across these themes, and to address Aim 3.1, a conceptual model of adjustment was presented as the process by which parents' gain a sense of control over an uncertain situation by actively working to balance acceptance and change, referred to as the Active Balance model. In line with this, and to address Aim 3.2, parents identified PMI as one way that they could work on both acceptance and change to facilitate their adjustment. However, participating in PMI was just one part of a more complex adjustment journey. Other adjustment support needs identified to address Aim 3.3 included increased guidance throughout the diagnostic process and at the time of diagnosis, and social support. Some parents also identified a desire for more targeted adjustment support, such as talking to a psychologist about their thoughts and feelings about the child's autism diagnosis.

Taken together, the findings from these three studies have implications for the definition of adjustment to autism diagnosis, measurement tools for adjustment, theoretical models of adjustment, understanding adjustment in the context of PMI, considerations for supporting adjustment, and ongoing research.

Defining Adjustment to Diagnosis

The research reported here identified a lack of clarity regarding the definition of adjustment to diagnosis in the literature. Firstly, the term ‘adjustment’ has been used to refer to both a process and an outcome, sometimes even within the same study. Furthermore, the construct of adjustment has subsumed concepts such as ‘grief’, ‘post-traumatic responses to diagnosis’, ‘benefit finding’ and ‘acceptance of diagnosis’. There are conceptual nuances that distinguish these concepts from one another. For example, defining adjustment as ‘acceptance of diagnosis’ implies an endpoint to the process of adjustment whereby the parent feels neutrally about their child’s diagnosis, whereas defining it as ‘benefit finding’ frames adjustment as a potentially ongoing process where autism is viewed positively rather than neutrally.

The terms used to define adjustment to diagnosis also have broader implications for the way we as a field, and wider society as an extension, view autism. Language such as ‘grief’ and ‘trauma’ perpetuates a deficit-focused perspective, framing autism as negative (Bottema-Beutel et al., 2020). This is inconsistent with the uptake of neurodiversity-affirming practice within the field (Happé & Frith, 2020). Moving away from this deficit-focused language is complicated, however, because this is how parents may describe their own experience, as seen in Study 3. It is important that, in the process of destigmatising autism, we do not exclude parent perspectives or dismiss the genuine difficulties experienced by autistic people and their families (Kapp et al., 2013). The complexity of autism as a valued neurological difference, that nevertheless brings real challenges for parents and for autistic people themselves, means that a clear but nuanced definition of parent adjustment to diagnosis is required.

Variability in how adjustment has been defined is a fundamental problem in the field. Without a clear conceptual definition of adjustment, it is not possible to evaluate theoretical models; develop and validate measures; empirically identify barriers, facilitators, predictors and outcomes of adjustment; or design and test supports for adjustment. As such, and based on the research reported here, I propose a preliminary conceptual definition of parent adjustment to autism diagnosis as the process of balancing acceptance of the autism diagnosis with striving for change in the parent themselves, the child, and the world around them focused around autism. However, merely proposing a new definition simply perpetuates the variability in definitions of adjustment. Rather, it would be useful for future research to establish a Delphi consensus definition from experts in the field (Dalkey & Helmer, 1963), so that the field has a single definition to use going forward. It would be important for this consensus definition to be co-produced with parents and autistic people (including autistic parents of autistic children) along with researchers and clinicians.

Measurement of Adjustment to Diagnosis

The current research identified a number of key issues with the measurement of adjustment to diagnosis across existing research, above and beyond the above problems noted regarding the definition of adjustment: variability in measures; limited validation of measures, particularly in regards to sensitivity to change over time; confounding of adjustment as a process and outcome within measures; measures predominantly validated on mothers of children (not fathers, or parents of adults); and a lack of normative data for existing measures. Across the systematic review of measures (Study 1), nearly half of the included articles utilised a measure that was not used in any other studies. This variability is unsurprising given inconsistencies in the definition of adjustment across the literature. However, it is also problematic. Use of different measures makes it hard to compare results across studies, particularly when measures have not been standardised. This variability in measurement has likely contributed to inconsistent findings across prior research, for example regarding correlates of parent adjustment.

Study 1 also identified insufficient reporting of psychometric properties for the majority of adjustment measures. Reporting of test-retest reliability or sensitivity to change in intervention (responsiveness) was particularly limited. The lack of longitudinal research into the natural trajectory of adjustment is also a key limitation of the field, but there is little point to conducting longitudinal research without knowing that we have measures that can reliably detect stability and change in adjustment over time. Similarly, while recent research examining novel interventions to improve adjustment is promising, rigorous evaluation of these interventions is hindered by the limitations of available measures.

As discussed above regarding the definitions of adjustment, confounding of adjustment as a process and an outcome is also an issue for measurement of adjustment. In fact, the measure of adjustment used in Study 2, the ADAQ (Da Paz et al., 2018), shows evidence of this confounding. The ADAQ includes present-focused items such as ‘When I think about my child’s difficulties, I ask myself, “Why me?”’, as well as items asking about changes over time such as “I have a greater acceptance of my child’s autism than I used to”. Confounding adjustment as a process and outcome may make it hard to identify whether a parent has high or low adjustment, at the time it was measured. For example, if a parent disagrees with the item “I have a greater acceptance of my child’s autism than I used to”, it is not clear whether this is because they do not accept their child’s diagnosis, or because they have always accepted their child’s diagnosis and therefore do not perceive a change in their acceptance. Including present-focused and changed-focused items within the same measure is also likely to interfere with the measure’s ability to detect changes in adjustment over time.

The utility of a measure is limited to the populations that it has been validated on. Measures of adjustment have predominantly been validated on mothers. Observed differences between mothers’ and fathers’ adjustment in Study 2 here, as well as previous studies (Yirmiya et al., 2015), suggests that it would be inappropriate to assume that a measure validated only on mothers is valid for use with fathers. Similarly, few studies have looked at adjustment to diagnosis for parents of autistic adults. Parents in Study 3 described that uncertainty regarding adult outcomes is an important consideration in adjusting to their child's autism diagnosis. It is therefore likely that the adjustment experiences of parents who have seen these outcomes play out into adulthood are distinct from those who are still wondering what their child's life will look like long term. Validating measures of adjustment in parents of adults would be an important precursor to longitudinal research. Finally, none of the studies identified in Study 1 assessed whether participating parents were themselves autistic. As such, we do not know whether or not these measures of adjustment are acceptable or valid for autistic parents of autistic children.

The final limitation identified for measures of adjustment is that most do not have normative data available. As such, most do not have cutpoints that allow for identification of a clinical range - that is, existing measures do not identify when adjustment difficulties are outside of the expected range. The exception to this is the Reaction to Diagnosis Interview (Pianta & Marvin, 1993), however this is an interview measure which may therefore not be practical for routine use in research or clinical settings. Gathering normative data for other measures would allow researchers to distinguish expected adjustment from more significant difficulties that may warrant intervention.

The Impact of Measurement Issues: Study 2 as an Example

Study 2 inadvertently demonstrated how these limitations in the measurement of adjustment may hinder research. Study 2 showed no effect of evidence-based PMI on adjustment relative to waitlist control and no effect of pre-treatment adjustment on intervention dropout, engagement or outcomes. The broader implications of these findings will be discussed later, with the focus here on understanding the impact of measurement issues. It is hard to distinguish whether there is truly no intervention effect for adjustment, and no interaction of adjustment and PMI, or whether these relations could not be detected due to limitations of the measure of adjustment used, the ADAQ (Da Paz et al., 2018). Specifically, the ADAQ had not been validated on fathers, had not previously been used to evaluate intervention outcomes, and confounds adjustment as a process and an outcome, as previously stated. In addition, the lack of normative data for the ADAQ makes it unclear what percentage of parents in the study, if any, had clinically low adjustment. It is therefore possible that their adjustment didn't either interfere with intervention engagement or improve from the intervention because the sample already had high adjustment. These are some possible explanations for the results of Study 2, and it is also possible that there actually was no effect of the intervention on adjustment or vice versa, as discussed later. However, this serves as an example to highlight the detriment that the identified measurement issues can have to research.

Recommendations for Measurement of Parent Adjustment to Autism Diagnosis

Drawing across the studies reported here as well as previous research, the following recommendations are made regarding measurement of parent adjustment to child autism diagnosis:

1) Measures should include either items evaluating adjustment at the time of assessment, or changes in adjustment over time, rather than both in the same measure;

2) Validation of measures should follow published guidelines, such as the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN; Mokkink et al., 2010) guidelines. Consideration of all measurement properties, including those regarding measurement over time (reliability and intervention responsiveness) is needed;

3) Measures should be validated with samples that are representative of the diversity of parents of autistic people, including fathers, parents of adults, autistic parents, and

culturally and linguistically diverse groups. New measures should be co-designed with these populations, and with autistic people;

4) Research assessing adjustment in a large, representative sample of parents of autistic people should be used to collect normative data. This normative data should be used to identify points that reliability distinguish normative adjustment to diagnosis from more significant adjustment challenges.

Specific recommendations for measurement based on the Active Balance model of adjustment which was proposed in Study 3 will be presented below. Before considering the implications of the Active Balance for measurement, it is important to discuss the model in greater detail, starting with the theoretical implications of the model.

Considering Adjustment as an Active Process: Implications for Theory

Active Adjustment to Ambiguous Change

In Study 3, a conceptual model of adjustment to diagnosis was proposed, as the process by which parents actively work to feel a sense of control in their role as a parent of an autistic child by balancing acceptance and change: the Active Balance model of adjustment. Acceptance may include accepting the fact that the child is autistic, acceptance of the challenges that autism brings for the child and parent, and a broader acceptance of the child as they are. Change may include striving for reasonable improvements in the child and in the parent themselves (e.g., building skills), as well as pushing for societal change to increase accessibility and neurodiversity-affirming practices in their community. Through change, parents are shifting the reality they are adjusting to, while acceptance refers to accepting their current reality as a parent of an autistic child as it is. The Active Balance model proposes that parents actively work to balance acceptance and change focuses in an ongoing, iterative process of adjusting to their child's diagnosis.

This model was proposed with the theoretical underpinning of ambiguous loss (Boss, 1999; O'Brien, 2007), reconceptualised here as 'ambiguous change'. The reported experiences of participants in Study 3 aligned with this concept of ambiguous change, as parents described their initial experiences of their child's autism diagnosis as feeling out of control. It is important to note that not all parents necessarily experience their child's autism diagnosis as uncertain or out of control; for instance, parents with more previous experience with autism may already understand the diagnosis and know the next steps to take at the time of diagnosis (Gentles et al., 2020). Nevertheless, parents in Study 3 who explained that they did feel more in control at the time of their child's diagnosis still described balancing acceptance and change as important for their ongoing adjustment.

The active balancing of acceptance and change identified in the current research closely aligns with Boss' conception of adjustment to ambiguous loss as a dialectical process (1999, 2007). Specifically, Boss describes "the combination of optimism and realistic thinking" (1999, p. 92) to be important in adjusting to ambiguous loss. This clearly parallels the combination of hope for change and acceptance of the way things are identified in the Active Balance model.

Following O'Brien's (2007) definition of adjustment to autism diagnosis as ambiguous loss, little research had applied this theory to understanding the actual process by which parents of autistic children respond to this change. Fernández-Alcántara and colleagues (2016) proposed that parents respond to the ambiguous change of an autism diagnosis by working towards acceptance, however oscillate between acceptance and barriers to this acceptance. Alimohamadi and colleagues (2024) similarly describe that parents oscillate between 'loss-oriented' coping, or sitting with negative emotions associated with the diagnosis, and 'restoration-oriented' coping, or acceptance of the ways things are and focusing beyond the child and their diagnosis. Both of these applications of ambiguous loss/ambiguous change theory focus on acceptance as a more optimal outcome. Parents' desire for change is seen to detract from, or act in opposition to, this acceptance. The Active Balance model instead suggests that acceptance and pushing for change support adjustment not in opposition, but in combination. Parents may have strong acceptance and a strong change focus simultaneously, rather than oscillating between the two.

The Active Balance model also sees a more active role for parents in their own adjustment; rather than naturally fluctuating between acceptance and non-acceptance over time (Alimohamadi et al, 2024; Fernández-Alcántara et al., 2016), parents are actively trying to work on adjusting to their child's diagnosis. That is, in the Active Balance model, adjustment is seen as something that parents work at, rather than something that happens to them without their active involvement. The results of Study 3 suggest that parents actively work on adjusting by accessing resources and supports that facilitate change and/or acceptance. However, further research is needed to better understand the specific process by which parents actively work on adjustment, and the barriers and facilitators to this process. Considering additional theoretical models of adjustment in addition to ambiguous change may also provide insight into the specific processes by which parents balance acceptance and change within the Active Balance model.

Active Adjustment Through Other Theoretical Lenses

While the Active Balance model of adjustment was developed with ambiguous loss theory (Boss, 1999; redefined here as ambiguous change) as its theoretical underpinning, it is relevant to also consider how the model fits with other theoretical approaches to understanding adjustment. The research reported here reiterates that staged models of grief are less appropriate for understanding adjustment to autism diagnosis (Negri & Castorina, 2014). In Kübler-Ross' grief model (1969), acceptance is seen as the endpoint of adjustment. The Active Balance model suggests that, in this context, acceptance is just one side of the picture. Conceptually, this difference from Kübler-Ross' model is logical. Parents are adjusting not to a conclusive event, like death, where a change to the situation is not possible. Rather, they are adjusting to a situation which continues to evolve as they and their child learn and develop. The Active Balance model is somewhat more aligned with Bowlby's stage model (1980), in that Bowlby's final stage of 'reorganisation' involves the parent having an accurate - or, balanced - understanding of their situation. However, both stage models see adjustment as having an endpoint (Kübler-Ross, 1969; Bowlby, 1980), whereas the Active Balance model assumes that work to maintain the balance of acceptance and change remains ongoing. This ongoing work to balance acceptance and change is associated with a sense of control over the situation for parents. The Active Balance model is therefore distinct from the theory of chronic sorrow; chronic sorrow conceptualises the ongoing nature of adjustment as a cycle parents are trapped in (Copley & Bodensteiner, 1987; Olshansky, 1962), rather than a dynamic process parents are actively in control of navigating.

The Active Balance model proposes that parents adjust through actively balancing the two concepts of acceptance and change. It is therefore useful to consider cognitive models of adjustment, as a way of understanding how parents cognitively maintain this balance. Lazarus and Folkman's stress and coping model (1984) describes adjustment as an ongoing process involving repeated reappraisal of the stressor (in this case, the autism diagnosis) and engagement of coping strategies based on this reappraisal. Taking this together with the Active Balance model suggests that parents may maintain a balance by appraising each situation, and deciding whether to use a strategy focused on acceptance or change in response to that particular situation. This may include appraisal of whether or not the parent believes that acceptance of the situation or change to the situation is possible. When asked what adjustment means, a parent in Study 3 shared a specific example that may illustrate the role of appraisal in balancing acceptance and change. This mother (son diagnosed age 3) explained that her son does not like to eat foods from the family's culture, or to even sit at the table where this food is being eaten, due to his sensory sensitivities. Cooking her cultural dishes was important to this mother's values, but she also recognised that her son had genuine difficulties with the sensory aspects of this food due to his autism. The family therefore started by continuing to eat their cultural dishes but having the child eat his food at a separate table in the same room. They also worked on him gradually getting comfortable sitting closer to the other food, as part of the child's therapy, such that he could eventually sit on the same table as the rest of the family. In this example, it appears that the mother made an evaluation that she could not immediately change the child by forcing him to sit with the food that bothers him, but also that she could not accept him eating separately from the rest of the family because this conflicted with her values. She therefore found a middle ground, or balance, between what she could accept and what she could change. She implemented change-focused strategies to gradually support the child to eat with the rest of the family; however this was done in a graduated fashion, suggesting some acceptance of the need to meet the child where he was at. This example demonstrates the parent using cognitive appraisal and coping strategies in a way that supported her ability to balance acceptance and change. Of note, this is a specific example that focuses on this parent's response to a specific behaviour, rather than her overall process of adjustment to diagnosis. However, considering the stress and coping model (Lazarus & Folkman, 1984) in combination with the Active Balance model suggests that these specific, day-to-day efforts to balance acceptance and change may contribute to parents' overall process of adjustment.

In considering the role of cognitive appraisal in adjustment to diagnosis, it is also important to consider whether parents are adjusting to the actual reality of parenting their autistic child, or to the idea of what parenting an autistic child may mean for them. In other words, cognitive models suggest that a parent's experience of adjustment may differ depending on how their appraisal of what the diagnosis means for their family aligns with their reality. As reported in prior research (Gentles et al., 2020), parents in Study 3 described beginning the journey of autism assessment and diagnosis with preconceived ideas about what an autism diagnosis would mean for their child. These ideas were often negative, and for some parents, led to expectations that parenting an autistic child would be a lot worse as compared to what their lived experience then was. Early in the adjustment journey, parents may therefore have been adjusting to an inaccurate appraisal of what autism means for their child and family, informed by prior knowledge about autism rather than by information specific to their own child and family. Learning about autism, and about their own child, may support more accurate appraisal of what autism means for the family. Nevertheless, it is impossible for parents to know definitively what autism will mean for their child and family into the future, necessitating an ongoing process of learning and reappraisal. Further research exploring the relation of accurate appraisal to acceptance and change beliefs would be of use in understanding the role of cognitive processes in the Active Balance model.

The theory of dialectical thinking (Peng & Nisbett, 1999) provides important context to the Active Balance model of adjustment, although it has not previously been applied to research into adjustment to autism diagnosis. Dialectical thinking refers to seeing two ideas that appear contradictory to both be true. According to the Active Balance model, parents are able to simultaneously hold in mind and work towards two seemingly opposing ideas: acceptance of the way things are, and goals for change. Further validation of the Active Balance model of adjustment alongside measures of dialectical thinking (e.g., Soler et al., 2025; Spencer-Rodgers et al., 2015) would be of use in understanding the role of dialectical thinking in adjustment to autism diagnosis.

Overall, the Active Balance model of adjustment is informed by ambiguous loss theory (Boss, 1999). It also draws on cognitive models, particularly dialectical thinking (Peng & Nisbett, 1999), to explain how parents actively work to maintain the balance of acceptance and change. Ambiguous change theory can explain the structure of the process, while cognitive models can explain how parents move through the process. The Active Balance model brings the structure and mechanisms of the process together within one conceptual model of adjustment. Of note, no prior theoretical model of adjustment has explained the overall 'journey' of adjustment and the specific mechanisms by which parents move through this journey within the one model. With further validation, the Active Balance model therefore has the potential to make an important contribution to our theoretical understanding of adjustment to diagnosis.

It is important to note that efforts to balance acceptance and change, as defined in the Active Balance model, are likely not unique to parents of autistic children. Researchers have applied grief and cognitive models to understanding parents' adjustment to a range of childhood conditions, such as cerebral palsy (Rentinck et al., 2007), Down Syndrome (e.g., Clark et al., 2020; Poehlmann et al., 2005) and cancer (Long et al., 2011). It would therefore be informative to understand parents' experiences of acceptance and change in adjusting to such conditions, and to explore whether the Active Balance model is relevant to these conditions. Indeed, it is possible that all parents need to work on balancing acceptance and change to some degree. Many of the challenges identified by parents in Study 3, and in past research exploring adjustment to autism diagnosis (e.g., Gentles et al., 2020), are likely experienced by most, if not all, parents. For example, many parents likely need to grapple with differences between the child that they had imagined and the child that they have, and worries about the child's future. That is, the Active Balance model conceptualises the balance of acceptance and change as a means of overcoming uncertainty, and therefore it is worth noting that all experiences of parenting (and, indeed, of life) are wrought with uncertainty. Nevertheless, these uncertainties are often amplified for parents of autistic children – worries about finding a school that is a good fit for the child are more challenging when the child requires more specialised support, and fears about how a child will do once the parent is gone are bigger when it is not clear whether the child will be able to work or live independently. While parenting is inevitably complex, it is vital to recognise that parents of autistic children do face unique challenges, described by a mother in Study 3 as "layers that typical parents don't have to navigate". It is also important to acknowledge that many of the challenges of parenting an autistic child are actually challenges of parenting an autistic child *in a world that is not designed for autistic people.* Understanding how all parents work to balance acceptance of their unique child with goals for change may be useful to distinguish how parents adjust to their child's autism diagnosis specifically from how parents manage and adjust to common parenting challenges.

Validating and Measuring Adjustment as an Active Process

The Active Balance model of adjustment proposed here is preliminary, and a number of next steps are needed to better understand and validate the model. The model was developed based on the experiences of a specific group of parents who had completed a PMI through a university clinic. Further qualitative research would be useful to explore perceptions of acceptance and change in adjustment for other groups of parents, including parents in community settings, parents of older children or adults, and parents who are autistic themselves. This work would provide insights into whether the Active Balance model is broadly useful in explaining adjustment to autism diagnosis. The use of co-design in subsequent research will be important to ensure that stakeholders are engaged in refining a model that is seen as useful and acceptable.

Use of the Active Balance model of adjustment in research and clinical practice would then require the development of a measure based on the model. There is a need for caution in suggesting the development of a new measure, especially since Study 1 showed that there are already a multitude of adjustment measures used in the field. However, existing measures either measure adjustment on a linear scale from low to high, or as a binary categorisation such as 'resolved' or 'unresolved' (Reaction to the Diagnosis Interview; Pianta & Marvin, 1993). These measures are therefore not consistent with the dialectical approach to adjustment explained in the Active Balance model. Based on the current research, there may be a need for development of a measure with subscales to assess acceptance and change focuses as components of adjustment to autism diagnosis. Rather than simply assessing adjustment as high or low overall, such a measure would allow for a more nuanced assessment of adjustment. For example, it may be clinically useful to identify when a parent may be low in acceptance but high in change focus, or vice versa, as this may impact which adjustment support is most suitable. The Active Balance model would suggest that parents who score high on both the acceptance and change subscales may have better adjustment to their child's autism diagnosis. However, validating such a measure with comparison to existing measures of adjustment would be important to confirm whether a high acceptance and high change focus, in combination, do indeed reflect better adjustment. It would also be integral to validate the test-retest reliability and intervention responsiveness of such a measure, so that it can be used in longitudinal and intervention research. As noted in Study 1, ongoing efforts to improve measurement of adjustment to diagnosis should be informed by a consensus between researchers, practitioners, parents, and autistic people. This would ensure that the measures designed are practical and useful, increasing the likelihood of more consistent use of the same measures across the field.

Adjustment as an Ongoing process: The Need for Longitudinal Research

The lack of longitudinal research on adjustment to diagnosis is a fundamental gap in the field. However, Study 1 highlighted that conducting robust longitudinal research on adjustment is precluded by limitations in the available measures. Most of the identified measures of adjustment cannot be deemed appropriate for use in longitudinal research, because they have not been assessed for test-retest reliability, nor for ability to detect changes over time.

Conflating adjustment as a process and an outcome within the same measure also limits the utility of many measures for longitudinal research.

A measure of adjustment as the balance of acceptance and change would be conducive to measurement over time. By asking about parents' acceptance-focused and changed-focus beliefs at a given time, such a measure would allow for an evaluation of stability or change in adjustment over time. In turn, this would answer important questions about the Active Balance model of adjustment. The model suggests that parents work to maintain a balance of acceptance and change over time, so longitudinal research would be important in understanding the trajectory of this process - is balance something that parents gradually work towards and then remain in, or do parents fluctuate in and out of balance? Longitudinal research using the Active Balance model could also explain the impact of stressors and changes in the child's functioning on parents' balance. Finally, longitudinal research would be helpful in establishing what normative adjustment looks like under the Active Balance model. Parents in Study 3 described adjustment as a process that occurs over time, however we do not yet know how soon after diagnosis parents are typically able to move out of uncertainty and work towards balance. With knowledge of the typical trajectory of adjustment, we could identify indicators that a parent is struggling more than expected, so as to effectively target support.

Adjustment in the Context of PMI

Parent-mediated intervention (PMI) is a widely-used evidence-based category of interventions for autistic children that improves parenting and child behaviour (Bearss et al., 2015; Liu & Schertz, 2022). While Study 1 identified six studies that examined adjustment-specific interventions, it found that no prior research had assessed whether PMI impacts on parents' adjustment to diagnosis. Study 2 directly addressed this gap by assessing adjustment before and after intervention with PWS, an evidence-based PMI (Leonard et al., 2025; Dadds et al., 2025) in an RCT with a waitlist control. PWS did not directly target adjustment.

However, the intervention included psychoeducation about autism, which could support understanding of, and therefore adjustment to, the diagnosis. The intervention also produced significant improvements in child externalising behaviour and conduct problems, core autism features, and parents' mental health and sense of competence (Dadds et al., 2025). It was feasible that these improvements may have, in turn, facilitated parents' adjustment. However, PWS did not result in changes in adjustment relative to the waitlist condition. Based on this finding, a broad intervention such as PMI may not be sufficient to improve adjustment, and a targeted intervention focused more specifically on parent adjustment may indeed be necessary. Study 2 also found no significant effect of adjustment on PMI engagement, dropout, or child outcomes. This may suggest that evidence-based PMI is generally effective for parents regardless of their adjustment. However, before drawing such conclusions from the current findings, it is important to consider the role of methodological limitations, and to discuss how the findings of Study 3 can inform the interpretation of Study 2.

Given the sampling and measurement limitations discussed in Study 2, it may be premature to conclude that a PMI cannot effectively facilitate adjustment. Specifically, it is not clear whether Study 2 participants were experiencing adjustment difficulties that may have been amenable to change through intervention, or whether the measure of adjustment used had adequate intervention responsiveness. Considering the potential for a broad intervention like PMI to deliver adjustment support with greater parsimony and accessibility as compared to a targeted intervention, further research to clarify the effect of PMI on adjustment is needed. In particular, it is important that further research examining adjustment in PMI be conducted using validated measures which have demonstrated intervention responsiveness, with diverse samples of children and parents, and in community settings.

The finding that pre-treatment adjustment did not impact on PMI dropout, engagement or outcomes also needs to be understood with the aforementioned methodological limitations in mind. In particular, it is not clear whether the sample included any parents with more significant adjustment difficulties that would be considered outside of the normal range. It may be that adjustment only impacts PMI when adjustment is particularly low. Following validation of an adjustment measure that can distinguish normative adjustment from clinical adjustment difficulties, it will be important for future research to examine the effect of adjustment on engagement and outcomes across a wider range of adjustment levels, and to identify whether the effect differs when parents are experiencing clinical adjustment difficulties. Research evaluating the role of adjustment on PMI engagement and outcomes when PMI is delivered in community settings, where the range of adjustment may be greater as compared to the university-recruited sample of Study 2, is also needed.

In fact, parents experiencing the most significant adjustment difficulties may be less likely to even participate in interventions such as PWS. Parents with significant adjustment difficulties may be in denial that their child is autistic, and therefore may not believe that they or their child would benefit from PMI for autism (Gentles et al., 2020; Smith et al., 2023). Parents experiencing significant difficulties with adjustment may also be too overwhelmed to find and participate in PMI (Rabba et al., 2019). Further research examining how adjustment affects parents' decisions to access (or not access) PMI, may provide important insights. It remains unclear whether parents experiencing significant adjustment difficulties are able to access, engage in, complete, and benefit from PMI – and indeed, whether PMI may benefit adjustment for parents experiencing more significant adjustment challenges.

Beyond these methodological considerations, the findings from Study 3 can add additional context to the findings of Study 2. In line with the lack of significant intervention effect for adjustment in Study 2, parents did not describe PWS as a turning point for their adjustment. PWS was, however, identified by participants in Study 3 as one of multiple supports which helped them to adjust by balancing acceptance and change. This finding needs to be cautioned given the duration of time that had elapsed between PWS participation and participation in Study 3 (20 months on average), which meant it is possible that parents simply could recall the specific impact of PWS on their adjustment. Nevertheless, parents in Study 3 described adjustment as something they gradually worked at over time by drawing on multiple supports, rather than a change brought about by any one particular support. The Active Balance model of adjustment captures this conceptualisation of adjustment as an iterative process and can therefore add a more nuanced interpretation of the results of Study 2. That is, it may not be that PMI did not effect adjustment at all, but rather that PMI added to a suite of supports that contributed to improving adjustment iteratively over time and in combination.

The rich qualitative information gained from Study 3 can also aid interpretation of the finding that pre-treatment adjustment did not impact intervention dropout, engagement, or outcomes in Study 2. Most parents in Study 3 described coping with adjustment difficulties by putting effort into helping the child. Therefore, adjustment challenges may not have made it harder for parents to engage in PWS, but instead motivated them to put effort into the program. This effort was rewarded with improvements in the child. These improvements, in turn, may have sustained engagement with the program. Again, though, it remains unclear whether parents' capacity to actively work on adjustment and to participate in PMI is reduced when their adjustment is particularly low.

The current research suggests that PMI may be one piece in a complex puzzle of supports that can iteratively facilitate adjustment through acceptance and change. PMI may not, on its own, be sufficient to produce meaningful change in parents' adjustment to diagnosis. This is in contrast with targeted adjustment supports, which have been shown to produce significant and immediate changes in adjustment (Bravo-Benítez et al., 2024; Leadbitter et al., 2025; Lodder et al., 2020). This suggests that targeted adjustment support may be indicated where there is greater need, such as when parents are particularly distressed by adjustment challenges. However, as discussed below, our ability to identify when parents are in greater need of targeted adjustment support is limited at present. It is also unclear whether methodological limitations across Study 2 and Study 3 may have limited the potential to detect an effect of PMI on adjustment. Given that addressing adjustment through a broad intervention such as PMI would offer greater parsimony, and potentially greater intervention reach, as compared to a targeted adjustment intervention, further research to better understand the role of PMI in adjustment is clearly needed. Nevertheless, the current findings provide considerations for improving support for parent adjustment.

Considerations for Supporting Adjustment

In combination with previous research, the findings presented here have implications for understanding how to best support parent adjustment to autism diagnosis. In particular, the Active Balance model of adjustment as a process that begins during initial assessment for autism and is then iterative and ongoing suggests a need to consider multiple possible supports across the entire adjustment journey– that is, during assessment for autism, at the time of diagnosis, and ongoing. Considering how best to deliver these supports, however, requires further research to understand how to identify which supports are indicated for which parent, as well as the ideal timing of supports.

It may be that the supports needed to facilitate adjustment differ from parent to parent. For example, a parent experiencing more significant adjustment difficulties may need more targeted or intensive support as compared to a parent experiencing normative difficulties in adjusting to their child's autism diagnosis. Indeed, in Study 3, some but not all parents reported seeking additional support for adjustment to diagnosis. Considering the importance of parsimony - and to avoid overburdening parents, practitioners, and systems, with supports that may not be needed for all parents to adjust to their child's autism diagnosis - it is important to understand how to match supports with parents' adjustment needs. However, as research has not yet developed normative data on adjustment, there is no means of empirically distinguishing more significant adjustment difficulties from normative adjustment. Furthermore, because of the lack of longitudinal research on adjustment (and, indeed, the lack of measures validated for use in longitudinal research), trajectories of adjustment are not well understood. Researchers are therefore unable to identify reliable indicators that adjustment challenges may resolve on their own over time without the need for additional support, or that adjustment challenges are unlikely to resolve and therefore require further support.

Aspects of child functioning may also inform how best to support parents' adjustment; however, again, further research is needed to identify reliable predictors of adjustment support needs. In Study 2, as in prior research (Da Paz et al., 2018), parents of children with higher autism features reported greater despair. In Study 3, parents explained that day-to-day challenges and concerns for the child's future contributed to this despair, especially when their child continued to need very high levels of ongoing support. However, no relation was found between level of autism features and self-blame or acceptance for parents in Study 2; in fact, Da Paz and colleagues (2018) found higher autism features to predict higher acceptance as well as higher despair. This may suggest that parents of children with a diagnosis of autism Level 3 might particularly benefit from adjustment supports which target despair. For example, a grief-focused intervention may be especially appropriate for this population. As such, there may be variability not only in terms of the need for targeted adjustment support, but also in terms of how best to deliver such support. Again, further research using a validated measure of adjustment to examine predictors of adjustment over time is needed to identify predictors that a parent may benefit from additional adjustment support and to inform the content of supports.

With no empirical way to identify a need for additional adjustment support, most adjustment interventions that were identified in Study 1 required parents to self-refer. Researchers don't yet understand under what circumstances a parent may decide to refer to additional adjustment support. We also do not know whether the parents with the most significant adjustment difficulties, who may therefore benefit the most from more targeted support, are likely to self-refer for such support. Only one targeted adjustment intervention has recruited through clinician referral (Empower Autism; Leadbitter et al., 2025). It is unclear how clinicians identified parents to refer for the Empower Autism intervention (Leadbitter et al., 2025), in the absence of published guidelines for identifying adjustment challenges. Therefore, further research is needed to inform recommendations regarding who is in need of, and most likely to benefit from, which adjustment support.

Further research is also needed to understand the ideal timing of each adjustment support relative to the diagnosis, and to other supports. For example, it is possible that targeted supported for adjustment may be most useful soon after the diagnosis, to reduce the initial uncertainty identified in Study 3 and to prevent more significant adjustment challenges becoming entrenched. It is also possible, though, that parents may be too overwhelmed to engage with an additional support immediately after diagnosis (Rabba et al., 2019). Considering the timing of effective targeted interventions for adjustment, The Empower Autism (Leadbitter et al., 2025) and SOLACE (Lodder et al., 2020) interventions were delivered within the first 12 months after diagnosis, whereas the Complicated Grief Intervention (Bravo-Benítez et al., 2024) was delivered later (though average time since diagnosis for participants was not reported). It may be that the ideal timing of adjustment support differs based on the type of support, and based on individual differences between parents. For example, it may be that some parents benefit from integrating adjustment-focused strategies throughout PMI, while parents with more significant adjustment difficulties may require a targeted adjustment intervention before accessing and engaging effectively in PMI. Further research is therefore needed to understand the ideal timing and combination of additional supports.

Parent preference is likely also important to consider with regards to the selection and timing of adjustment supports. For example, in Study 3, some parents reported a preference to receive post-diagnosis guidance from a practitioner, whereas others would have preferred to receive this guidance from another parent. Training practitioners on shared decision-making strategies (Charles et al., 1997), as discussed in Study 3, would allow for parent preferences to guide adjustment support choices.

Despite the need for further research to examine what supports are needed for who and when, the findings of this thesis in combination with past research suggest some considerations for supporting adjustment. Overall guiding principles, based on clinical recommendations for ambiguous loss (Boss, 2006) and for neurodiversity-affirming support (Brown et al., 2021b; Pritchard-Rowe & Gibson, 2024; Wagland et al., 2025), will first be discussed. Considerations for some specific supports will then be reviewed, including: improvements to screening, assessment and diagnosis of autism; psychoeducation and guidance at the time of diagnosis; social support or parent support groups; broad supports such as PMI, potentially augmented with more targeted supports; targeted adjustment support programs; and initiatives to improve public understanding of autism and reduce stigma.

Considering adjustment to autism diagnosis as a process of responding to ambiguous change, supports for adjustment should therefore draw on recommendations for adjustment to ambiguous loss. Boss (2006) defined six clinical goals for adjustment to ambiguous loss: normalising ambivalence, adjusting mastery, developing new hope, revising attachment, reconstructing identity, and finding meaning. Each of these can be applied to guide supports for parent adjustment to autism diagnosis:

- Normalising ambivalence: This goal recognises the importance of helping parents to recognise the ambivalence or dialectic they are experiencing – between acceptance and change – and of validating that this experience is a normal part of the adjustment process. Parents may therefore benefit from receiving psychoeducation about adjustment to diagnosis. This psychoeducation may note that adjusting to an autism diagnosis can be challenging for parents. It may also describe that many parents experience feelings of acceptance and a desire for change, at the same time. Psychoeducation can explain that parents may believe that these goals of acceptance and change are in conflict, and may feel confused by experiencing both. Psychoeducation may validate this confusion, and explain how both acceptance and change are important for adjustment. Presenting the Active Balance model of adjustment may be helpful in explaining to parents how acceptance and change can work together, in balance, to support adjustment.

- Adjusting mastery: This goal focuses on helping parents to define mastery, or success, in ways that are likely to be achievable for themselves and their child. At the time of diagnosis, and following any further assessment, receiving clear information about their child's strengths and challenges may aid parents in this goal. Providers should avoid focusing only on deficits, but also should not encourage unrealistic expectations for improvement. It may be helpful to explain to parents that it is not possible to predict the child's long-term outcomes, as being open about this uncertainty may help parents to adjust to it (Anderberg & South, 2021; Jacobs et al., 2020).
- Developing new hope: This involves guiding parents to develop goals for themselves and the child that are aspirational but reasonable. Providers can work collaboratively with parents to use assessment information to set reasonable, short-term goals for the child. Parents may benefit from receiving specific information about how to work towards these goals. It may be helpful for providers to specifically highlight parents' involvement in working towards their child's goals, so that parents feel empowered and

capable of supporting change. Progress towards goals, and parents' role in this progress, should be celebrated.

- Revising attachment: This goal builds on the concept that parents' grieving the child they had imagined may make it harder for them to connect and build an attachment with the child they do have (Pianta & Marvin, 1993). Supports may therefore help parents strengthen their connection with their child, by accepting that this child may be different from the child they had expected to raise. This may include psychoeducation about autism, to help parents better understand their child. For example, psychoeducation may help parents to understand their child's communication style so that they are better able to connect with the child, and to explore the benefits of connecting with the child on their special interest. Psychoeducation may also help parents to better accept behaviours rather than blaming the child, thus enhancing the parent-child relationship. It may also help parents to make changes to the environment, such as reducing sensory overstimulation, so that the child is calmer and better able to enjoy connecting with the parent. Beyond psychoeducation, support for revising attachment may also include interventions such as PMI. Learning evidence-based strategies to reduce the challenging behaviours that increase parental stress and impact on the parent-child relationship may support attachment. More targeted attachment-based strategies such as child-led play (Eyberg & Funderburk, 2011; Green et al., 2010) may also be of use here.
- Reconstructing identity: This goal involves the parent developing their own identity as a parent of an autistic child. This can include disclosing the diagnosis to family and friends (Rabba et al., 2019). It can also include building new relationships that help the parent to develop their identity as a parent of an autistic child, such as making friends with other parents of autistic children. Practitioners can help parents to recognise the

importance of social support and the potential benefit of connecting with other parents of autistic children. Parents may have trouble finding and connecting with other parents themselves, so providers may direct them towards specific groups or programs. For some parents, reconstructing identity following their child's diagnosis will involve recognising that they themselves are autistic. Parents may want to discuss queries regarding their own neurodivergence with their child's providers. Providers can direct parents towards appropriate services for their own diagnostic assessment, if the parent wants.

- Finding meaning: This goal refers to finding a broader meaning or purpose associated with the child's autism, sometimes referred to as benefit finding (Pakenham et al., 2004; Taylor, 1983). Supports here should generally not focus on encouraging the parent to try to find out why the child is autistic, although genetic testing may contribute to adjustment where a genetic diagnosis is suspected (Wynn et al., 2024). Rather, clinicians may support parents to engage in consideration of how autism positively contributes to the life of the child, parent, and family. This may include identifying autistic traits that are strengths for the child, as well as broader and potentially more abstract positive changes that have come from the child's diagnosis, such as personal growth and development for the parent (Samios et al., 2012). Supporting parents to identify these positive contributions may be done by encouraging them to engage with their existing values systems, such as religion (White, 2009). It may also be done by providing neurodiversity-affirming support, or by engaging parents in a values-based intervention such as Acceptance and Commitment Therapy (ACT; Hayes et al., 2012). It is important that encouraging parents to find meaning is done in a way that does not dismiss difficulties they have with adjustment or with the day-to-day realities of parenting an autistic child. Rather, finding meaning should be encouraged in balance with validation of parents' challenges.

With these goals in mind, supports can guide parents to adjust to the ambiguous change of their child's autism diagnosis, by balancing acceptance and change.

It may also be important for adjustment supports to draw from neurodiversity-affirming practices (e.g., Brown et al., 2021b; Lerner et al., 2023; Pritchard-Rowe & Gibson, 2024; Wagland et al., 2025). Neurodiversity promotes acceptance and valuing of autistic people, conceptualising autism as a variation, rather than deficit, in development (Kapp et al., 2013). Much of the relevant literature, though, also acknowledges that changes, such as developing skills, may be needed when an individual's autistic traits negatively impact their quality of life or that of their important people such as parents (Brown et al., 2021b; Lerner et al., 2023). Neurodiversity-affirming support is therefore theoretically aligned with the Active Balance model of adjustment. It is likely that supporting parents to develop a neurodiversity-affirming perspective may allow them to view their child more positively (acceptance) while also maintaining hope for change, thus supporting adjustment. In fact, one study found that parents with neurodiversity-affirming beliefs about autism reported lower psychological distress (Ferenc et al., 2023). To apply a neurodiversity-affirming lens to autism supports, practitioners can use language that frames autism as a difference, rather than a deficit. Practitioners should also emphasise and aim to develop the child's strengths. Intervention goals should focus not just on reducing challenges, but on building functional capacity and improving quality of life for the child and the parent (Fitzpatrick et al., 2024; Wagland et al., 2025).

These general guidelines for supporting adjustment to ambiguous change with a neurodiversity-affirming lens can be applied across a range of supports. First, Study 3 clearly demonstrated a need to improve the screening, assessment and diagnosis of autism in order to better support parental adjustment from the outset. Practitioner training on autism screening tools (e.g., Barbaro et al., 2022; Robins et al., 2001) is recommended so that decisions to refer for autism assessment can be based on empirical information. Practitioners may also benefit from training on how to deliver screening and assessment results to parents, so that feedback and next steps are communicated clearly and in neurodiversity-affirming language (Bickel et al., 2022; Guan et al., 2022). Brown and colleagues (2021b) explain that the language that practitioners use to discuss autism sets parents' expectations for the diagnosis. The language used throughout assessment for an autism diagnosis is therefore likely to impact on parents' adjustment. When the practitioner uses deficit-focused language, or phrases like "I'm sorry to tell you…", parents begin their adjustment journey with negative attitudes towards autism that likely make it harder to adjust.

At the time of diagnosis, receiving psychoeducation and guidance regarding the next steps may aid parents' adjustment. In Study 3, and across past research, parents have reported receiving insufficient information at the time of diagnosis regarding what autism is, their child's individual strengths and challenges, and the available support options (Crane et al., 2016; Osborne & Reed, 2008). Parents therefore report low confidence to make decisions about appropriate support immediately after diagnosis (Grant et al., 2016). Yet, they are expected to quickly become "de facto experts" (Gentles et al., 2019, p. 2) in autism, their child's unique needs, and understanding and selecting from the available supports to meet these needs. As described in Study 3, the lack of collaborative professional guidance for parents at this stage adds to uncertainty and overwhelm, thus hindering adjustment. Providing clear and neurodiversity-affirming information at the time of diagnosis, and engaging parents in shared decision-making regarding the next steps (Angell et al., 2023; Charles et al., 1997), would therefore likely support parents' adjustment to diagnosis. Critically, this would require practitioner training on neurodiversity-affirming diagnosis (Brown et al., 2021b; Pritchard-Rowe & Gibson, 2024) and on using shared decision-making tools (Angell et al., 2023; Charles et al., 1997). Additional research is needed to understand parent and practitioner perspectives on the feasability, acceptability and usefulness of shared decision-making. Also, in addition to psychoeducation about autism and the available next steps for the child, parents may benefit from receiving psychoeducation specifically about adjustment to diagnosis.

Given the importance of social support for adjustment (Alon, 2019; Wayment & Brookshire, 2018), it may be helpful for practitioners to recommend that parents engage with social supports following a diagnosis. For example, it may be helpful for practitioners to provide parents with resources that explain the potential benefits of disclosing the child's diagnosis to friends and family and provide suggestions regarding how to do so; however such resources should also note that decisions about who to disclose the child's diagnosis to should be carefully considered given the potential for others' negative responses to exacerbate adjustment difficulties (Rabba et al., 2019). Parents may also benefit from information explaining that connecting with other parents of autistic children can support adjustment. Parents in Study 3 noted that forming friendships with other parents of autistic children was particularly helpful for their adjustment. These relationships can offer non-judgemental support from parents who "get it", which can be a means to supporting acceptance. Peer support can also include information about topics like available therapies or useful strategies, thus building parents' capacity for change. As such, peer navigator programs (Hock et al., 2022; Lee et al., 2024) may be of benefit, although the effects of such programs on adjustment specifically are yet to be evaluated. Support groups may also be a helpful avenue for social support (Lee et al., 2024). However, some parents in Study 3 noted concerns that support groups may become detrimental to adjustment when they are largely deficit-focused or allow for the spread of misinformation. A trained facilitator (such as a mental health practitioner and/or a peer facilitator) may assist in keeping the content of a support group accurate and balanced, so that parents can derive the social benefits without the risk of iatrogenic effects. Chase (2022) presented a case study of a support group for parents of autistic adolescents that was informed by ambiguous loss theory (Boss, 1999; Boss, 2006). This provides a potential model for facilitator-assisted social support, however the benefits for adjustment require evaluating.

As discussed above, the potential for broad autism interventions, including PMI, to support parent adjustment remains unclear. PMI may play some role in supporting adjustment through acceptance and change. However, additional research is needed to understand whether PMI can be an effective support for adjustment. For some parents, there may a benefit to augmenting PMI with optional adjustment-focused modules. Components of targeted adjustment interventions - such as psychoeducation and ACT (Empower-Autism; Leadbitter et al., 2025) or cognitive restructuring and self-compassion (SOLACE; Lodder et al., 2020) - could be delivered within PMI, rather than as standalone programs. For example, PWS included a module focused on strategies to support parent mental health. The specific content included in this module was decided collaboratively by the parent and clinician based on parent goals, from options including partner support strategies and pleasant activity scheduling. Content targeting adjustment more specifically could be developed and added to PWS. It is important to note that not all PMI includes components focused on the parent's own mental health and well-being. It may be harder to add targeted support for adjustment into a program with less of a clear parent well-being component than PWS. Nevertheless, there is research to suggest that strategies focused on parent mental health can be incorporated in PMI simply and effectively (Andrews et al., 2022; Lushin & O'Brien, 2016; Pennefather et al., 2018; Rosenbrock et al., 2021a). It will be important for research to address parent and provider perspectives on the feasibility and acceptability of incorporating adjustment support into PMI, and to test its effectiveness.

Study 1 captured an emerging body of evidence for targeted interventions for parent adjustment to autism diagnosis. The SOLACE (Lodder et al., 2020) and Complicated Grief

Intervention (Bravo-Benítez et al., 2024) programs demonstrated efficacy in randomised controlled trials, as did the Empower-Autism program (Leadbitter et al., 2025) which was published after Study 1 was conducted. Dissemination and ongoing evaluation of these programs in community settings may therefore be of use in supporting access to targeted adjustment support. Again, though, there is a need to better understand who is in need of these targeted supports, and whether a broad program may be as effective in supporting adjustment for some parents, in order to inform recommendations to refer parents to targeted adjustment support.

Providing supports directly to parents of autistic children is likely necessary, but not sufficient, to adequately strengthen adjustment. Parents are trying to adjust in the context of negative and ableist attitudes towards autism in wider society (Turnock et al., 2022). Study 3 revealed that parents' pre-diagnosis understanding of autism was derived from public discourse and popular media such as television and movies. Parents described this societal picture of autism as overwhelmingly negative, and explained how this led them to fear an autism diagnosis and made it harder to adjust once their child was diagnosed. Ongoing, experiences of judgement and exclusion from friends, strangers, and organisations (for example, one mother described that her children had been banned from multiple local sports groups) continued to hinder parents' adjustment. Increasing accurate and neurodiversity-affirming awareness of autism in the community would likely decrease parents' initial negative feelings towards an autism diagnosis, and support adjustment ongoing (Anthony et al., 2020).

These implications for clinical practice involve an array of possible supports, because adjustment appears to be a complex process. There is emerging evidence for targeted adjustment-specific interventions, but also a clear need for more general support throughout assessment for autism, and following diagnosis. Improvements to the process of screening, assessment and diagnosis in the community are integral in ensuring that parents are starting their adjustment journey in a more positive place. Finally, it is important to recognise that challenges adjusting to an autism diagnosis will likely persist so long as autism continues to be highly stigmatised. Efforts to improve adjustment therefore need to look beyond the parent, and promote greater understanding and acceptance of autism in society.

Strengths and Limitations of the Current Research

There are three key strengths of the current research. First, the samples in Study 2 and Study 3 were relatively diverse. Of the families that participated in Study 2, 67% were culturally and linguistically diverse (CALD), a greater proportion than is often seen in research on PMI for autism (Trembath et al., 2019). Similarly, 55% of participants in Study 3 identified as CALD. Second, the focus on fathers' experiences of adjustment and PMI, and high rates of father participation, is a notable strength which addresses a key gap in past research. Study 1 identified that much of the research on parent adjustment to autism diagnosis has not included fathers. Fathers comprised less than 20% of the sample for any of the adjustment intervention studies identified in Study 1, compared to father participation for 77% of families in Study 2. In fact, the current research was the first time that intervention outcomes for adjustment in fathers have been evaluated separately to outcomes for mothers. Fathers have also been left out of much of the research on PMI (Factor et al., 2019; Rankin et al., 2019). Prioritising father inclusion in research ensures that fathers' experiences of adjustment can be understood, and that the clinical supports developed for adjustment can therefore meet their needs.

Finally, the mixed methods approach was a strength of this research in that it facilitated a deeper and more complex understanding of adjustment. Study 2 allowed for the relationships between adjustment and PMI to be directly evaluated. Study 3 complemented this by providing more in-depth insights for a smaller subset of this same sample, and by allowing us to situate PMI within parents' broader adjustment journey. Particularly because Study 3 drew from the same sample as Study 2, it provided added context that may explain the results of Study 2.

Considering the results from these two studies in combination therefore facilitated a better understanding of adjustment than the two studies in isolation would have.

It is, though, important to consider the five main limitations of the current research. First, as discussed in Study 2 and Study 3, the sample of parents may not be representative of parents of autistic children in the community, which may have impacted the research in important ways. This research examined adjustment for parents involved in PMI through a specialised university clinic. These parents may not have been struggling with adjustment to their child's autism diagnosis, limiting our ability to assess the interplay of adjustment challenges and PMI in Study 2. To be recruited into Study 2 parents needed to report challenges with their child's externalising behaviour. It's therefore possible that parents in the current sample may have been more concerned with their child's externalising behaviour problems rather than adjustment to their autism diagnosis specifically. There is a need to examine the relationships between PMI and adjustment for representative samples of parents of autistic children in community settings. The Active Balance model of adjustment proposed in Study 3 will also require further assessment with more representative samples.

Second, despite the high proportion of CALD parents in the current research, cultural considerations were not examined. Study 3 used semi-structured interviewing to ascertain parent perceptions of their adjustment journey. I therefore followed parents' lead by probing further about barriers and facilitators to adjustment that they mentioned, and did not ask specifically about particular barriers or facilitators. Some parents discussed the influence of culture on their adjustment, but this was not consistently assessed. Culture therefore did not feature in the themes or subthemes derived in Study 3. Other research, however, has identified that cultural beliefs about autism can impact experiences of parenting an autistic child (Blanche et al., 2015; Naicker et al., 2023). CALD parents also often encounter additional barriers in the health care system which may influences experiences of adjustment (Lim et al., 2020; Zhang

& Chen, 2024). Therefore, the role of culture is a nuance that is missing from the Active Balance model of adjustment.

Third, there may have been differences between PWS intervention participants in whether and how adjustment to diagnosis was addressed during PWS. While specific support for adjustment was not included in the manualised intervention, there was scope within PWS to address additional content. Some parents in Study 3 reported that they discussed adjustment difficulties with their PWS therapist. This may have occurred because the parent asked the treating clinician about adjustment to diagnosis, or because the treating clinician identified that discussing adjustment may have been of benefit to the particular parent. However, because specific support for adjustment was not a component of the manualised intervention, it was not recorded as part of intervention fidelity assessment. It was therefore not possible to identify how many parents accessed more specific support for adjustment as part of PWS, what this support involved, or whether those families who received this specific support experienced greater improvement in adjustment than those who did not.

Fourth, the Active Balance model of adjustment was developed using thematic analysis, rather than grounded theory which is the more widely accepted methodology to use for developing a theoretical model (Charmaz, 2014; Glaser & Straus, 1967). This is because developing a theoretical model was not an aim of Study 3. Rather, it became apparent through the process of thematic analysis that a model would be of use in explaining the experiences that parents were reporting. Also, thematic analysis was appropriate because the Active Balance model of adjustment was not developed completely inductively, but rather was informed by the existing theory of ambiguous loss (Boss, 1999). Thematic analysis is considered appropriate for defining relationships between themes, especially where informed by existing theory (Braun & Clarke, 2006). Nevertheless, further research is needed to more rigorously validate the Active Balance model of adjustment.

Fifth, the research presented here investigated parent adjustment at the individual parent level. However, there is a broader need to consider adjustment to autism diagnosis at the level of family systems (Negri & Castorina, 2014). In particular, research has identified the Double ABCX model (McCubbin & Patterson, 1983) and its variations to provide insights into family-wide adjustment to autism diagnosis (Pickard & Ingersoll, 2017). This model posits that a family's coping with a stressor (in this case, the child's autism diagnosis) is impacted by family resources (including practical, cognitive and emotional factors) prior to the stressor, perception of the stressor itself, as well as the pileup of crises stemming from the initial stressor (which may include challenges such as child behaviour problems, difficulty accessing therapies, and financial strain). Relevant research has therefore highlighted the role of family-level barriers and facilitators such as overall family stress and availability of social support in adjustment (Pickard & Ingersoll, 2017). Beyond identifying differences in adjustment between mothers and fathers, as in the current research, there is also a need to understand how parents influence one another's experiences of adjustment (Gentles et al., 2020; McStay et al., 2015; Oppenheim et al., 2024). It may also be useful for adjustment research to look beyond parents, to consider the role of the extended family in adjustment (Rabba et al., 2019). Broadly, there is a need to consider how the entire family unit adjusts to a diagnosis of autism within the family, rather than focusing only on adjustment in the individual family members.

Future Directions for Research

Future directions for research have been proposed throughout this General Discussion. These are summarised here to present a clear program for ongoing research. Overarching these specific research directions should be a goal of co-design with stakeholders such as mothers and fathers, autistic people including autistic parents, and health practitioners where relevant.

- Definition and measurement of adjustment: Future research should focus on developing a consensus definition of adjustment, including defining what is and is not included in the construct. There is then a need to develop and validate a gold-standard measure of adjustment based on this definition. Validation needs to include test-retest reliability and intervention responsiveness, and should be conducted with a representative sample including fathers, parents of adults, and parents who are autistic. Publication of normative data and clinical cutoffs for this gold standard measure is also needed.

- Validation of the Active Balance model of adjustment: Further qualitative work is needed to validate and explore perceptions of the model in diverse groups of parents. This work can inform the development and validation of a measure based on the Active Balance model, with consideration to the need to validate the measure with diverse samples and to assess sensitivity to change over time and with intervention, as above.
- Longitudinal research on adjustment: Research is needed to plot typical trajectories of adjustment over time, including the trajectory of acceptance, change and their balance. Longitudinal research is also needed to identify the impact that changes such as stressors, major milestones, or developments in the child may have on parent adjustment.
- Development and evaluation of supports to improve assessment and diagnosis of autism, with the goal of facilitating better adjustment from initial assessment: Evaluation of practitioner training on autism screening and neurodiversity-affirming diagnosis, and research into increasing the uptake of such training, is needed. Parent and practitioner perspectives on supports to be provided prior to and at the time of diagnosis, such as psychoeducation and shared decision-making, need to be assessed.
- Further research on adjustment in the context of PMI: Research is needed to address the methodological limitations that may have reduced the ability to detect an effect of PMI on adjustment, or of adjustment on PMI dropout, engagement or child outcomes. Research investigating adjustment when PMI is delivered in community settings to

representative populations is needed. It is also important for research to use well-validated measures that are able to detect a possible intervention effect of PMI on adjustment. Research examining the feasibility, acceptability, and efficacy of augmenting PMI with more targeted adjustment support may also be indicated, though (as per the point below), it is important to understand how to identify when a parent may benefit from this additional adjustment support. This research will be vital to understand whether and how broad supports such as PMI may affect adjustment.

- Identification of who benefits from targeted adjustment support, and the ideal timing: Research is needed to identify indicators that a parent is likely to need and benefit from targeted adjustment support, and to evaluate the ideal timing of supports for adjustment following a diagnosis.
- Further evaluation and dissemination of targeted supports for adjustment: Further evaluation of targeted adjustment support programs is needed, including with fathers. Dissemination and evaluation in community settings will be important to address the accessibility of targeted adjustment programs.

Overall Conclusion

This thesis presented a mixed-methods program of research to better understand parents' adjustment to their child's autism diagnosis. This research has identified fundamental limitations in the definition and measurement of adjustment to diagnosis, and proposed specific steps to address these limitations in future research. The research also investigated how PMI fits into parents' journey of adjustment, and presented the first study to examine changes in parent adjustment to diagnosis as an outcome of PMI. Changes were not found in the PMI intervention group relative to the waitlist control. A qualitative study found that parents reported some benefits in adjustment from PMI, although adjustment was considered a more gradual, iterative process and PMI was seen as one of multiple supports that contributed to this process. Stemming from this research, the Active Balance model of adjustment is proposed. This model highlights parents' active role in their own adjustment. The model also identifies the importance of accepting the child and their neurodivergence, at the same time as pushing for change to improve the child's - and parent's - quality of life. The current research suggests that while acceptance and change may appear to work in opposition, holding them in balance may allow parents to adjust. Adjustment is therefore effortful, and iterative. Such a complex process may require a network of supports. Considerations for these supports have been described here. One participant in Study 3, a mother of a son diagnosed at age 2, reflected back on the day of her son's autism diagnosis as "just the start of the journey as different parents". It is our role as researchers and clinicians in this space to provide guidance and support that empowers parents to venture confidently along this journey of adjustment.

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PRISMA 2020 Checklist

Appendix 1 - PRISMA Checklist (Study 1)

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title (Pg40)
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 40
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 41-44
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 44
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 46-47, Figure 1
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 45
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 45, Appendix 3
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 46-47
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 48
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 48
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 48
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 48
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Appendix 4 and 5
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 48-49
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	N/A
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 2
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Appendix B1
Study characteristics	17	Cite each included study and present its characteristics.	Appendix B2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Appendix B2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Appendix B2
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 54-60
	23b	Discuss any limitations of the evidence included in the review.	Page 54-60
	23c	Discuss any limitations of the review processes used.	Page 60
	23d	Discuss implications of the results for practice, policy, and future research.	Page 54-61
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Appendix 2
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Appendix 2
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	viii
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendix B2

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. This work is licensed under CC BY 4.0. To view a copy of this license, visit https://creativecommons.org/licenses/by/4.0/

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PROSPERO
International prospective register of systematic reviews

Caregiver adjustment to their child's diagnosis of Autism Spectrum Disorder: Systematic review of measures and interventions

Elysha Clark-Whitney, Lucy Tully, Bridie Leonard, Adrienne Turnell, Erika Moelle, Mark Dadds

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REVIEW TITLE AND BASIC DETAILS

Review title
Caregiver adjustment to their child's diagnosis of Autism Spectrum Disorder: Systematic review of measures and interventions

Review objectives
1. To examine how caregiver adjustment to their child's diagnosis of Autism Spectrum Disorder is measured, including the psychometric properties of measures.
2. To examine the effectiveness of intervention for changing caregiver adjustment to their child's diagnosis of Autism Spectrum Disorder.

Keywords
adjustment to autism diagnosis, autism spectrum disorder, parents

SEARCHING AND SCREENING

Searches
Sources searched: PsycINFO, MEDLINE, Scopus, Web of Science, and the Cochrane Central Register of Controlled Trials.
Restrictions: Language (English), methodology (quantitative) (where database allows), peer reviewed articles.
Search date 30/08/2023
Studies that were eligible for inclusion met the following criteria:
1) Study sample is primary or secondary caregivers of a child or adolescent/adult offspring with a confirmed DSM-5 diagnosis of Autism Spectrum Disorder (or diagnosis of PDD-NOS or Aspergers syndrome if the study was conducted prior to the publication of the DSM-5 in 2013). Includes permanent primary or secondary caregivers (e.g., biological parents, adoptive parents, step-parents, other relatives

acting in the primary or secondary caregiver role). Does not include samples exclusively comprised of foster caregivers, and does not include people employed to provide care such as teachers or support workers, or siblings.
2) Study includes quantitative measurement of caregiver response to their child's ASD. Caregiver response to the child's ASD diagnosis includes any of the following: adjustment, reaction, resolution, acceptance, grief. Does not include studies that measure only aspects of adjustment other than perceptions of diagnosis (e.g., family adjustment). Does not include studies that measured only other aspects of caregiver wellbeing, such as caregiver mental health symptoms, or child outcomes, without measuring response to diagnosis. For any intervention studies to be included, adjustment will have been included as a primary or secondary outcome (to answer question 2)
3) Original research articles published in peer reviewed journals in English.

Study design

Quantitative studies - includes studies using entirely quantitative methodology, as well as mixed method studies with a quantitative component. For mixed method studies, only information pertaining to the quantitative component will be included. Studies involving quantitative measurement of caregiver adjustment to autism diagnosis will be included, including but not limited to measure validation studies, randomised control trials, pilot trials without a comparator group. Excludes single case designs. Excludes studies using exclusively qualitative methodology.

ELIGIBILITY CRITERIA

Condition or domain being studied

Autism Spectrum Disorder
Confirmed DSM-5 diagnosis of Autism Spectrum Disorder (or diagnosis of PDD-NOS or Aspergers syndrome if the study was conducted prior to the publication of the DSM-5 in 2013).
Child, parent and family wellbeing.

Population

1. Study sample is primary or secondary caregivers of a child or adolescent/adult offspring with:
a) a confirmed DSM-5 diagnosis of Autism Spectrum Disorder (or diagnosis of PDD-NOS or Aspergers syndrome if the study was conducted prior to the publication of the DSM-5 in 2013).
• Exclude suspected ASD if not confirmed diagnosis
• Exclude if part of sample is ASD but not full sample (e.g., mixed disability group) with results reported together
• Include if there are multiple groups (e.g., ASD compared with TD or ASD compared with another disability) in which results for ASD group are reported separately such that extraction would be possible for ASD group only
• Include if full sample is diagnosed with ASD as well as a comorbidity (e.g., 100% ASD with ID)
b) Includes permanent primary or secondary caregivers (e.g., biological parents, adoptive parents, stepparents, other relatives acting in the primary or secondary caregiver role).
Excludes samples exclusively comprised of foster caregivers, and does not include people employed to provide care such as teachers or support workers, or siblings.

Intervention(s) or exposure(s)

Inclusion of an intervention is not required for inclusion in the study; publications that include an intervention component meeting the below criteria will be included in analyses relating to the second research questions.
1) Interventions with a primary aim of improving caregiver adjustment, reaction, resolution, acceptance, or grief following their child's diagnosis of ASD; OR
2) Interventions with an alternative primary aim, in which caregiver adjustment, reaction, resolution,

acceptance, or grief following their child's diagnosis of ASD is measured as a secondary outcome.
Includes studies in which the intervention is compared to a comparator/control condition, including randomised and non-randomised allocation, as well as intervention studies without a comparison group.
Does not include single case designs.
Interventions may involve direct intervention provided to the caregiver, or intervention provided to the child, where caregiver adjustment is a measured outcome.

Comparator(s) or control(s)
Includes studies in which the intervention is compared to a comparator/control condition, including randomised and non-randomised allocation, as well as intervention studies without a comparison group (e.g., pilot trials).
Does not include single case designs.

Context
Research across contexts including clinical settings (hospital, psychology clinic), home settings, and school settings if measurement of outcomes occurs for parents or other primary caregivers; online and in-person settings. Research from any country is eligible for inclusion if the original article is published in English.

OUTCOMES TO BE ANALYSED

Main outcomes
Caregiver adjustment to their child's diagnosis of Autism Spectrum Disorder. Includes measures of response to or perception of diagnosis: adjustment, reaction, resolution, acceptance, grief.
• Include caregiver attitudes specifically to their own child's ASD diagnosis; also include caregiver attitudes to the concept/diagnosis of ASD in general
• Exclude measures of beliefs, attributions etc that are not about the diagnosis of ASD, such as beliefs about challenging behaviour, attitudes towards the child overall (rather than to the child's ASD), coping with ASD symptoms (rather than coping with the concept of ASD)
• Exclude measures of the impact of ASD that are not about cognitions, beliefs etc – such as burden, impact on the family, stress
• Exclude trait/general measures that are not specific to caregiver attitudes towards autism diagnosis – e.g., general coping styles would be excluded whereas coping with ASD diagnosis would be included
• Exclude studies that measured only other aspects of caregiver wellbeing, such as caregiver mental health symptoms, or child outcomes, without measuring response to diagnosis.
The first research question will identify measures of this construct, including psychometric properties of measures, where reported.
The second research question will identify the effectiveness of intervention for this construct.

Measures of effect
Research question 1: Psychometric properties of measures including reliability and validity
Research question 2: Intervention effect sizes, clinical significance where reported

Additional outcomes
Not applicable.

Measures of effect
Not applicable.

DATA COLLECTION PROCESS

Data extraction (selection and coding)

Inclusion criteria:
1) Sample is primary or secondary caregivers of a child or adolescent/adult offspring with a confirmed DSM-5 diagnosis of Autism Spectrum Disorder (or diagnosis of PDD-NOS or Aspergers syndrome if the study was conducted prior to 2013). Includes permanent primary or secondary caregivers (e.g., biological parents, adoptive parents, step-parents, other relatives acting in the role); doesn't include samples exclusively of foster caregivers or people employed to provide care.
2) Quantitative measurement of caregiver adjustment to ASD diagnosis.
3) Original research articles published in peer-reviewed journals in English.
Covidence will be used for screening.
1. Title/abstract screening: One reviewer will screen 100% of articles. Four additional reviewers will each screen 5% of articles (total of 20% of articles double screened). Conflicts will be resolved through group discussion. At least 85% agreement required.
2. Full-text screening: One reviewer will screen 100% of all articles. Four additional reviewers will each screen 5% of articles, (total of 20% of articles double screened). At least 85% agreement required. Conflicts will be resolved through discussion between the two reviewers, with remaining conflicts taken to the full group of reviewers for further discussion.
3. Data Extraction: A codebook will be developed by all reviewers. One reviewer will extract 100% of articles. Extraction will be completed by entering data into a table in Excel or similar.
The extraction table will include the following: Participant characteristics; child age at diagnosis; time since diagnosis; criteria used for diagnosis; type of measure; psychometric properties of measure.
For publications included in the second research question:
Intervention type; measure of adjustment; statistical significance, effect sizes, clinical significance.
The review will only include data provided by the published papers. The reviewers will not contact study investigators for unreported data.

Risk of bias (quality) assessment

The Mixed Methods Appraisal Tool (MMAT) will be used to assess quality. Quality assessment will be randomly divided between all reviewers. Reviewers will calibrate through consensus coding of several articles before independently assessing remaining articles. Where reviewers have questions or unsure about how to rate the quality of an included study, reviewers will discuss with the other reviewers.
Evaluation of risk of bias will occur at the individual study level.
Characteristics assessed by the MMAT will include representativeness of sample, outcomes measures reported, control for relevant confounds, features of randomisation (where appropriate)
Studies will be included in the review regardless of the quality determined, with no exclusion criteria applied for lower quality studies. The quality of each study will be reported, as will an overall summary of the quality of reported studies.

PLANNED DATA SYNTHESIS

Strategy for data synthesis

Research question 1: Psychometric properties of measures will be compared (E.g., presented in table format so that performance on multiple criteria can be compared); measures will not be synthesised, given that the aim of this research question is to understand the properties of individual measures.
Research question 2: Average effect size per study design type (e.g., RCT, non-randomised experimental study, single group pilot design) will be calculated for study designs for which there are at least 3 included papers. Intervention features will be reported in table form.

Analysis of subgroups or subsets

It is anticipated that insufficient papers will meet inclusion criteria to allow for subgroup analysis. Participant characteristics such as mean child age and time since diagnosis will be reported for included studies to

allow
for identification of characteristics of participants included in relevant research.

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

- Miss Elysha Clark-Whitney, University of Sydney
- Dr Lucy Tully, University of Sydney
- Dr Bridie Leonard, University of Sydney
- Miss Adrienne Turnell, University of Sydney
- Miss Erika Moelle, University of Sydney
- Professor Mark Dadds, University of Sydney

Review affiliation

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Funding source

None

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TIMELINE OF THE REVIEW

Review timeline

Start date: 30 August 2023. End date: 11 November 2023

Date of first submission to PROSPERO

13 September 2023

Date of registration in PROSPERO

02 October 2023

CURRENT REVIEW STAGE

Publication of review results

The intention is to publish the review once completed.The review will be published in English

Stage of the review at this submission

Review stage	Started	Completed
Pilot work		
Formal searching/study identification	✓	✓
Screening search results against inclusion criteria	✓	
Data extraction or receipt of IP		
Risk of bias/quality assessment		
Data synthesis		

Not applicable

Review status
The review is currently planned or ongoing.

ADDITIONAL INFORMATION

PROSPERO version history

- Version 1.0 published on 02 Oct 2023

Review conflict of interest
None known

Country
Australia

Medical Subject Headings
Autism Spectrum Disorder; Autistic Disorder; Caregivers; Child; Humans; Parents; Psychometrics

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Any enquiries about the record should be referred to the named review contact

Appendix 3 – Search Strategy, All Databases (Study 1)

PSYCINFO
1. autism.mp or Autism Spectrum Disorders/
2. caregiver.mp or exp Caregivers/
3. exp Parents/ or parent.mp.
4. 2 or 3
5. exp Adjustment/ or adjust*.mp.
6. accept*.mp.
7. resol*.mp.
8. grief.mp or exp Grief/
9. respon* to diagnosis.mp.
10. react* to diagnosis.mp.
11. 5 or 6 or 7 or 8 or 9 or 10
12. 1 and 4 and 11
13. Limit 12 to (peer reviewed journal and English language and 1800 quantitative study)

Medline
1. autism.mp or Autism Spectrum Disorders/
2. caregiver.mp or exp Caregivers/
3. exp Parents/ or parent.mp.
4. 2 or 3
5. exp Adjustment/ or adjust*.mp.
6. accept*.mp.
7. resol*.mp.
8. grief.mp or exp Grief/
9. respon* to diagnosis.mp.
10. react* to diagnosis.mp.
11. 5 or 6 or 7 or 8 or 9 or 10
12. 1 and 4 and 11
13. Limit 12 to (English language and "remove preprint records")

Scopus
(asd OR autis* OR asperger*) AND (parent* OR caregiver*) AND (adjust* OR accept* OR resol* OR grief OR "respon* to diagnosis" or "react* to diagnosis")
Limit search to subject area = (Medicine, Psychology, social sciences, neuroscience, health professions, multidisciplinary), document type = article, language = English

Web of Science
((ALL=(asd OR autis* OR asperger*) AND ALL=(parent* OR caregiver*) AND ALL=(adjust* OR accept* OR resol* OR grief OR "respon* to diagnosis" or "react* to diagnosis"))
Refined by: Document types = article; Languages = English; Research areas = Psychology or pediatrics or neurosciences neurology or behavioral sciences or family studies or health care sciences services or science technology other

Cochrane Central Register of Controlled Trials
1. autism.mp or Autism Spectrum Disorders/
2. caregiver.mp or exp Caregivers/
3. exp Parents/ or parent.mp.

4. 2 or 3
5. exp Adjustment/ or adjust*.mp.
6. accept*.mp.
7. resol*.mp.
8. grief.mp or exp Grief/
9. respon* to diagnosis.mp.
10. react* to diagnosis.mp.
11. 5 or 6 or 7 or 8 or 9 or 10
12. 1 and 4 and 11
13. Limit 12 to (journal article and English language)

Appendix 4 – Measures of Caregiver Adjustment to the Child's Autism Diagnosis

Measure name and original citation italicized where the measure was first reported in a study included in the current review. 'Original citation' indicates that first use of the measure in the form used to measure adjustment in included studies; where this was an adaptation of a previous measure (e.g., a measure was reworded to ask about autism), the previous measure is cited as 'Adapted from'.

*Psychometric properties as reported in studies included in the current review; does not report original psychometric properties of measure with populations other than caregivers of autistic offspring. Ranges are reported where the measure was used across multiple included studies.

Table 7 - Measures of adjustment to diagnosis and reported psychometric properties.

Measure name	**Acceptance of Children with Autism**	***Adjustment to the Diagnosis of Autism Scale***	**Affiliate Stigma Scale**	**Appraisal of Life Events Scale**	***Attitudes Towards Autism Questionnaire***
Original citation	Harnum et al., 2007	*Da Paz et al., 2018*	Mak & Cheung, 2008	Cappé et al., 2017	*Ferenc et al., 2023*
Adapted from	N/A	N/A	N/A	Ferguson et al., 1999	N/A
Construct measured	Acceptance of autism	Adjustment	Self-stigma	Appraisal of stress from raising an autistic child	Perceptions of autism
Number of studies used	1 (Anthony et al., 2020)	2 (Abd Latif et al., 2023; Da Paz et al., 2018)	8 (e.g., Anthony et al., 2020; Cheung et al., 2019)	1 (Downes et al., 2022)	1 (Ferenc et al., 2023)
Languages available	English	English, Malay (Abd Latif et al., 2023)	Chinese, English, Arabic (Salami & Alhalal, 2024)	French	Polish
Type of measure	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Subscales	None	Despair, self-blame, acceptance	Affective, cognitive, behavioural	Threat, challenge, loss	None
Psychometric properties*					
Number of items	7	29	22 Ting et al., 2018: 12 Lodder et al., 2020: 19	16	10
Cronbach's alpha	0.61	0.74-0.80 Subscales: 0.40-0.79	0.68-0.95	Subscales: 0.77-0.79	0.93
Test-retest reliability	Not reported	Not reported	Not reported	Not reported	$r = 0.84$
Demonstrated sensitivity to change?	Yes	Yes	Yes	Yes	Not reported
Demonstrated validity?	Not reported	Not reported	Not reported	Not reported	Yes
Conducted factor analysis?	Not reported	Yes	Not reported	Not reported	Not reported

Measure name	*Autism Acceptance Scale*	*Benefit Finding*	*Benefit Finding Scale*	*Benefit Finding Scale for Parents of a Child with Asperger's Syndrome*	**Burden Assessment Scale – Mental Burden Subscale**
Original citation	*White, 2009*	*Pakenham et al., 2004*	*Ekas et al., 2015*	*Samios et al., 2009*	Reinhardt & Horowitz, 1984
Adapted from	Zuk et al., 1961	N/A	Carver & Antoni, 2004	N/A	N/A
Construct measured	Acceptance of autism	Positive contribution of autism to life	Positive contribution of autism to life	Positive contribution of autism to life	Mental burden of autism
Number of studies used	1 (White, 2009)	1 (Pakenham et al., 2004)	4 (e.g., Lovell & Wetherell, 2020; Vitale et al., 2022)	2 (Samios et al., 2012)	1 (Mohammad et al., 2022)
Languages available	English	English	English	English	English
Type of measure	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Subscales	None	None	None	Global benefit finding; new possibilities, personal growth, appreciation, spiritual growth, positive effects of the child, greater awareness.	Only Mental Burden subscale used
Psychometric properties*					
Number of items	7	3	17	40	10
Cronbach's alpha	Not reported	Not reported	0.87-0.92	0.95 Subscales: 0.71-0.93	Not reported
Test-retest reliability	Not reported	Not reported	Not reported	Not significant	Not reported
Demonstrated sensitivity to change?	Not reported	No	Not reported	Not reported	Not reported
Demonstrated validity?	Not reported	Not reported	Not reported	Yes	Not reported
Conducted factor analysis?	Not reported	Not reported	Not reported	Yes	Not reported

Measure name	**Caregiver Grief Scale**	**Coping Orientation to Problems Experienced Inventory (COPE/Brief COPE)**	**Coping Health Inventory for Parents: Coping Pattern III (understanding the health situation)**	**Health Specific Locus of Control measure – Parental Control Subscale**
Original citation	Meichsner et al., 2016	Carver, 1997; Carver et al., 1989	McCubbin et al., 1981	Lau & Ware, 1981
Adapted from	N/A	N/A	N/A	N/A
Languages available	English, Spanish (Bravo-Benítez et al., 2021)	English, Spanish (Moran et al., 2010)	English	English
Construct measured	Grief about autism	Strategies used to cope with diagnosis	Perceptions about autism	Locus of control regarding autism
Number of studies used	1 (Bravo-Benítez et al., 2024)	3 (e.g., Montoya et al., 2024; Roselló et al., 2022)	1 (Hall & Graff, 2011)	1 (Wayment & Brookshire, 2018)
Type of measure	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Subscales	Emotional pain, relational loss, absolute loss, emotional loss	Emotional support, instrumental support, religious, positive framing, acceptance	Only Coping Pattern III: Understanding the Health Situation used	Only Parental Control subscale used
Psychometric properties*				
Number of items	11	20; Brief 10	8	2
Cronbach's alpha	0.85 Subscales: 0.55-0.85	0.77	0.70	N/A – only two items, $r = 0.43$
Test-retest reliability	Not reported	Not reported	Not reported	Not reported
Demonstrated sensitivity to change?	Yes	Not reported	Not reported	Not reported
Demonstrated validity?	Not reported	Not reported	Not reported	Not reported
Conducted factor analysis?	Not reported	Yes	Not reported	Not reported

Measure name	*Illness Perception Questionnaire Revised for ASD*	Impact of Event Scale - Revised	*Locus of Control Scale*	Parents' Perception of Uncertainty in Illness Scale	Positive Gain Scale
Original citation	*Mire et al., 2018*	Creamer et al., 2003	Cappé et al, 2011	Mishel & Epstein, 1990	Jess et al., 2020
Adapted from	Moss-Morris et al., 2002; Weinman et al., 1996	N/A	Cousson-Gélie et al., 2005	N/A	N/A
Construct measured	Perceptions about autism	Post-traumatic stress symptoms associated with autism diagnosis	Locus of control regarding autism	Uncertainty regarding autism	Positive contribution of autism to life
Number of studies used	7 (e.g., Grebe et al., 2022; Rosenbrock et al., 2021)	1 (Nguyen et al., 2016)	3 (e.g., Cappé et al, 2018; Cappé et al., 2024)	1 (O'Brien, 2016)	1 (Lunsky et al., 2021)
Languages available	English, Persian (Norozi et al., 2023)	English	French	English	English
Type of measure	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Subscales	Timeline (acute/chronic), timeline cyclical, consequences, personal control, treatment control, illness coherence, emotional representation	Intrusion, avoidance, hyperarousal	Perceived control over the onset; perceived control over development; irrational beliefs regarding the disorder	Ambiguity, lack of clarity, lack of information, unpredictability	None
Psychometric properties*					
Number of items	38	22	17	31	7
Cronbach's alpha	Subscales: 0.40-0.91	0.94	Subscales: 0.60-0.77	0.86	0.77
Test-retest reliability	Subscales r = 0.194-0.884	1 (Nguyen et al., 2016)	Not reported	Not reported	Not reported
Demonstrated sensitivity to change?	Not reported	Not reported	Not reported	Not reported	No
Demonstrated validity?	Not reported	Yes	Not reported	Not reported	Not reported
Conducted factor analysis?	Yes	Not reported	Yes	Not reported	Not reported

Measure name	Post-Traumatic Growth Scale	Questionnaire on Resources and Stress – Pessimism Subscale	Reaction to Diagnosis Interview	Reaction to Diagnosis Questionnaire
Original citation	Tedeschi & Calhoun, 2004	Friedrich et al., 1983	Pianta & Marvin, 1993	Sher-Censor et al., 2020
Adapted from	Tedeschi & Calhoun, 1996	N/A	N/A	Pianta & Marvin, 1993
Construct measured	Posttraumatic growth/positive contribution of autism to life	Pessimism about the child	Resolution of autism diagnosis	Resolution of autism diagnosis
Number of studies used	7 (e.g., Ebrahim & Alothman, 2021; Feng et al., 2022)	1 (Abbedutto et al., 2004)	13 (e.g., Dolev et al., 2016; Hutman et al., 2009)	1 (Naicker et al., 2024)
Languages available	English, Arabic (Ebrahim & Alothman, 2021), Chinese (Wang et al., 2011), Spanish (Castro et al., 2015), Turkish (Cetinbakis et al., 2020)	English	English, Arabic (Dolev et al., 2016), Dutch (Poslawsky et al., 2014), Hebrew (Oppenheim et al., 20009), Italian (Leccisco et al., 2013), Persian (Norozi et al., 2023)	English
Type of measure	Questionnaire	Questionnaire	Semi-structured interview	Questionnaire
Subscales	Appreciation of life, personal strength, new possibilities, relating to others, self-transformation	Only Pessimism subscale used	None Wachtel & Carter, 2008 – created coding scheme allowing for continuous measurement in addition to categorical classification	None
Psychometric properties*				
Number of items	20/21 (different versions) 10 (Short-form; Castro et al., 2015)	11	5	40
Cronbach's alpha	0.91-0.96; Subscales: 0.63-0.95	0.72	N/A	N/A – McDonald's $\omega = 1.20$
Test-retest reliability	Not reported	Not reported	Not reported	Not reported
Demonstrated sensitivity to change?	Yes	Not reported	Yes	Not reported
Demonstrated validity?	Not reported	Not reported	Not reported	Not reported
Conducted factor analysis?	Not reported	Not reported	Not reported	Yes

Measure name	**Self-Blame and Responsibility Scale**	**Self-stigmatizing Thinking's Automaticity and Repetition Scale**	***Sense Making***	***Sense Making Scale for Parents of Children with Asperger's Syndrome***	**Stress-Related Growth Scale**
Original citation	Mak & Kwok, 2008	Chan & Mak, 2017	*Pakenham et al., 2004*	*Samios et al., 2008*	Park et al., 1996
Adapted from	N/A	N/A	N/A	N/A	N/A
Construct measured	Self-blame for child's autism	Stigma processes	Making sense of autism	Making sense of autism	Positive contributions of autism to life
Number of studies used	1 (Lodder et al., 2020)	1 (Chan & Lam, 2018)	1 (Pakenham et al., 2004)	2 (Samios et al., 2012)	1 (Alon et al., 2019)
Languages available	Chinese, English (Lodder et al., 2020)	Chinese	English	English	English
Type of measure	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Subscales	None	Repetition, automaticity	None	Spiritual sense making, causal attributions, changed perspective, identification, reframing, luck/fate	Personal growth, social growth, religious growth
Psychometric properties*					
Number of items	Not reported	8	3	28	26
Cronbach's alpha	0.75	0.91 Subscales: 0.81-0.94	Not reported	0.68-0.89	0.92 Subscales: 0.85-0.87
Test-retest reliability	Not reported	Not reported	Not reported	Subscales $r = 0.56 – 0.86$	Not reported
Demonstrated sensitivity to change?	Yes	Not reported	No	Not reported	Not reported
Demonstrated validity?	Not reported	Yes	Not reported	Yes	Not reported
Conducted factor analysis?	Not reported	Yes	Not reported	Yes	Not reported

Measure name	**Ways of Coping Checklist - Revised**	***Unnamed measure of changes to relationships and behaviour following diagnosis***	***Unnamed measure of parent reaction post diagnostic feedback session***	***Unnamed measure of coping strategies used following diagnosis***	***Unnamed measure of caregiver acceptance of having an autistic child***
Original citation	Cappé et al., 2011	*Al-Kandari et al., 2017*	*Anderberg & South, 2021*	*Ayyash et al., 2023*	*Kheir et al., 2012*
Adapted from	Vitaliano et al., 1985; Cousson et al., 1996	N/A	N/A	N/A	N/A
Construct measured	Coping strategies used following diagnosis	Changes to relationships and behaviour	Reaction to diagnosis	Coping strategies used following diagnosis	Acceptance of autism
Number of studies used	1 (Cappé et al., 2018)	1 (Al-Kandari et al., 2017)	1 (Anderberg & South, 2021)	1 (Ayyash et al., 2023)	1 (Kheir et al., 2012)
Languages available	French	Arabic	English	English, Arabic	Arabic
Type of measure	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Subscales	Problem solving, emotional strategies, social support-seeking	None	Difficult emotions, preparedness, positive emotion, confusion	None	None
Psychometric properties*					
Number of items	27	7	18	5	2
Cronbach's alpha	Subscales: 0.74-0.80	Not reported	Subscales: 0.75-0.86	Not reported	Not reported
Test-retest reliability	Not reported	Not reported	Not reported	Not reported	Not reported
Demonstrated sensitivity to change?	Not reported	Not reported	Not reported	Not reported	Not reported
Demonstrated validity?	Not reported	Not reported	Not reported	Not reported	Not reported
Conducted factor analysis?	Not reported	Not reported	Yes	Not reported	Not reported

Measure name	***Unnamed measure of family beliefs about autism***	***Unnamed measure of perception of autism diagnosis as a loss***	***Unnamed measure of perceived injustice of autism diagnosis***	***Unnamed measure of autism-related rumination***	***Unnamed measure of perceived cause of the child's autism***
Original citation	*Su et al., 2013*	*Wayment & Brookshire, 2018*	*Wayment & Brookshire, 2018*	*Wayment et al., 2019*	*Wynn et al., 2024*
Adapted from	N/A	N/A	Lepore et al., 1996	Several unspecified measures	N/A
Construct measured	Perceptions of autism	Perception of autism as a loss	Perception of autism as unfair	Autism-related rumination	Beliefs about the cause of autism
Number of studies used	1 (Su et al., 2013)	1 (Wayment & Brookshire, 2018)	1 (Wayment & Brookshire, 2018)	1 (Wayment et al., 2019)	1 (Wynn et al., 2024)
Languages available	Chinese	English	English	English	English
Type of measure	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Subscales	Not reported	None	None	None	None
Psychometric properties*					
Number of items	Not reported	9	2	4	14
Cronbach's alpha	Not reported	0.84	N/A – only two items, r = 0.31	0.81	Not reported
Test-retest reliability	Not reported	Not reported	Not reported	Not reported	Not reported
Demonstrated sensitivity to change?	Not reported	Not reported	Not reported	Not reported	Yes
Demonstrated validity?	Not reported	Not reported	Not reported	Not reported	Not reported
Conducted factor analysis?	Not reported	Not reported	Not reported	Not reported	Not reported

Appendix 5 - Interventions targeting caregiver adjustment to their child's autism diagnosis

Table 8 - Intervention summary information.

Intervention name	*Problem-Solving Skills Training*	*SOLACE*	*Sesame Street "See Amazing in All Children"*
Citation	Nguyen et al., 2016 Intervention citation: Nezu, 1986	Lodder et al., 2020	Anthony et al., 2020
Study design	Single group[b]	Randomised controlled trial	Single group[b]
Sample size, intervention	24	9	176
Sample size, control	N/A	8	N/A
Adjustment outcome measure	Impact of Event Scale – Revised (Creamer et al., 2003)	Affiliate Stigma Scale (Mak & Cheung, 2008); Self-Blame and Responsibility Scale (Mak & Kwok, 2010)	Affiliate Stigma Scale (Mak & Cheung, 2008); Unnamed measure of acceptance of Children with ASD (Harnum et al., 2007)
Intervention features			
Participants	Parents only	Parents only	Parents only
Mean child age (SD)	Not reported; range 2-5 years	5.91 years (2.59)	4.46 years (1.08)
Content	Problem-solving skills	Psychoeducation, cognitive restructuring and compassion focused techniques	Psychoeducation with an autism affirming focus
Format	Individual	Group	Self-directed
Setting	In-person or phone	In-person and online videoconference	Online
Length	8 sessions	8 sessions	1 week
Intervention outcomes			
Effectiveness: post-intervention	$p = 0.007$** Effect sizes not reported	Affiliate stigma: $p = 0.004$** Self-blame and responsibility: N.S[a]., $p > 0.05$ Effect sizes not reported	Affiliate stigma: N.S., partial eta squared = 0.011 Acceptance of children with ASD: partial eta squared = 0.025*
Effectiveness: follow-up	6-months post-baseline $p = 0.004$** Effect sizes not reported	6-week follow-up Affiliate stigma: $p < 0.001$*** Self-blame and responsibility: N.S., $p > 0.05$ Effect sizes not reported	1-month post-baseline Affiliate stigma: N.S., partial eta square = 0.004 Acceptance of children with ASD: N.S., partial eta squared = 0.004

Intervention name	*Mindfulness-Based Cognitive Therapy*	*Complicated Grief Intervention Program*	*Family-child reading picture book*
Citation	Lunsky et al., 2021	Bravo-Benítez et al., 2024 Intervention citation: Shear & Bloom, 2017	Yang et al., 2024
Study design	Single group	Randomised controlled trial	Single group
Sample size, intervention	21	14	139
Sample size, control	N/A	14	N/A
Adjustment outcome measure	Positive Gain Scale (Jess et al., 2020)	Caregiver Grief Scale (Meichsner et al., 2016); Post Traumatic Growth Inventory Short Form (Castro et al., 2015; Tedeschi & Calhoun, 1996)	Affiliate Stigma Scale (Mak & Cheung, 2008)
Intervention features			
Participants	Parents only	Parents only	Parents and children only
Mean child age (SD)	20.92 years (5.32)	Not reported; range 6-12 years	Not reported
Content	Mindfulness-based cognitive therapy	Processing grief associated with child's autism	Shared book reading of a story about autism
Format	Group	Group	Group; home implementation
Setting	Online	In-person	In-person
Length	6 sessions	10 sessions	1 session; 4 weeks of home implementation
Intervention outcomes			
Effectiveness: post-intervention	N.S., $p > 0.05$ Effect sizes not reported	Caregiver grief scale: Emotional pain $p = 0.040$* Cohen's $d = 0.74$; relational loss $p = 0.030$* Cohen's $d = 1.29$; absolute loss N.S. $p = 0.130$ Cohen's $d = 1.85$; acceptance of loss $p = 0.020$* Cohen's $d = 0.88$ Post traumatic growth inventory: N.S. $p = 0.050$ Cohen's $d = 0.40$	N.S., $p = 0.513$ Effect sizes not reported
Effectiveness: follow-up	3-month follow-up N.S., $p > 0.05$ Effect sizes not reported	N/A – no follow-up	N/A – no follow-up

THE UNIVERSITY OF SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Tuesday, 3 October 2023

Prof Mark Dadds
Psychology; Faculty of Science
Email: [redacted]

Dear Mark,

Your request to modify this project, which was submitted on 05/09/2023, has been considered.

The project has been approved to proceed with the proposed amendments.

If your research project is a clinical trial and is being sponsored by the University or is to be conducted on a University of Sydney site, you must comply with additional University governance requirements prior to commencing your Clinical Trial.

Details of the approval are as follows:

Project Title: **ParentWorks Spectrum: An integrated parenting intervention for children with autism**

Project No.: **2020/854**

Addition of Authorised Persons: **Elysha Clark-Whitney, PhD student**

Removal of Authorised Persons:

New Sites Approved:

Revised Completion Date:

Next Annual Report Due: **22/12/2023**

New Approved Documents:

Date Uploaded	Version Number	Document Name
05/09/2023		Attachment R_Adjustment information sheet
05/09/2023	Version 1	Attachment S_PIS_Parent_Carer_FollowUp
05/09/2023	Version 1	Attachment T_Consent Form_FollowUp
05/09/2023		Attachment U - Email regarding follow-up interview
05/09/2023	Version 11	Attachment V - PWS Follow-up Interview Guide
05/09/2023	Version 3	Protocol_ParentWorks Spectrum_V3_clean

Special Conditions of Approval for Clinical Trials

- **This letter constitutes ethical approval only.** This modification cannot proceed at any site until the necessary research governance authorisation is obtained. If your study is conducted on a University of Sydney site you must comply with additional University governance requirements prior to commencing your project at site. Please contact the Clinical Trials Governance Office at clinical-trials.research@sydney.edu.au

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

[signature removed]

Ms Eleanor Ramsey
Acting Deputy Chair
Modification Review Committee Chair (MRC 3)

The University of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018).

Appendix 7 - Brief Adjustment to the Diagnosis of Autism Questionnaire

When was your child diagnosed with Autism Spectrum Disorder (month and year)?

Please indicate the degree with which you agree with the following statements.

	1 – Don't agree at all	**2 – Slightly disagree**	**3 – Slightly agree**	**4 – Very strongly agree**
1. My child's autism will always cast a shadow on our family	1	2	3	4
2. I imagine going back in time and re-doing the things that I might have done to have caused my child's difficulties	1	2	3	4
3. My child's diagnosis of autism feels more real to me than it used to	1	2	3	4
4. When I think about my child's difficulties, I ask myself, "Why me?"	1	2	3	4
5. There are things I did that make me worry that I contributed to my child's difficulties	1	2	3	4
6. I have a greater acceptance of my child's autism than I used to	1	2	3	4
7. I worry my child won't get any better	1	2	3	4
8. I should have anticipated the risk factors that may have contributed to my child's autism	1	2	3	4
9. My child's diagnosis has brought my spouse/partner and me closer together in some ways	1	2	3	4

Adapted from Da Paz, N. S., Siegel, B., Coccia, M. A., & Epel, E. S. (2018). Acceptance or despair? Maternal adjustment to having a child diagnosed with autism. *Journal of Autism and Developmental Disorders, 48*, 1971-1981.

Subscales

Despair

My child's autism will always cast a shadow on our family.

When I think about my child's difficulties, I ask myself, "Why me?"

I worry my child won't get any better

Self-blame

I imagine going back in time and re-doing the things that I might have done to have caused my child's difficulties

There are things I did that make me worry that I contributed to my child's difficulties

I should have anticipated the risk factors that may have contributed to my child's autism

Acceptance

My child's diagnosis of autism feels more real to me than it used to

I have a greater acceptance of my child's autism than I used to

My child's diagnosis has brought my spouse/partner and me closer together in some ways

Scoring

To score, add the responses for each item within a subscale, and divide by 3 to obtain the average score for that subscale.

Despair score = (sum of items 1, 4, and 7)/3

Self-blame score = (sum of items 2, 5, and 8)/3

Acceptance score = (sum of items 3, 6 and 9)/3

Adjustment is conceptualised as low scores on the despair and self-blame subscales and high scores on the acceptance subscale.

Appendix 8 – Skewness, Kurtosis of Predictor and Outcome Variables; Analysis of Missingness for Post-treatment Adjustment (Study 2)

Table 9 – Skewness and kurtosis.

Variable	Skewness (Standard error)	Kurtosis (standard error)
Pre-treatment Despair (Mothers)	0.019 (0.244)	-0.902 (0.483)
Pre-treatment Despair (Fathers)	0.139 (0.276)	-0.799 (0.545)
Pre-treatment Self-Blame (Mothers)	-0.092 (0.244)	-1.015 (0.483)
Pre-treatment Self-Blame (Fathers)	0.337 (0.276)	-1.075 (0.545)
Pre-treatment Acceptance (Mothers)	-0.611 (0.244)	0.161 (0.483)
Pre-treatment Acceptance (Fathers)	-0.454 (0.276)	-0.315 (0.545)
Post-treatment Despair (Mothers)	0.172 (0.261)	-1.007 (0.517)
Post-treatment Despair (Fathers)	0.444 (0.309)	-0.195 (0.608)
Post-treatment Self-Blame (Mothers)	0.307 (0.261)	-0.945 (0.517)
Post-treatment Self-Blame (Fathers)	0.476 (0.309)	-0.869 (0.608)
Post-treatment Acceptance (Mothers)	-0.840 (0.261)	0.955 (0.517)
Post-treatment Acceptance (Fathers)	-0.571 (0.309)	0.224 (0.608)
Self-report engagement (Mothers)	-0.532 (0.374)	-0.461 (0.733)
Self-report engagement (Fathers)	-0.772 (0.414)	0.276 (0.918)
Clinician report engagement	-1.080 (0.357)	2.189 (0.702)
Post-treatment ECBI Intensity (Mothers)	0.395 (0.260)	-0.128 (0.514)
Post-treatment ECBI Intensity (Fathers)	0.217 (0.302)	0.019 (0.595)
Post-treatment ECBI Problem (Mothers)	0.089 (0.271)	-1.070 (0.535)
Post-treatment ECBI Problem (Fathers)	0.060 (0.309)	-0.993 (0.608)
Post-treatment SRS-2 Total (Mothers)	0.258 (0.260)	0.126 (0.514)
Post-treatment SRS-2 Total (Fathers)	-0.060 (0.304)	0.130 (0.599)
Post-treatment DISCAP Conduct Problems	-0.212 (0.260)	-1.011 (0.514)

Table 10 - Missing Data Analysis.

	Little's MCAR Test		Logistic regression*	
Variable	χ^2	*p*	Odds ratio	*p*
Mother Despair	0.424	0.515	1.256	0.514
Mother Self-Blame	2.843	0.092	1.779	0.098
Mother Acceptance	0.294	0.660	1.223	0.659
Father Despair	2.998	0.083	1.048	0.088
Father Self-Blame	0.552	0.457	0.790	0.456
Father Acceptance	0.035	0.851	0.919	0.850

*Predictor: Pre-treatment despair, self-blame or acceptance. Outcome: Post-treatment questionnaire present or missing.

Appendix 9 – Pre-treatment Equivalence of PWS and WL Groups (Study 2)

Table 11 - Pre-treatment equivalence for demographic variables.

Variable	PWS mean (SD)	WL mean (SD)	*t*	*p*
Mother education	4.96 (1.04)	5.00 (1.02)	-0.196	.845
Father education	4.89 (1.23)	4.88 (1.02)	0.030	.976
Mother age (years)	36.27 (5.03)	38.12 (5.17)	-1.802	.075
Father age (years)	38.83 (4.34)	40.12 (5.20)	-1.165	.248
Child age (years)	4.50 (0.97)	4.46 (1.10)	0.190	.850
Time since diagnosis (months)	13.35 (11.11)	12.32 (10.35)	0.464	.644

Table 12 - Pre-treatment equivalence for outcome variables.

Variable	PWS mean (SD)	WL mean (SD)	*t*	*p*
Despair (Mothers)	2.32 (0.84)	2.42 (0.90)	-0.543	.588
Despair (Fathers)	2.21 (0.84)	2.24 (0.79)	-0.183	.855
Self-Blame (Mothers)	2.36 (0.98)	2.46 (0.91)	-0.536	.593
Self-Blame (Fathers)	2.05 (0.94)	2.05 (0.92)	-0.005	.996
Acceptance (Mothers)	2.65 (0.78)	2.88 (0.56)	-1.697	.093
Acceptance (Fathers)	2.85 (0.64)	2.72 (0.62)	0.909	.366
ECBI Intensity (Mothers)	145.18 (38.92)	152.71 (34.60)	-1.012	.314
ECBI Intensity (Fathers)	144.60 (38.03)	139.75 (36.21)	0.565	.574
ECBI Problem (Mothers)	17.96 (8.47)	20.33 (7.67)	-1.413	.161
ECBI Problem (Fathers)	18.74 (9.82)	16.27 (8.17)	1.133	.261
SRS-2 Total (Mothers)	100.31 (23.81)	103.00 (18.83)	-0.617	.538
SRS-2 Total (Fathers)	94.26 (24.87)	98.59 (21.26)	-0.818	.416
DISCAP Conduct Problems	3.33 (1.49)	3.42 (1.46)	-0.315	.753

Appendix 10 – Linear regression models for Study 2 Research Question 1

Research Question 1: Do parents in the PWS intervention group show greater improvement in adjustment to their child's autism diagnosis as compared to a waitlist control group?

Models are pooled across 5 imputed datasets. Linear regression models generated using 'stats' package on RStudio (RCore Team,. 2025). Holm-corrected *p* values reported.

Reference groups:

DSM-5 Autism Level: Level 3

Treatment allocation: Waitlist

Table 13 - Pooled Imputed Model: Despair (Mothers).

Dependent variable: Post-treatment despair

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	0.434	0.216	2.011	214.429	0.046	0.158	0.145
Pre-treatment despair	0.741	0.092	8.034	51.810	0.000	0.385	0.304
DSM-5 Autism Level	0.010	0.146	0.068	419.736	1.000	0.108	0.102
Treatment allocation	0.224	0.165	1.357	30.428	0.393	0.569	0.401
Residual~~Residual	0.422						

Table 14 - Pooled Imputed Model: Despair (Fathers).

Dependent variable: Post-treatment despair

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	0.577	0.191	3.014	245.784	0.003	0.146	0.135
Pre-treatment despair	0.680	0.074	9.245	654.275	0.000	0.085	0.081
DSM-5 Autism Level	0.018	0.149	0.122	29.910	1.000	0.577	0.404
Treatment allocation	0.029	0.131	0.224	71.830	1.000	0.309	0.256
Residual~~Residual	0.244						

Table 15 - Pooled Imputed Model: Self-Blame (Mothers).

Dependent variable: Post-treatment self-blame

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	0.704	0.223	3.158	2729.107	0.002	0.040	0.039
Pre-treatment self-blame	0.583	0.081	7.182	1881.550	0.000	0.048	0.047
DSM-5 Autism Level	0.068	0.164	0.414	215.264	1.000	0.158	0.144
Treatment allocation	0.198	0.156	1.265	356.735	0.393	0.118	0.111
Residual~~Residual	0.533						

Table 16 - Pooled Imputed Model: Self-Blame (Fathers).

Dependent variable: Post-treatment self-blame

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	0.281	0.182	1.545	85.762	0.126	0.275	0.234
Pre-treatment self-blame	0.706	0.073	9.722	55.139	0.000	0.369	0.294
DSM-5 Autism Level	0.062	0.134	0.466	85.100	1.000	0.277	0.235
Treatment allocation	0.149	0.121	1.225	248.708	0.666	0.145	0.134
Residual~~Residual	0.240						

Table 17 - Pooled Imputed Model: Acceptance (Mothers).

Dependent variable: Post-treatment acceptance

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	1.229	0.223	5.502	6790.346	0.000	0.025	0.025
Pre-treatment acceptance	0.605	0.078	7.707	3443.946	0.000	0.035	0.035
DSM-5 Autism Level	0.047	0.109	0.429	1221.953	1.000	0.061	0.059
Treatment allocation	-0.165	0.109	-1.511	598.563	0.393	0.089	0.085
Residual~~Residual	0.260						

Table 18 - Pooled Imputed Model: Acceptance (Fathers).

Dependent variable: Post-treatment acceptance

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	0.838	0.352	2.384	38.490	0.022	0.476	0.355
Pre-treatment acceptance	0.667	0.121	5.533	28.728	0.000	0.595	0.413
DSM-5 Autism Level	0.073	0.133	0.546	217.896	1.000	0.157	0.143
Treatment allocation	-0.026	0.131	-0.194	162.222	1.000	0.186	0.167
Residual~~Residual	0.269						

Appendix 11 – Figures: Pre-treatment and Post-Treatment Adjustment for Treatment (PWS) and Waitlist (WL) groups (Study 2)

Figures developed using the original dataset without multiple imputation of missing data.

For all Figures shown here, pale dots represent individual participant scores; solid diamonds represent estimated marginal means for each group. Error bars represent 95% confidence interval.

Note that lower scores for Despair and Self-Blame subscales, and higher scores on Acceptance subscales, are considered to indicate more optimal adjustment.

Figure 6 - Despair (Mothers).

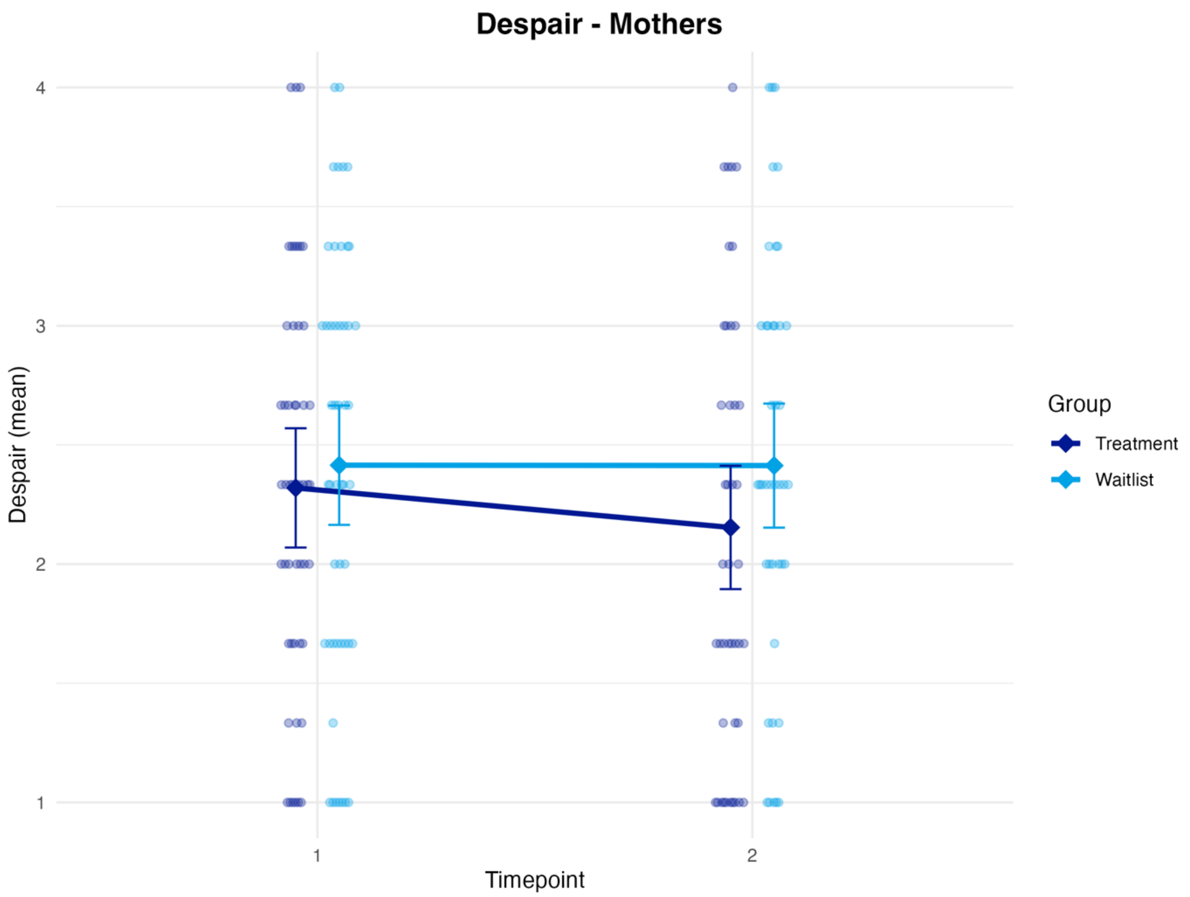


Figure 7 - Despair (Fathers).

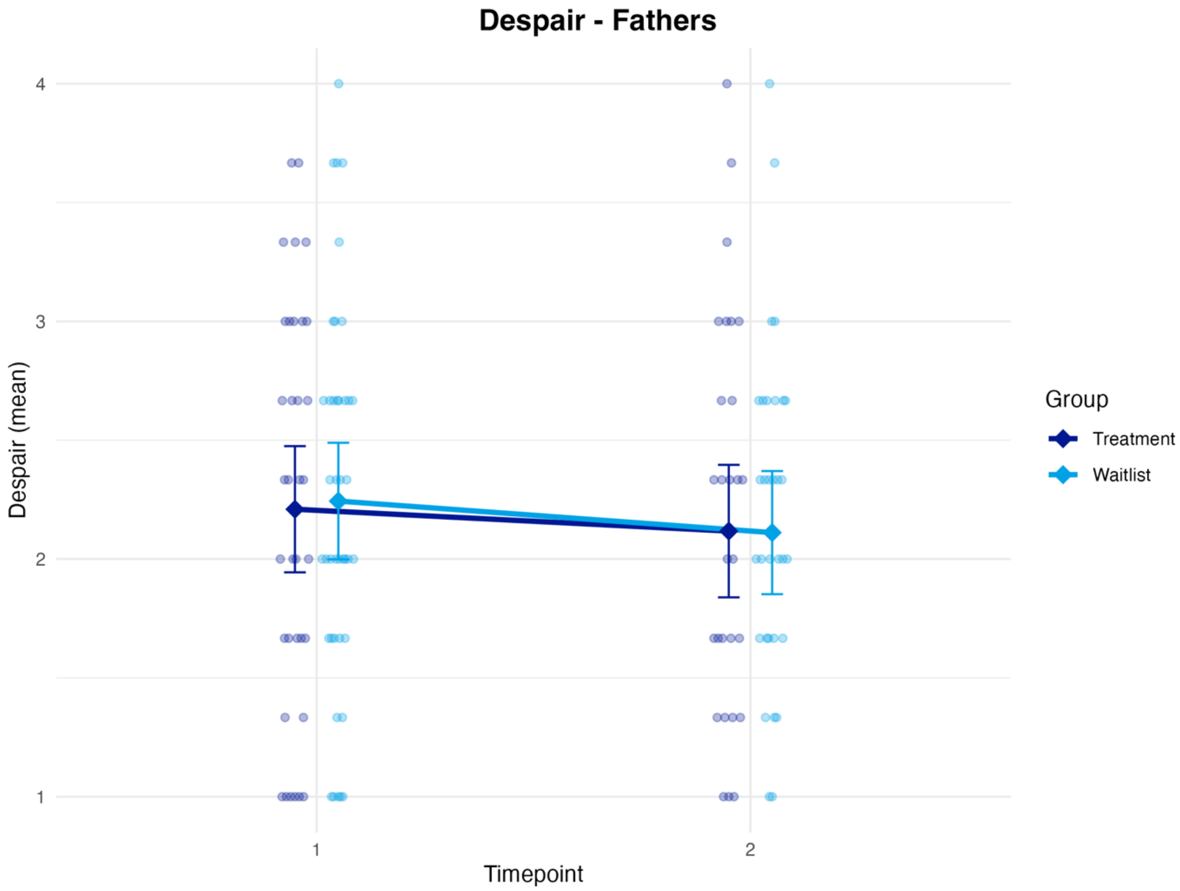


Figure 8 - Self-Blame (Mothers).

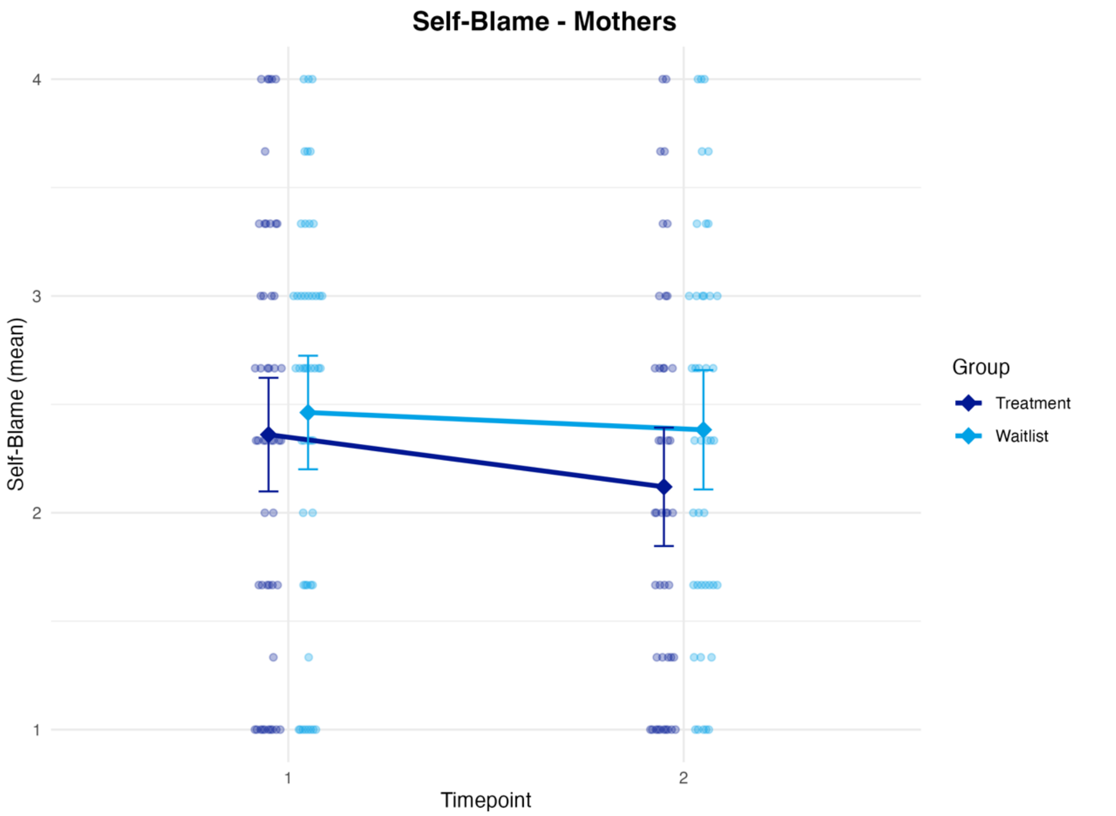


Figure 9 - Self-Blame (Fathers).

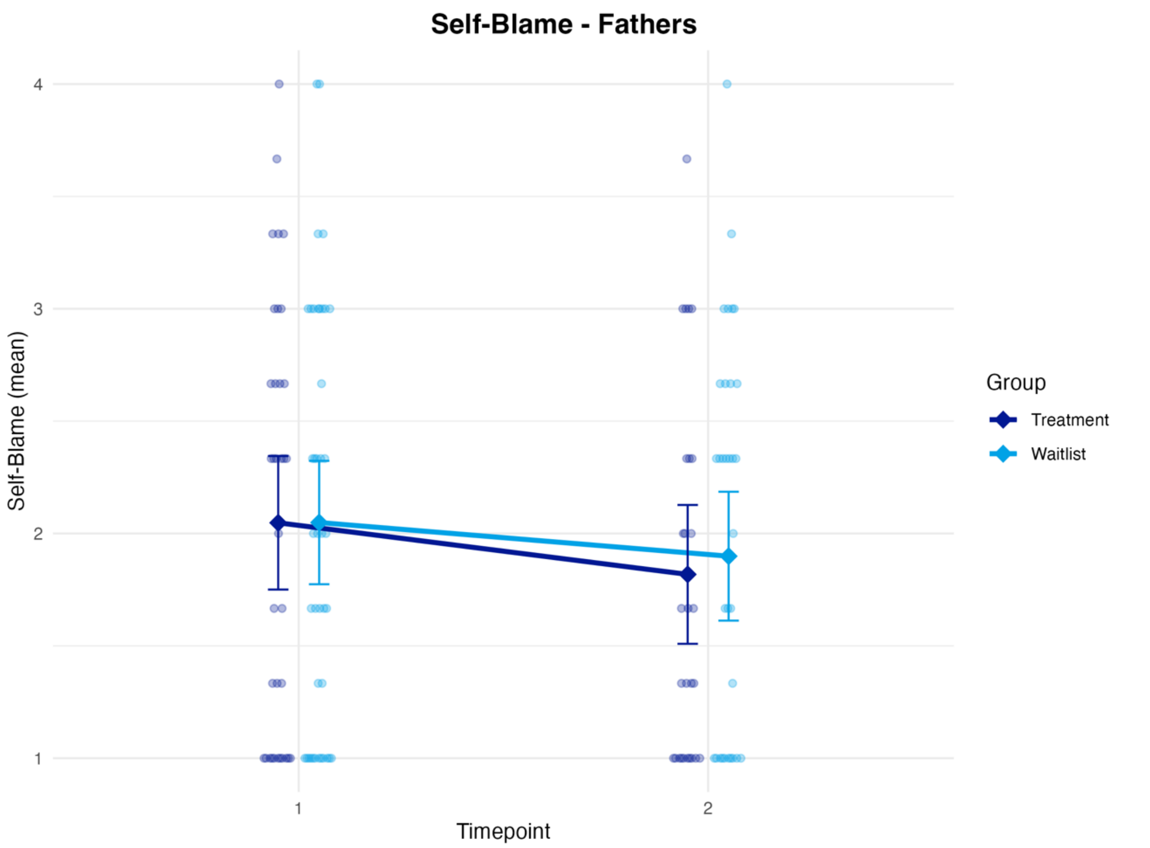


Figure 10 - Acceptance (Mothers).

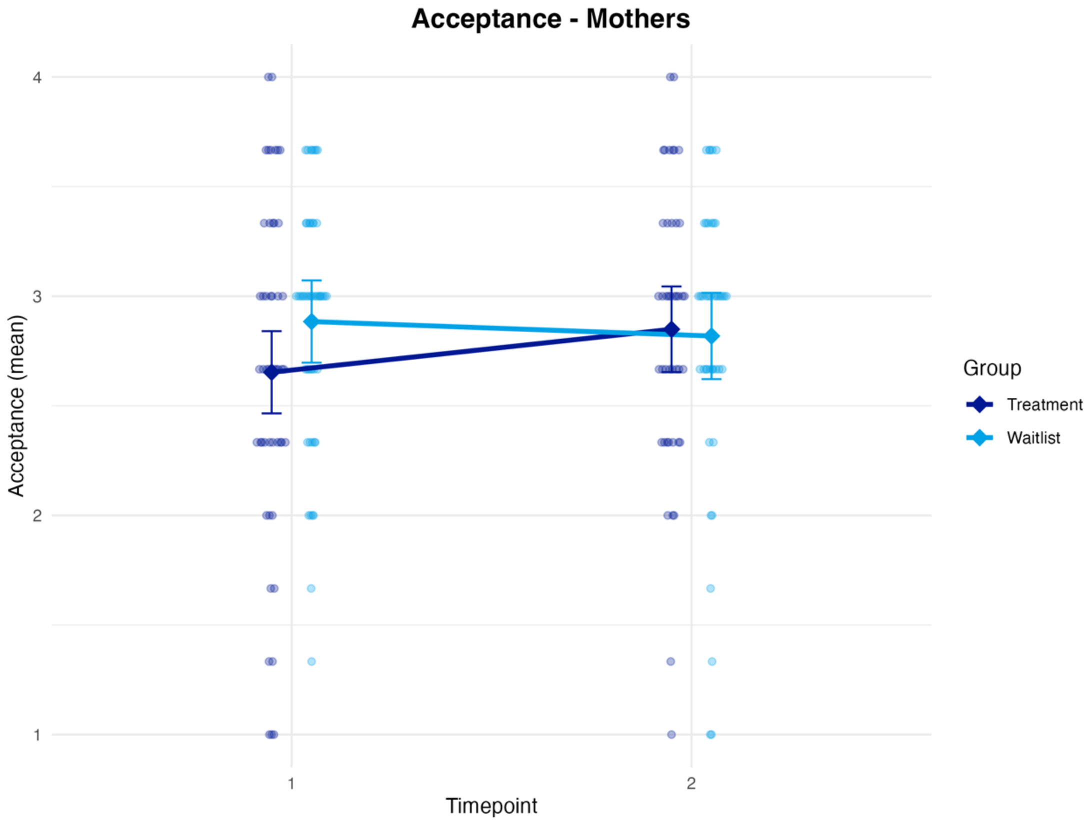
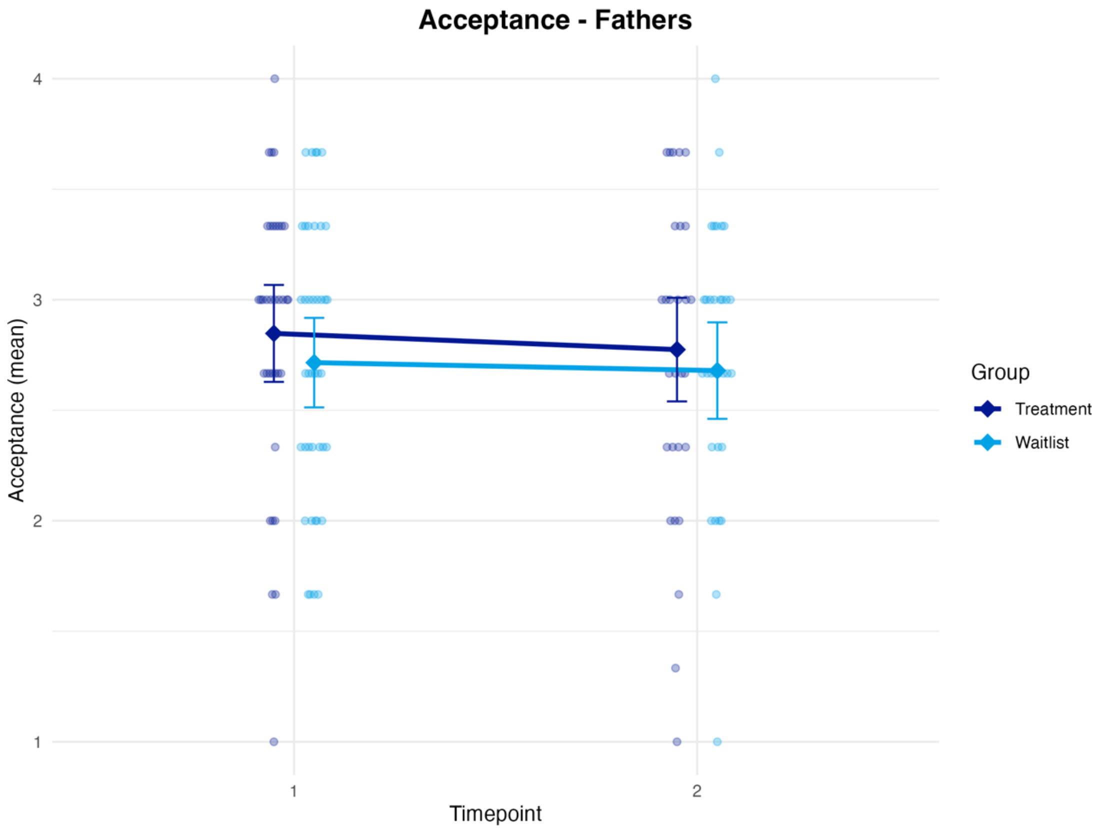


Figure 11 - Acceptance (Fathers).



Appendix 12 – Linear regression models for Study 2 Research Question 2

Research Question 2: Does parents' pre-treatment adjustment to their child's autism diagnosis predict intervention dropout, engagement, and child outcomes (child conduct problems, challenging behaviour, and core autism symptoms) at post-treatment?

Please note that self-report and clinician-report engagement was not imputed, therefore analyses for self-report engagement and clinician-report engagement were conducted as a standard linear regression, whereas analyses for child outcomes were conducted using 5 imputed datasets, with models pooled across 5 imputed datasets. Additional model summary statistics are therefore available for self-report and clinician report engagement, which were not able to be derived for the pooled imputed models.

Linear regression models generated using 'stats' package on RStudio (RCore Team, 2025). Holm-corrected *p* values reported.

Reference groups DSM-5 Autism Level: Level 3

Table 19 - Linear Regression Model: Self-report engagement (Mothers).

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
	.356	.126	.027	.73609

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	2.745	4	.686	1.267	.302
	Residual	18.964	35	.542		
	Total	21.709	39			

Coefficients

Model	Unstandardized Coefficients B	Std. Error	Standardized Coefficients Beta	t	Sig.
(Constant)	8.097	.619		13.077	<.001
DSM-5 Autism Level	.469	.245	.312	1.916	.256
Pre-treatment Despair	-.095	.173	-.110	-.550	1.000
Pre-treatment Self-Blame	.016	.149	.021	.106	1.000
Pre-treatment Acceptance	.168	.147	.183	1.143	1.000

Table 20 - Linear Regression Model: Self-report engagement (Fathers).

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.439	.193	.023	.91420

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3.798	4	.950	1.136	.369
	Residual	15.879	19	.836		
	Total	19.678	23			

Coefficients

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	6.546	1.075		6.089	<.001
	DSM-5 Autism Level	.225	.417	.117	.540	1.000
	Pre-treatment Despair	.283	.277	.269	1.020	1.000
	Pre-treatment Self-Blame	-.224	.269	-.246	-.834	1.000
	Pre-treatment Acceptance	.563	.337	.399	1.672	.555

Table 21 - Linear Regression Model: Clinician-report engagement (Mothers).

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.461[a]	.213	.132	.95583

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	9.615	4	2.404	2.631	.049[b]
	Residual	35.631	39	.914		
	Total	45.246	43			

Coefficients

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	7.662	.739		10.372	<.001
	DSM-5 Autism Level	.799	.301	.388	2.653	.055
	Pre-treatment Despair	-.335	.215	-.284	-1.558	.762
	Pre-treatment Self-Blame	.018	.183	.018	.098	1.000
	Pre-treatment Acceptance	.212	.182	.166	1.168	1.000

Table 22 - Linear Regression Model: Clinician-report engagement (Fathers).

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.354	.125	-.005	1.06784

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4.397	4	1.099	.964	.443
	Residual	30.788	27	1.140		
	Total	35.185	31			

Coefficients

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	6.967	1.152		6.047	<.001
	DSM-5 Autism Level	.464	.429	.210	1.082	.867
	Pre-treatment Despair	.032	.283	.024	.112	1.000
	Pre-treatment Self-Blame	-.229	.287	-.202	-.798	1.000
	Pre-treatment Acceptance	.448	.351	.264	1.274	.856

Table 23 - Pooled Imputed Model: Post-treatment ECBI Intensity (Mothers).

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	67.626	37.916	1.784	169.800	0.076	0.181	0.163
Pre-treatment ECBI Intensity	0.474	0.142	3.349	75.537	0.001	0.299	0.250
DSM-5 Autism Level	3.346	10.530	0.318	146.714	1.000	0.198	0.176
Pre-treatment Despair	6.060	6.986	0.868	3380.727	1.000	0.036	0.035
Pre-treatment Self-Blame	-6.837	5.871	-1.165	9913.627	1.000	0.020	0.020
Pre-treatment Acceptance	-4.287	6.078	-0.705	2063.442	1.000	0.046	0.045
Residual~~Residual	941.381						

Table 24 - Pooled Imputed Model: Post-treatment ECBI Intensity (Fathers).

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	104.959	37.356	2.810	1051.586	0.005	0.066	0.063
Pre-treatment ECBI Intensity	0.358	0.180	1.990	25.886	0.057	0.648	0.435
DSM-5 Autism Level	-8.146	14.154	-0.576	44.373	1.000	0.429	0.330
Pre-treatment Despair	12.800	8.143	1.572	77.811	0.720	0.293	0.246
Pre-treatment Self-Blame	-7.698	8.737	-0.881	58.974	1.000	0.352	0.284
Pre-treatment Acceptance	-9.552	10.340	-0.924	112.616	1.000	0.232	0.203
Residual~~Residual	915.732						

Table 25 - Pooled Imputed Model: Post-treatment ECBI Problem (Mothers).

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	-1.909	7.667	-0.249	264.878	0.804	0.140	0.129
Pre-treatment ECBI Problem	0.747	0.143	5.228	277.254	0.000	0.137	0.126
DSM-5 Autism Level	2.118	2.331	0.908	997.076	1.000	0.068	0.065
Pre-treatment Despair	0.710	1.662	0.427	7764.028	1.000	0.023	0.023
Pre-treatment Self-Blame	-1.480	1.465	-1.016	909.779	1.000	0.071	0.068
Pre-treatment Acceptance	0.839	1.476	0.568	570.748	1.000	0.091	0.087
Residual~~Residual	54.243						

Table 26 - Pooled Imputed Model: Post-treatment ECBI Problem (Fathers).

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	15.924	8.607	1.850	601.828	0.065	0.089	0.085
Pre-treatment ECBI Problem	0.466	0.182	2.554	35.220	0.015	0.508	0.372
DSM-5 Autism Level	-4.094	3.268	-1.253	904.489	0.844	0.071	0.069
Pre-treatment Despair	-1.279	2.205	-0.580	104.267	1.000	0.244	0.211
Pre-treatment Self-Blame	1.160	2.374	0.489	62.888	1.000	0.337	0.275
Pre-treatment Acceptance	-1.578	2.656	-0.594	417.065	1.000	0.109	0.102
Residual~~Residual	65.514						

Table 27 - Pooled Imputed Model: Post-treatment SRS-2 Total Score (Mothers)*.

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	26.926	17.333	1.553	248.295	0.122	0.145	0.134
Pre-treatment SRS-2	0.698	0.122	5.737	129.150	0.000	0.214	0.188
Pre-treatment Despair	-1.369	4.148	-0.330	1033.047	1.000	0.066	0.064
Pre-treatment Self-Blame	-4.454	3.432	-1.298	5529.901	1.000	0.028	0.027
Pre-treatment Acceptance	1.960	3.514	0.558	345.098	1.000	0.121	0.113
Residual~~Residual	315.233						

* Please note: DSM-5 Autism Level was not included in a covariate for SRS-2 model

because both SRS-2 Total and DSM-5 Autism Level are measures of level of autism features.

Table 28 - Pooled Imputed Model: Post-treatment SRS-2 Total Score (Fathers)*.

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	21.016	18.828	1.116	76.972	0.268	0.295	0.224
Pre-treatment SRS-2	0.649	0.129	5.043	682.399	0.000	0.083	0.079
Pre-treatment Despair	1.798	4.685	0.384	92.622	1.000	0.262	0.224
Pre-treatment Self-Blame	1.977	4.779	0.414	41.435	1.000	0.451	0.342
Pre-treatment Acceptance	-2.616	5.590	-0.468	148.375	1.000	0.196	0.175
Residual~~Residual	279.143						

* Please note: DSM-5 Autism Level was not included in a covariate for SRS-2 model

because both SRS-2 Total and DSM-5 Autism Level are measures of level of autism features.

Table 29 - Pooled Imputed Model: Post-treatment DISCAP Conduct Problems (Mothers).

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	1.999	1.307	1.529	1221.007	0.126	0.061	0.059
Pre-treatment DISCAP CP	0.457	0.146	3.137	500.670	0.002	0.098	0.093
DSM-5 Autism Level	0.203	0.431	0.470	976.632	1.000	0.068	0.066
Pre-treatment Despair	0.346	0.321	1.076	542.152	1.000	0.094	0.089
Pre-treatment Self-Blame	-0.291	0.261	-1.117	7865.084	1.000	0.023	0.023
Pre-treatment Acceptance	-0.679	0.259	-2.622	2976.479	0.054	0.038	0.037
Residual~~Residual	1.857						

Table 30 - Pooled Imputed Model: Post-treatment DISCAP Conduct Problems (Fathers).

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	1.221	1.810	0.674	223.462	0.501	0.154	0.141
Pre-treatment DISCAP CP	0.450	0.199	2.256	3511.438	0.024	0.035	0.034
DSM-5 Autism Level	0.947	0.612	1.549	262.101	0.615	0.141	0.130
Pre-treatment Despair	0.041	0.392	0.104	71.434	1.000	0.310	0.257
Pre-treatment Self-Blame	0.211	0.381	0.555	407.565	1.000	0.110	0.103
Pre-treatment Acceptance	-0.828	0.452	-1.832	3249.642	0.402	0.036	0.036
Residual~~Residual	2.074						

Appendix 13 – Research Question 2 Figures (Study 2)

All Figures presented here are for the PWS group only.

Figures developed using the original dataset without multiple imputation of missing data.

Note that lower scores indicate more optimal outcomes on all measures except Acceptance; higher scores for Acceptance indicate more optimal outcomes.

Figure 12 - Pre-treatment Despair and Post-treatment ECBI Intensity (Mothers).

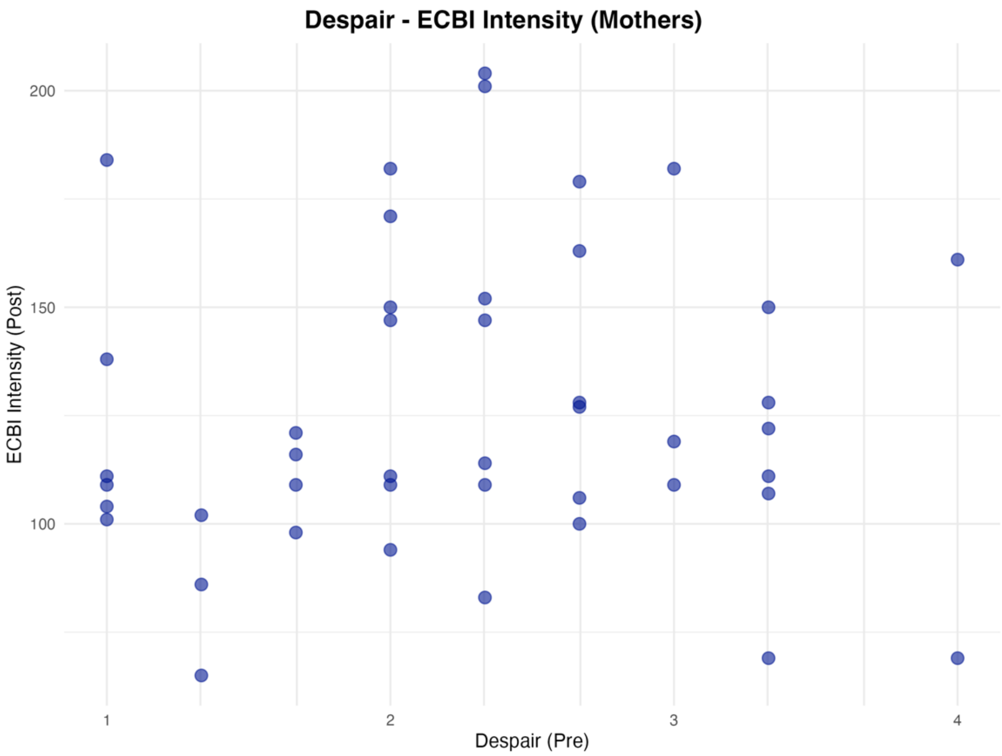


Figure 13 - Pre-treatment Despair and Post-treatment ECBI Intensity (Fathers).

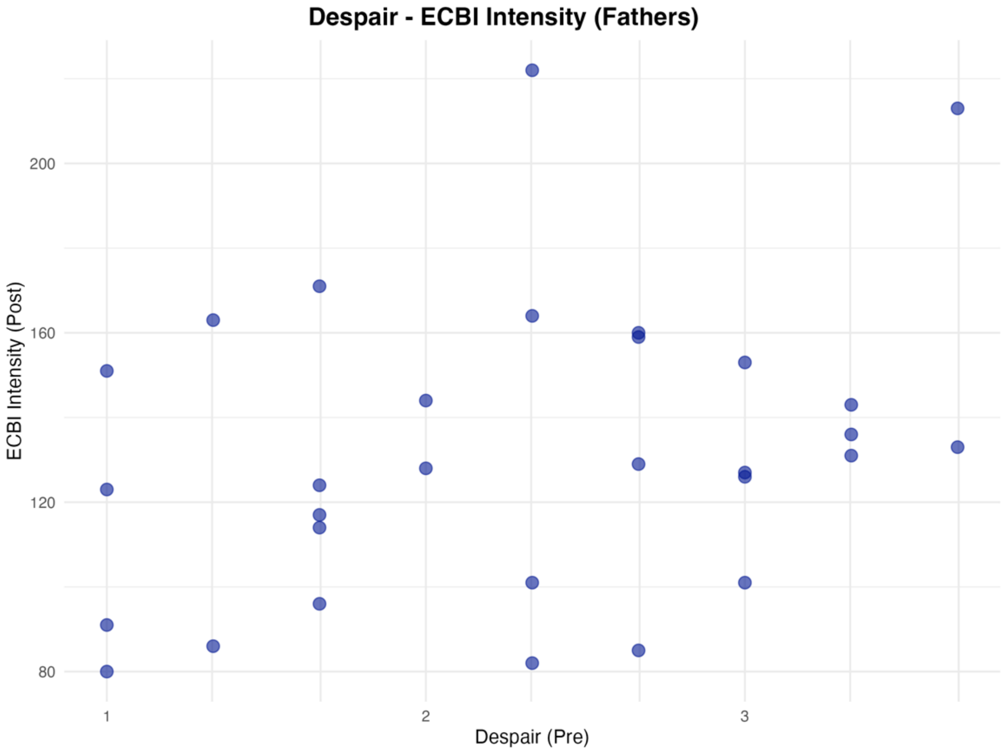


Figure 14 - Pre-treatment Despair and Post-treatment ECBI Problem (Mothers).

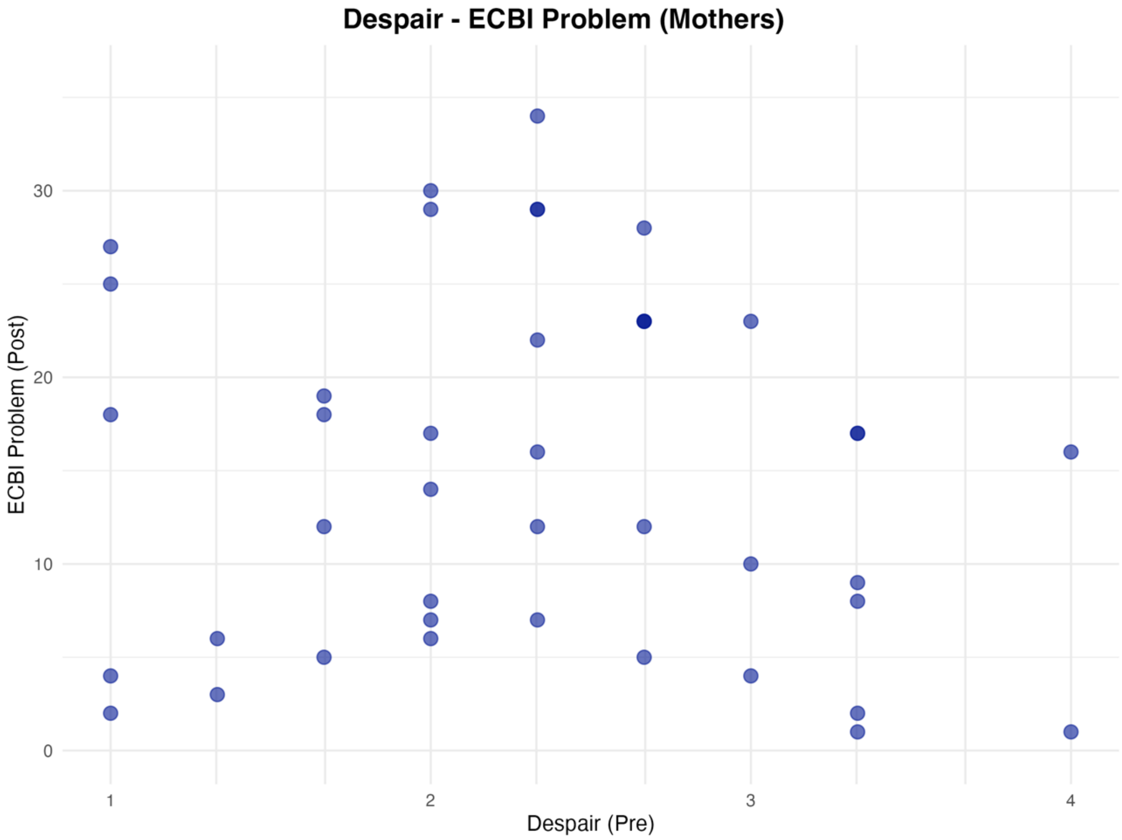


Figure 15 - Pre-treatment Despair and Post-Treatment ECBI Problem (Fathers).

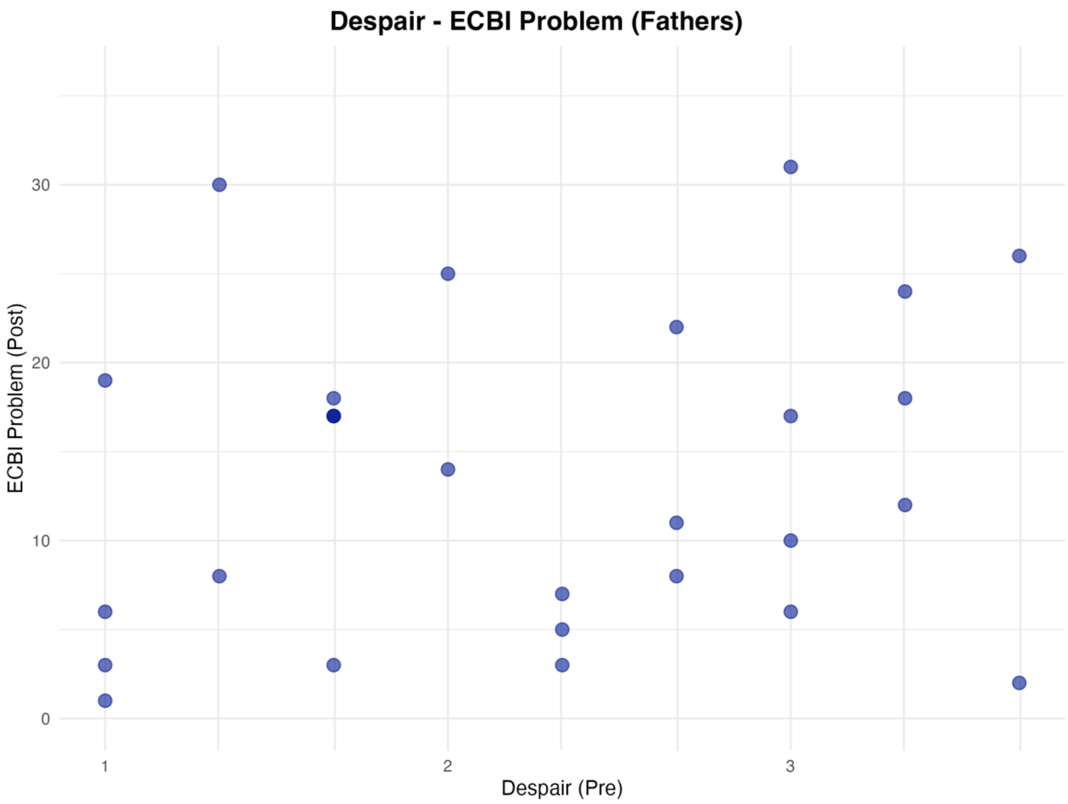


Figure 16 - Pre-treatment Despair and Post-Treatment SRS-2 Total (Mothers).

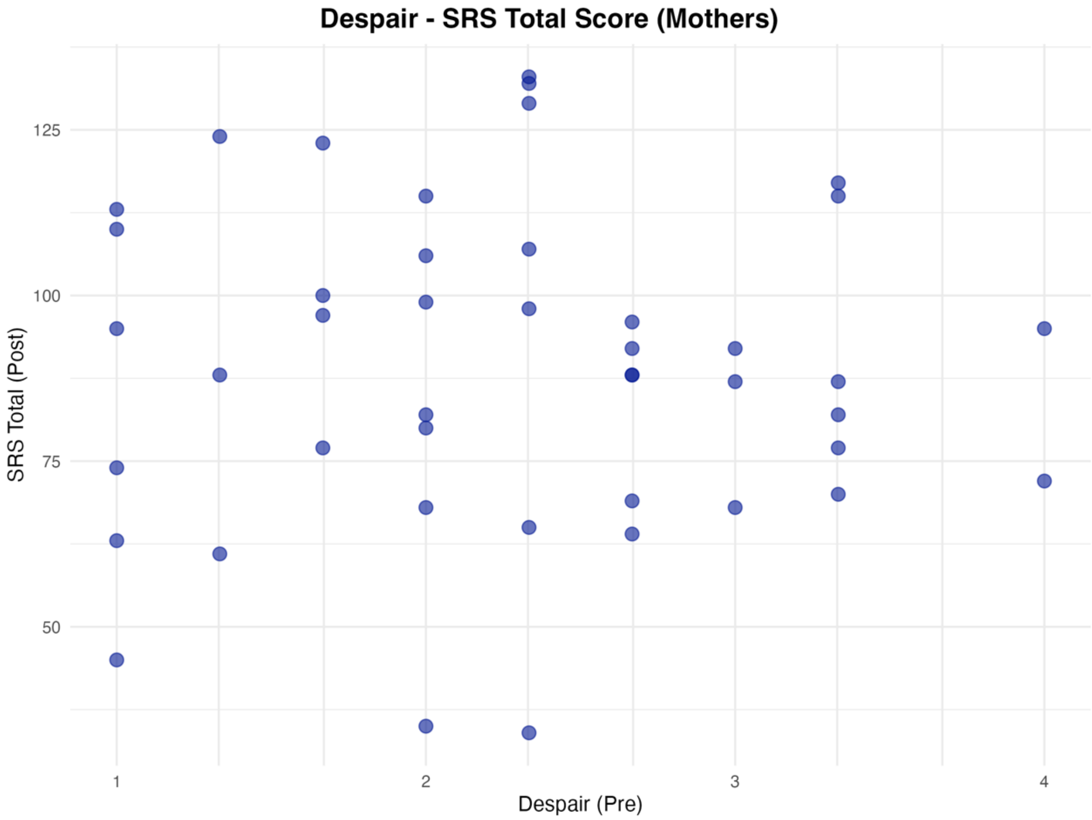


Figure 17 - Pre-treatment Despair and Post-treatment SRS-2 Total (Fathers).

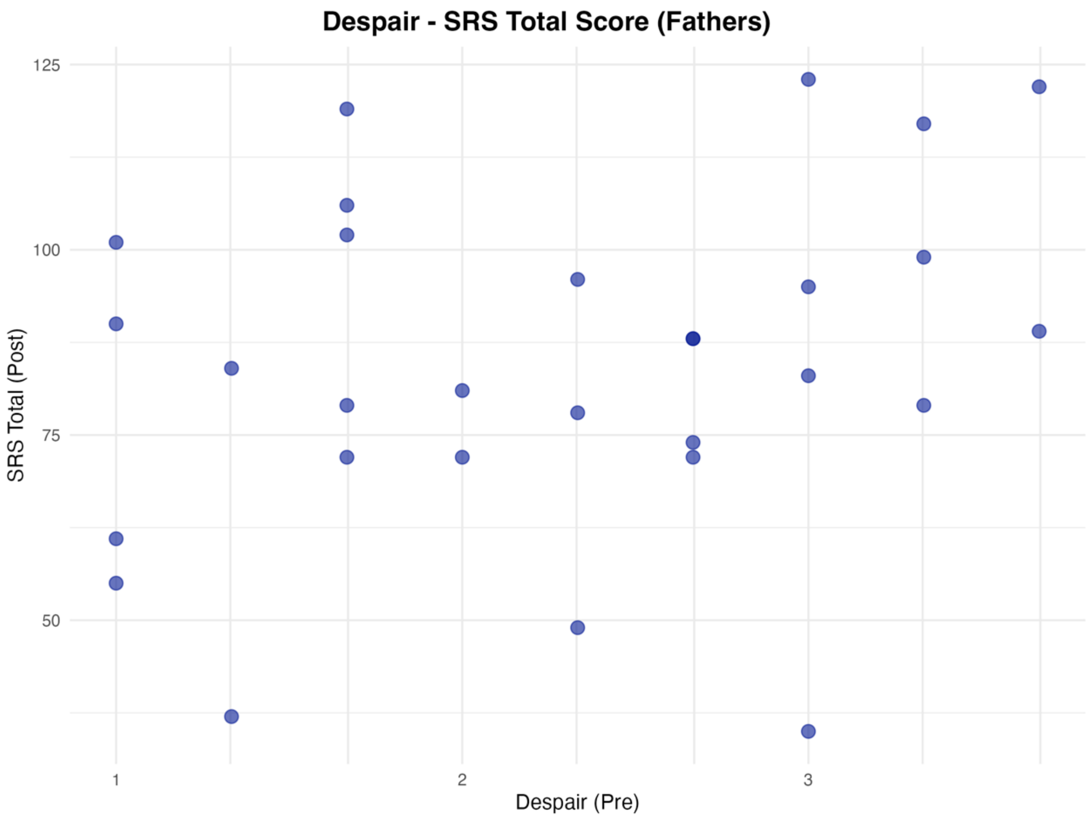


Figure 18 - Pre-treatment Despair and Post-treatment DISCAP Conduct Problems (Mothers).

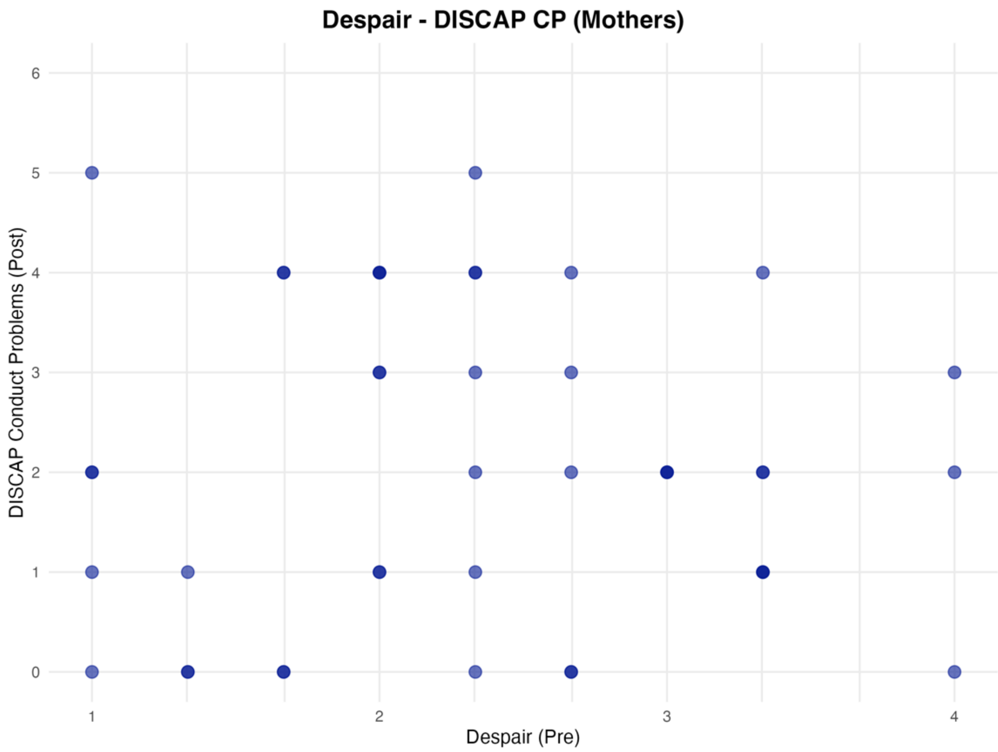


Figure 19 - Pre-treatment Despair and Post-treatment DISCAP Conduct Problems (Fathers).

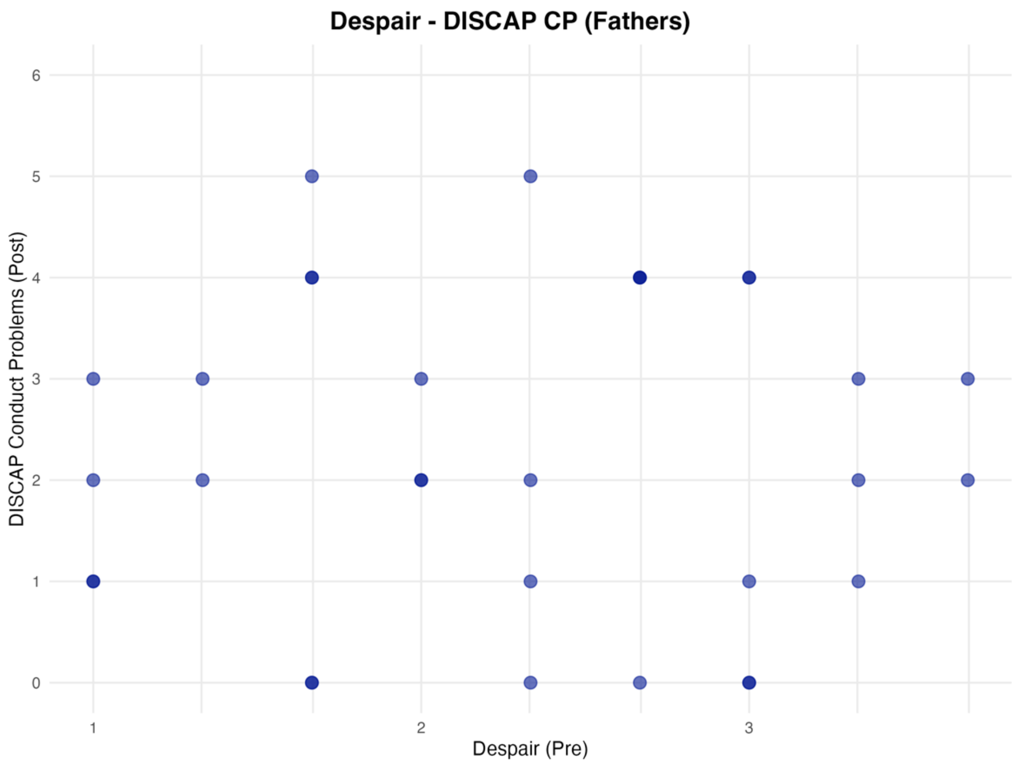


Figure 20 - Pre-treatment Self-Blame and Post-treatment ECBI Intensity (Mothers).

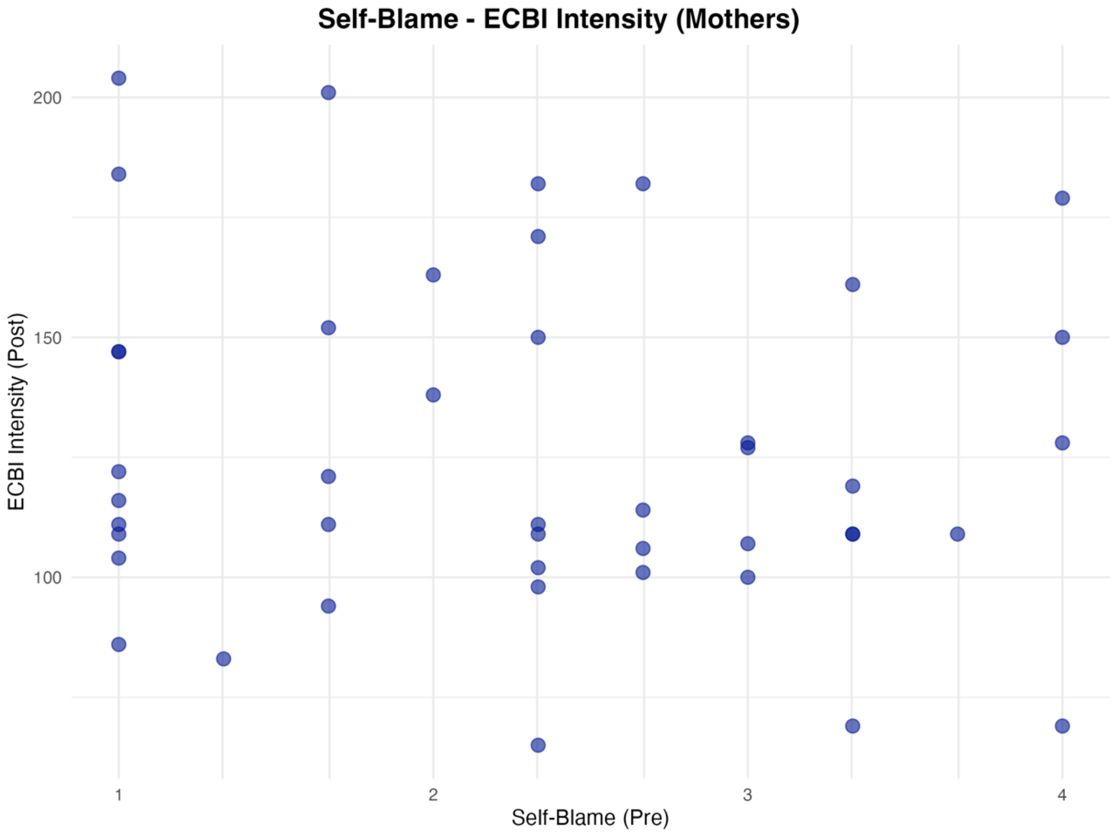


Figure 21 - Pre-treatment Self-Blame and Post-treatment ECBI Intensity (Fathers).

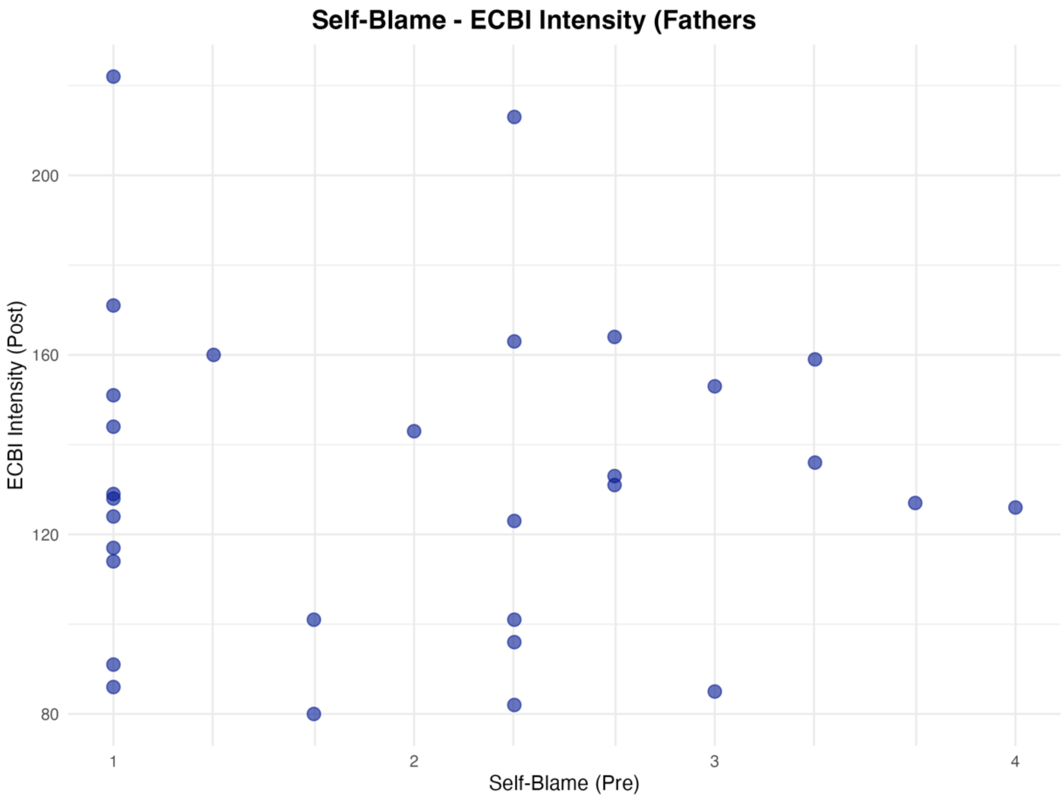


Figure 22 - Pre-treatment Self-Blame and Post-treatment ECBI Problem (Mothers).

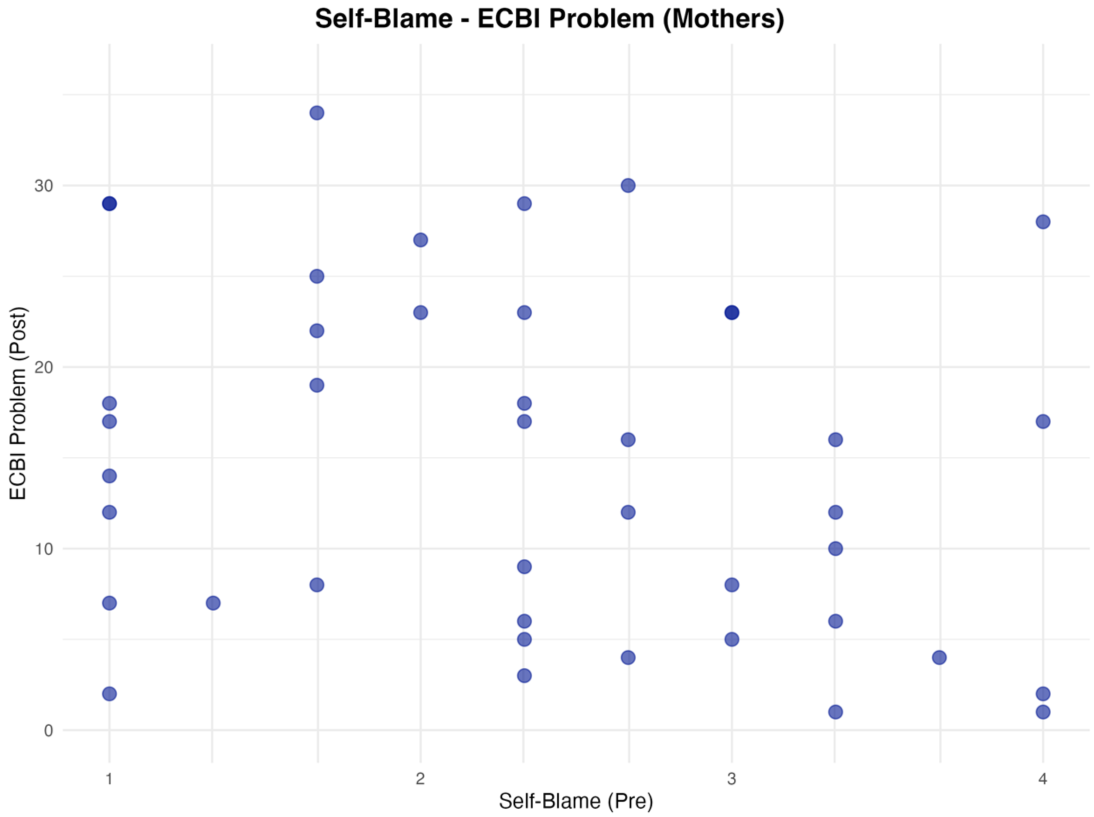


Figure 23 - Pre-treatment Self-Blame and Post-Treatment ECBI Problem (Fathers).

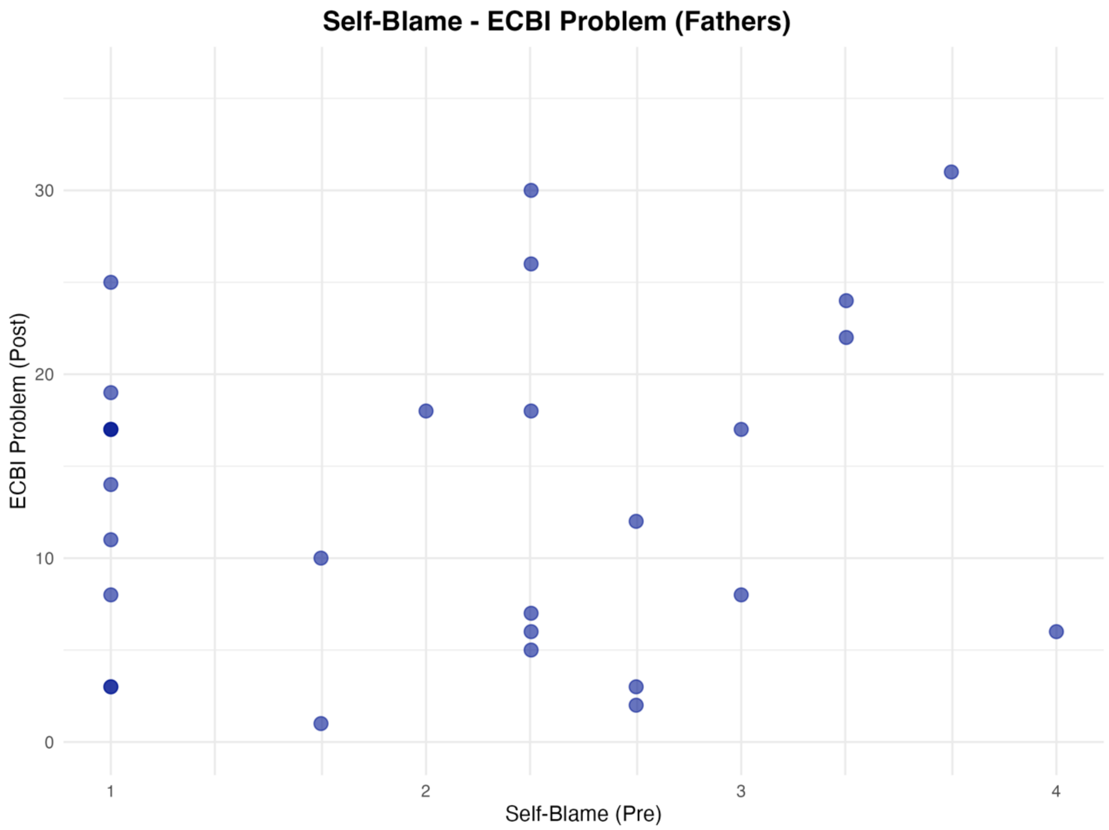


Figure 24 - Pre-treatment Self-Blame and Post-Treatment SRS-2 Total (Mothers).

Figure 25 - Pre-treatment Self-Blame and Post-Treatment SRS-2 Total (Fathers).

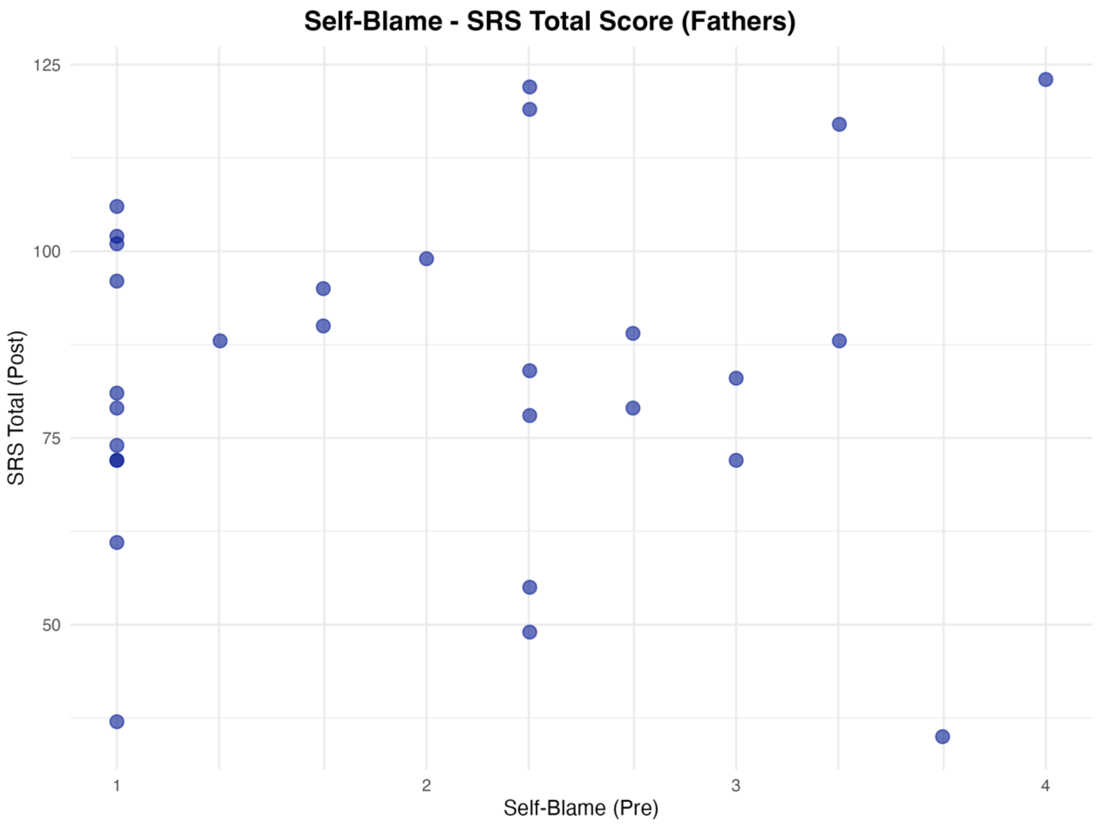


Figure 26 - Pre-treatment Self-Blame and Post-Treatment DISCAP Conduct Problems (Mothers).

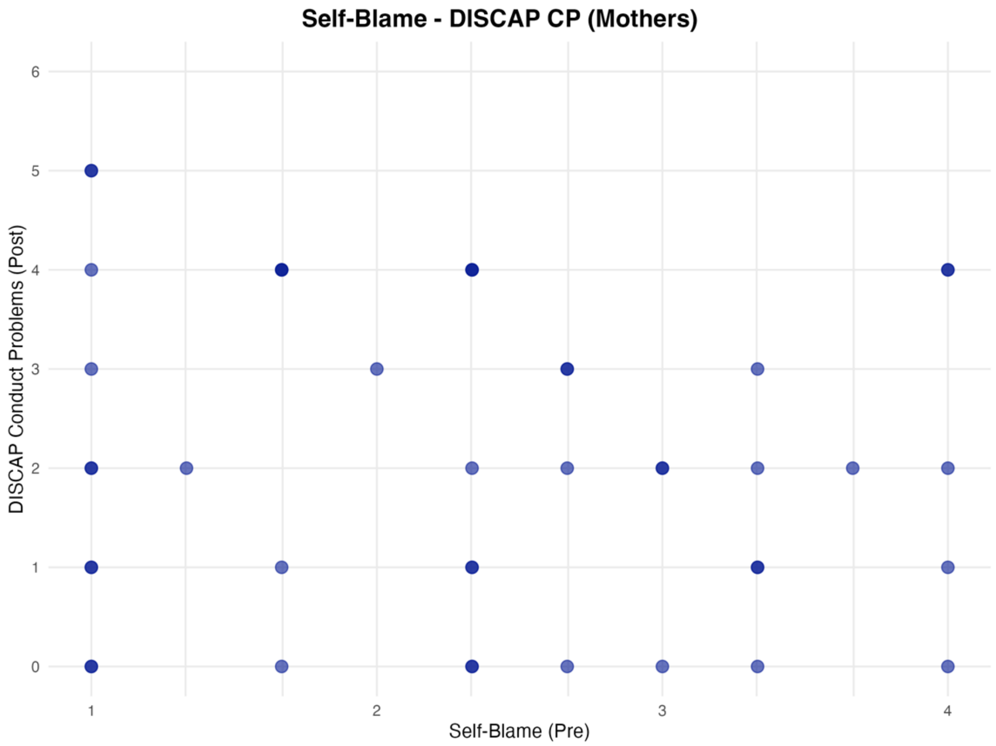


Figure 27 - Pre-treatment Self-Blame and Post-Treatment DISCAP Conduct Problems (Fathers).

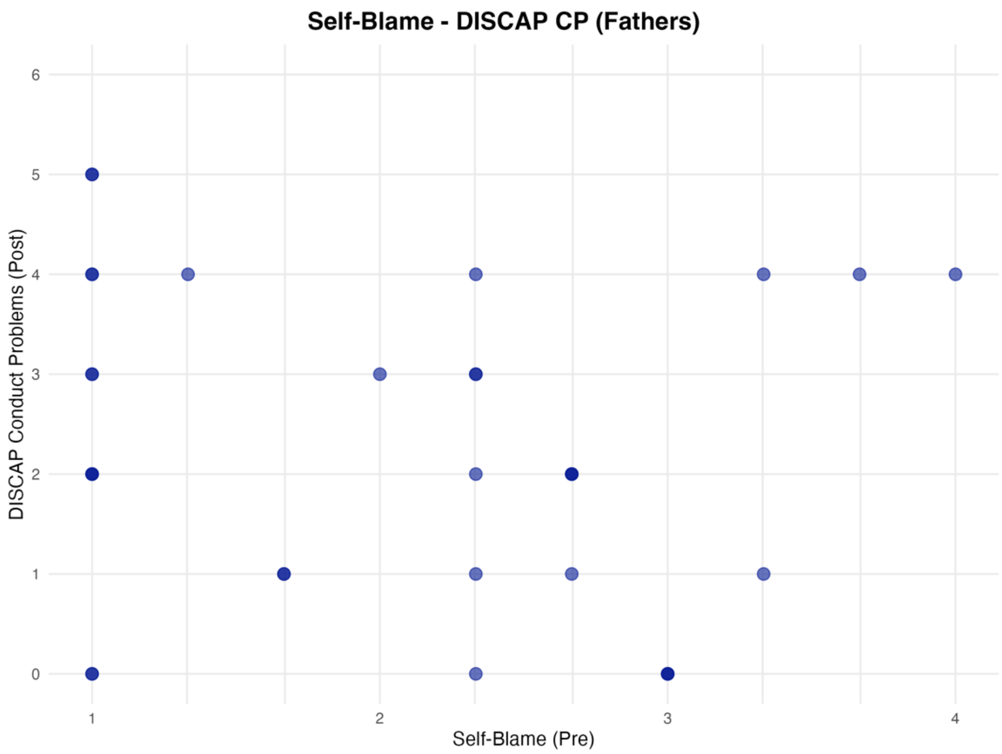


Figure 28 - Pre-treatment Acceptance and Post-Treatment ECBI Intensity (Mothers).

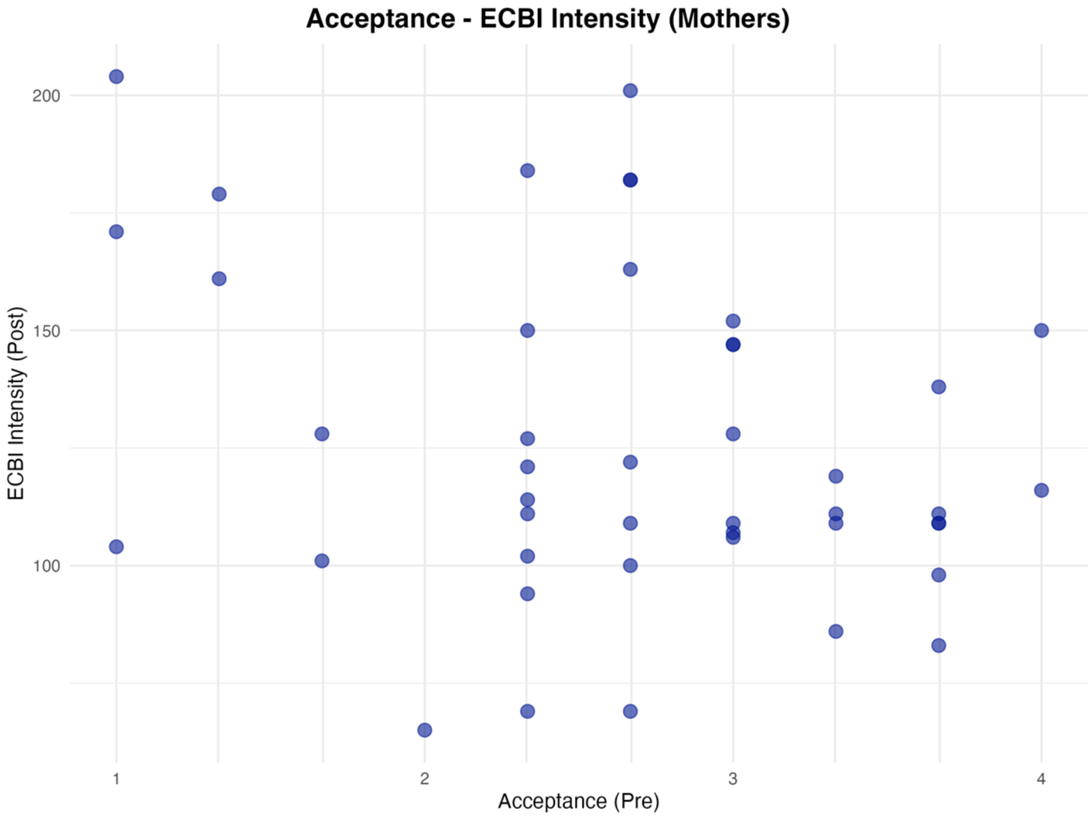


Figure 29 - Pre-treatment Acceptance and Post-Treatment ECBI Intensity (Fathers).

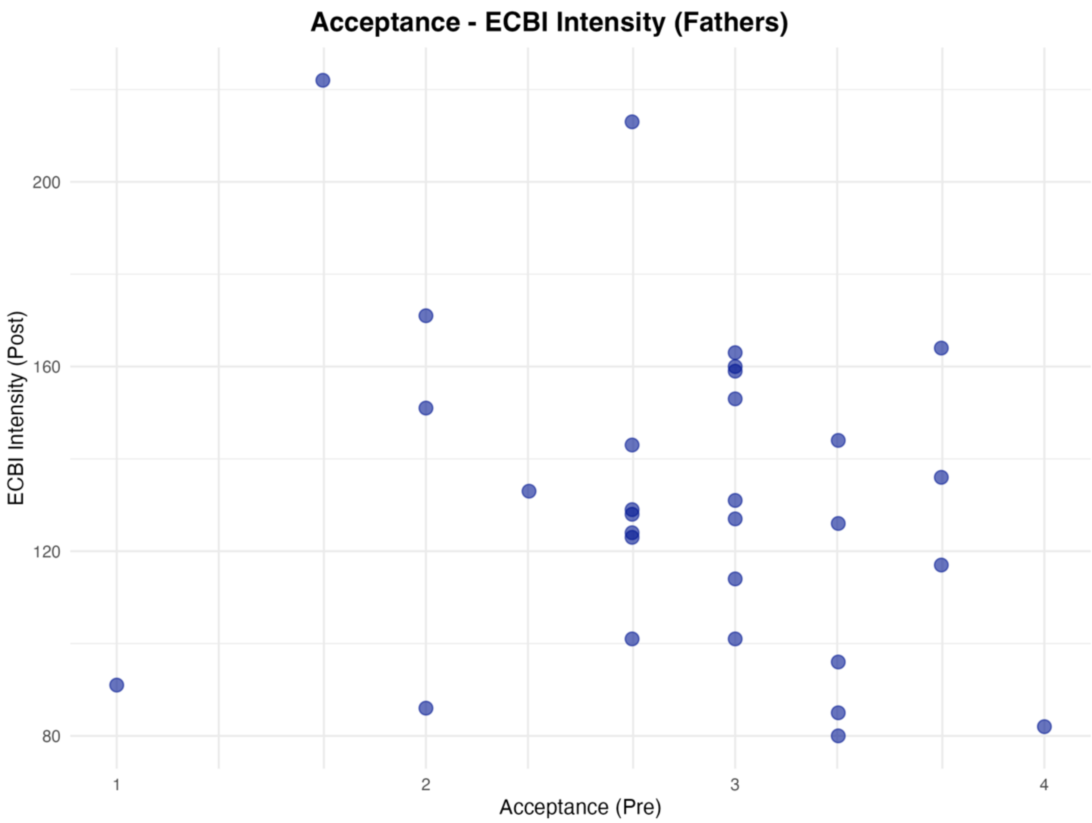


Figure 30 - Pre-treatment Acceptance and Post-treatment ECBI Problem (Mothers).

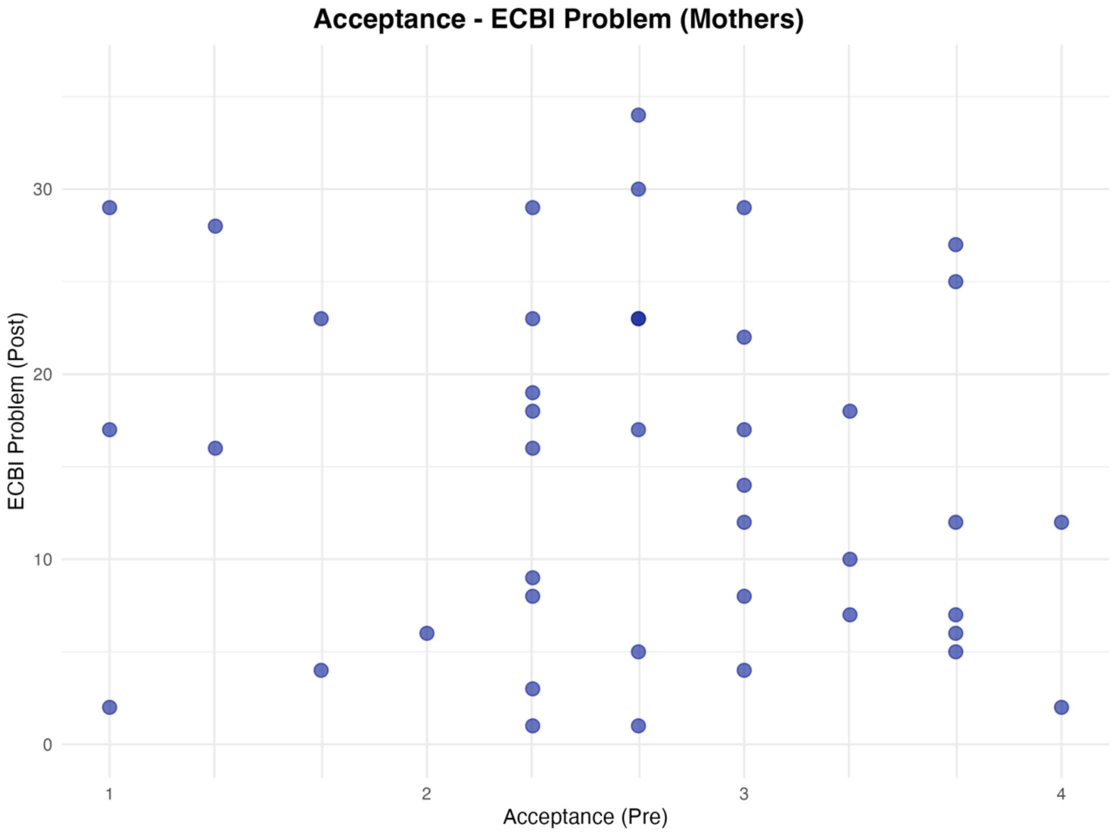


Figure 31 - Pre-treatment Acceptance and Post-Treatment ECBI Problem (Fathers).

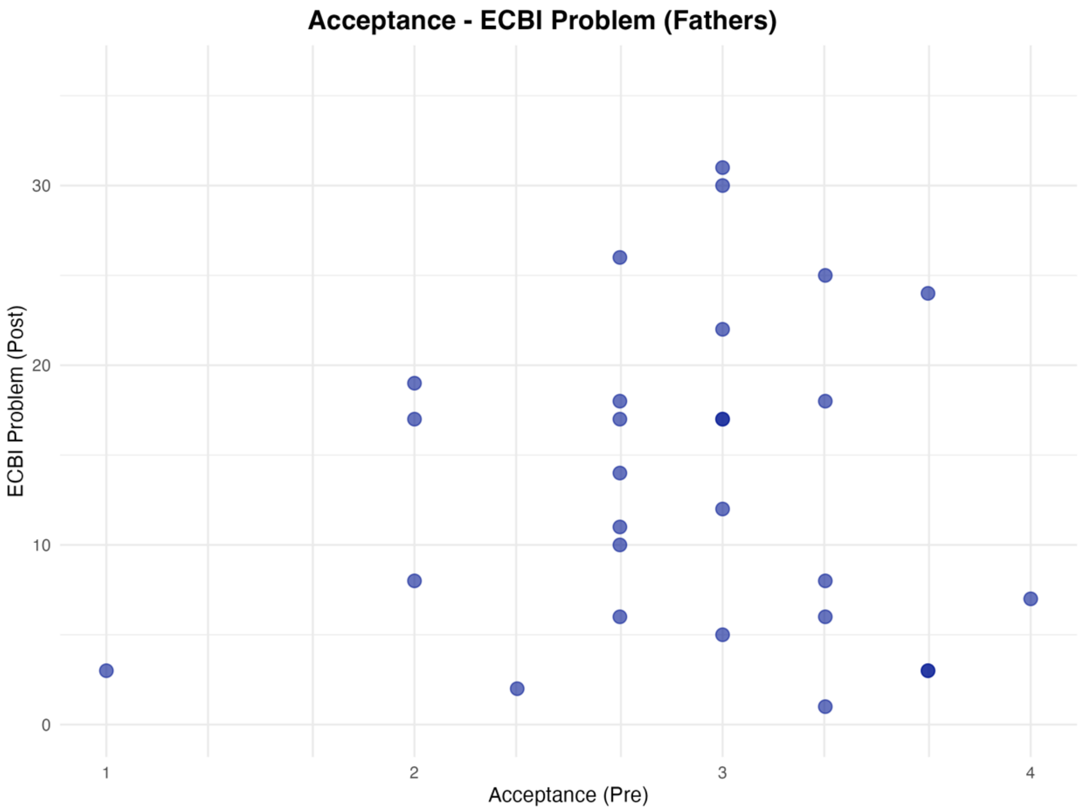


Figure 32 - Pre-treatment Acceptance and Post-Treatment SRS-2 Total (Mothers).

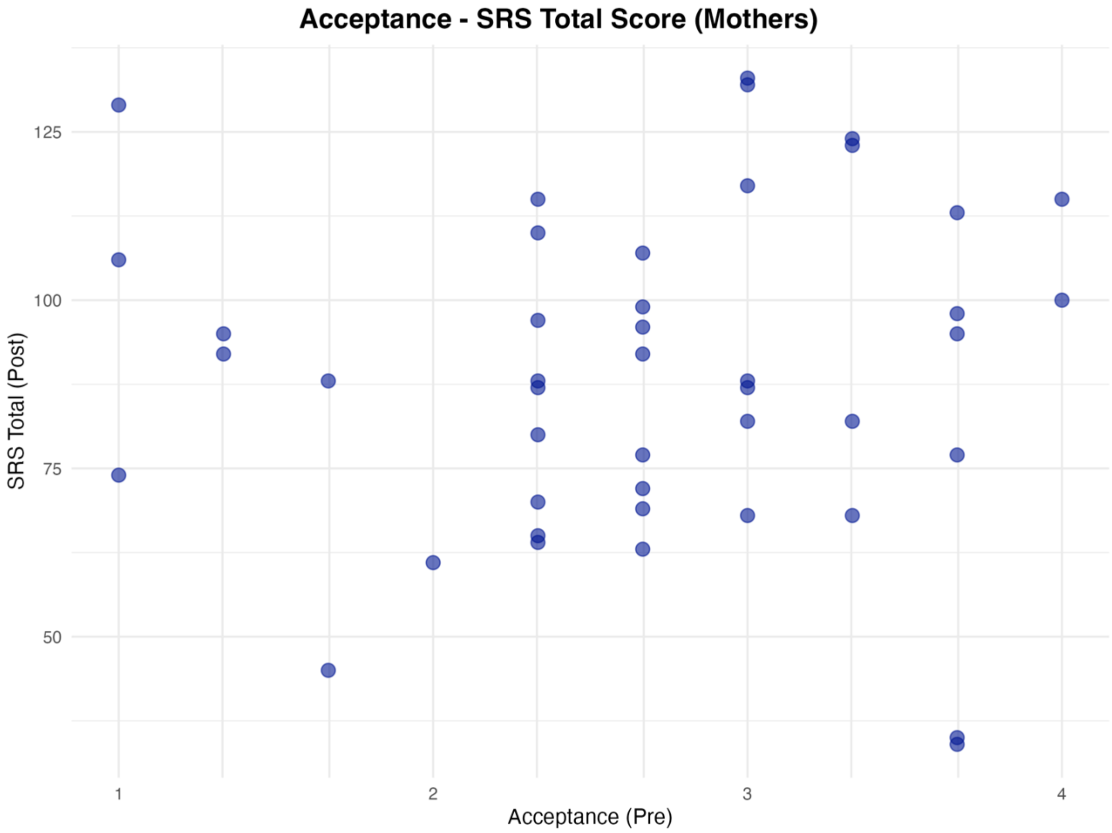


Figure 33 - Pre-treatment Acceptance and Post-Treatment SRS-2 Total (Fathers).

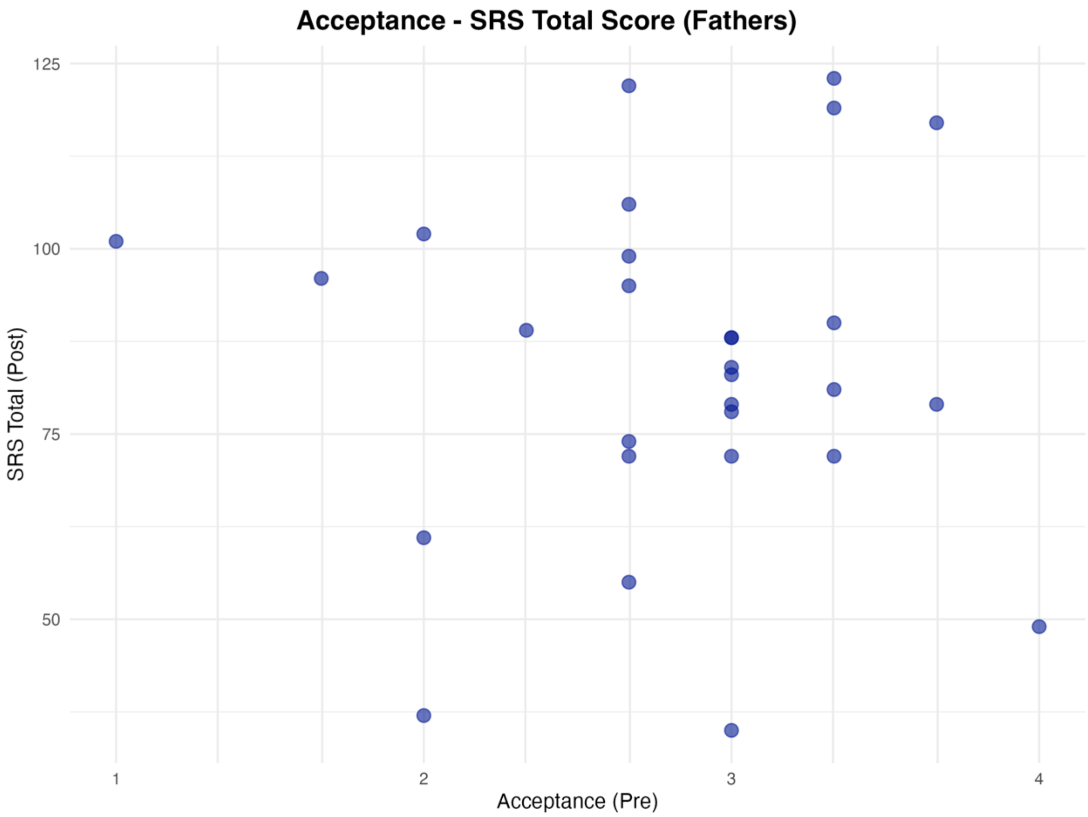


Figure 34 - Pre-treatment Acceptance and Post-treatment DISCAP Conduct Problems (Mothers).

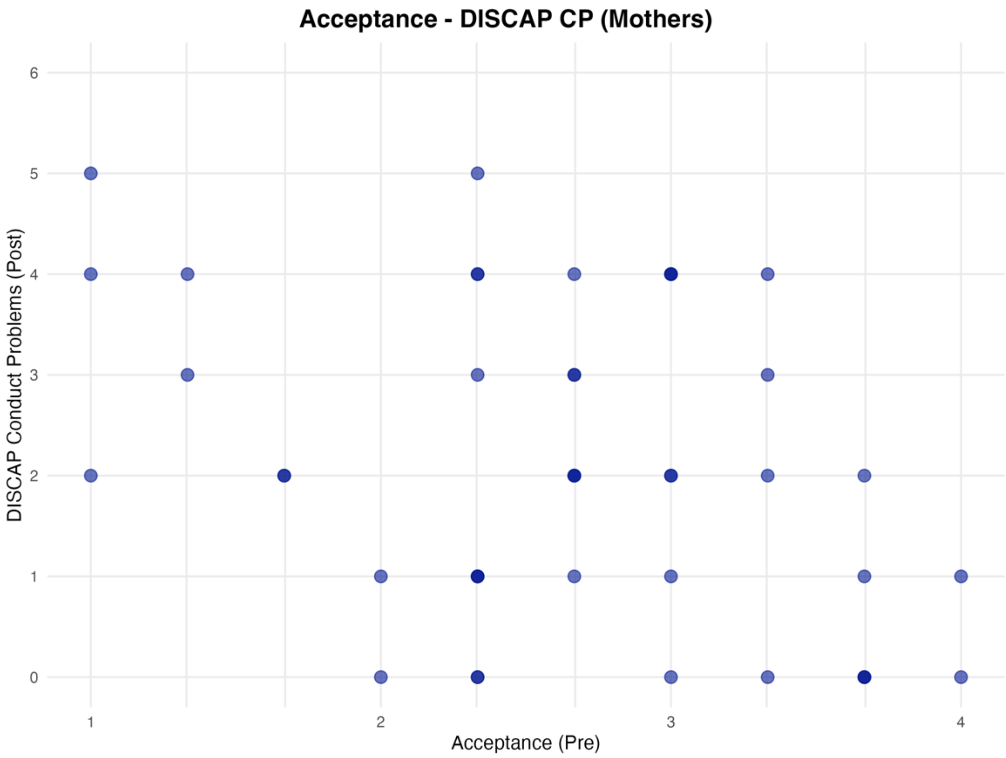
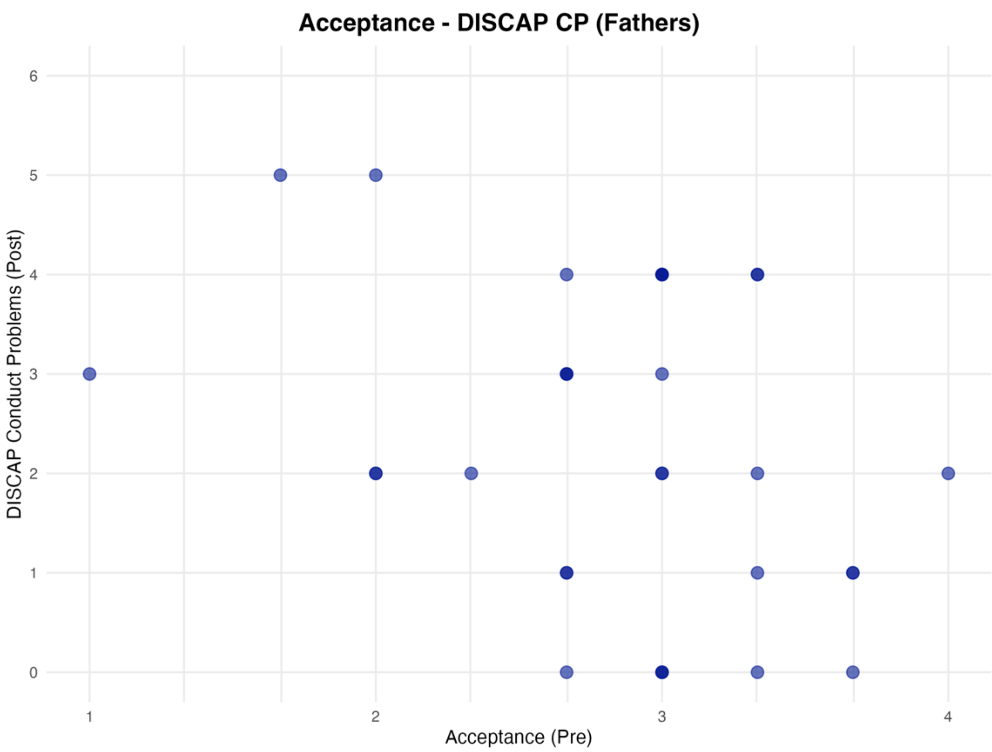


Figure 35 - Pre-treatment Acceptance and Post-treatment DISCAP Conduct Problems (Fathers).



Appendix 14 – Linear mixed models for Study 2 Research Question 4a

Research Question 4a: Does the effect of PMI on adjustment differ between mothers and fathers?

Linear mixed models generated using 'stats' package on RStudio (RCore Team, 2025).

Holm-corrected *p* values reported.

Table 31 - Pooled Imputed Model: Despair with parent gender moderator analysis.

Dependent variable: Post-treatment Despair.

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	0.782	0.227	3.444	22.723	0.002	0.723	0.465
Pre-treatment Despair	0.588	0.077	7.614	31.751	0.000	0.550	0.392
DSM-5 Autism Level	-0.014	0.125	-0.112	165.578	1.000	0.184	0.165
Treatment allocation	0.207	0.145	1.426	223.625	0.465	0.154	0.141
Parent gender	0.111	0.147	0.757	153.929	0.900	0.192	0.172
Allocation*Parent gender	-0.164	0.195	-0.841	444.684	0.939	0.105	0.099
Intercept~~Intercept|StudyID	0.090						
Residual~~Residual	0.357						
ICC|StudyID	0.199						

Table 32 - Pooled Imputed Model: Self-blame with parent gender moderator analysis.

Dependent variable: Post-treatment Self-Blame.

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	0.788	0.185	4.260	313.734	0.000	0.127	0.119
Pre-treatment Self-Blame	0.534	0.064	8.354	87.321	0.000	0.272	0.231
DSM-5 Autism Level	0.002	0.129	0.018	312.177	1.000	0.128	0.231
Treatment allocation	0.195	0.150	1.297	265.223	0.465	0.140	0.129
Parent gender	-0.083	0.148	-0.558	150.631	0.900	0.195	0.174
Allocation*Parent gender	0.014	0.191	0.071	1525.953	0.943	0.054	0.052
Intercept~~Intercept|StudyID	0.134						
Residual~~Residual	0.352						
ICC|StudyID	0.273						

Table 33 - Pooled Imputed Model: Acceptance with parent gender moderator analysis.

Dependent variable: Post-treatment Acceptance.

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	1.375	0.206	6.671	1058.926	0.000	0.065	0.063
Pre-treatment Acceptance	0.542	0.070	7.746	719.310	0.000	0.081	0.077
DSM-5 Autism Level	0.077	0.103	0.749	106.507	1.000	0.240	0.209
Treatment allocation	-0.177	0.151	-1.173	23.931	0.465	0.692	0.453
Parent gender	-0.169	0.148	-1.142	38.616	0.780	0.475	0.354
Allocation*Parent gender	0.214	0.209	1.024	34.547	0.939	0.516	0.375
Intercept~~Intercept|StudyID	0.029						
Residual~~Residual	0.296						
ICC|StudyID	0.094						

Appendix 15 – Linear mixed models for Study 2 Research Question 4b

Research Question 4b: Does the effect of adjustment on PMI engagement or outcomes differ between mothers and fathers?

Please note that self-report engagement was not imputed, therefore analyses for self-report engagement. Additional model summary statistics are therefore available for self-report engagement, which were not able to be derived for the pooled imputed models.

Linear mixed models generated using ‘stats’ package on RStudio (RCore Team, 2025). Holm-corrected *p* values reported.

Table 34 - Linear mixed model: Effect of pre-treatment adjustment on self-report engagement with parent gender moderator.

Dependent variable: Self-report engagement

Reference groups: DSM-5 autism level = Level 2; parent gender = mothers

Information Criteria

-2 Restricted Log Likelihood	146.53808113
Akaike's Information Criterion (AIC)	150.53808113
Hurvich and Tsai's Criterion (AICC)	150.76885036
Bozdogan's Criterion (CAIC)	156.55274750
Schwarz's Bayesian Criterion (BIC)	154.55274750

The information criteria are displayed in smaller-is-better form

Intraclass Correlation Coefficients (Study ID)

Overall ICCs	Adjusted	.656
	Conditional	.496

Estimates of Fixed Effects

Parameter	Estimate	Std. Error	df	t	Sig.	95% Confidence Interval
Intercept	5.903	.699	47.614	8.443	<.001	4.497-7.310
DSM-5 Autism Level	.326	.242	39.372	1.345	.558	-0.164-0.815
Pre-treatment Despair	.438	.190	36.023	2.302	.108	0.052-0.824
Pre-treatment Self-Blame	-.435	.171	27.656	-2.550	.068	-0.785- -0.085
Pre-treatment Acceptance	.786	.231	36.662	3.403	.008	0.318-1.254
Parent gender	1.924	.678	26.556	2.839	.036	0.532-3.316
Despair*Parent gender	-.459	.210	25.827	-2.188	.152	-0.891- -0.028
Self-Blame*Parent gender	.592	.210	29.783	2.819	.032*	0.163-1.021
Acceptance*Parent gender	-.627	.232	26.733	-2.699	.048*	-1.104 - -0.150

*Corrected $p < 0.05$

Table 35 - Pooled imputed model: Effect of pre-treatment adjustment on post-treatment ECBI Intensity with parent gender moderator.

Dependent variable: Post-treatment ECBI Intensity

Reference groups: DSM-5 autism level = Level 3; parent gender = fathers

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	94.786	27.639	3.429	443.759	0.001	0.105	0.099
Pre-treatment ECBI Intensity	0.317	0.102	3.115	338.862	0.002	0.122	0.114
DSM-5 Autism Level	0.048	8.883	0.005	755.162	1.000	0.078	0.075
Pre-treatment Despair	10.526	6.334	1.662	667.189	0.291	0.084	0.080
Pre-treatment Self-Blame	-9.789	5.110	-1.916	5721.276	0.165	0.027	0.027
Pre-treatment Acceptance	-5.973	5.413	-1.103	2175.143	0.810	0.045	0.044
Parent gender	-2.916	26.850	-0.109	2289.387	1.000	0.044	0.043
Despair*Parent gender	3.565	8.446	0.422	172.240	1.000	0.180	0.162
Self-Blame*Parent gender	-1.232	8.720	-0.141	63.892	1.000	0.334	0.273
Acceptance*Parent gender	-0.075	8.911	-0.008	319.636	1.000	0.126	0.117
Intercept~~Intercept|StudyID	522.749						
Residual~~Residual	414.988						
ICC|StudyID	0.557						

Table 36 - Pooled imputed model: Effect of pre-treatment adjustment on post-treatment ECBI Problem with parent gender moderator.

Dependent variable: Post-treatment ECBI Problem

Reference groups: DSM-5 autism level = Level 3; parent gender = fathers

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	9.773	5.837	1.674	938.901	0.094	0.068	0.066
Pre-treatment ECBI Problem	0.287	0.117	2.462	29.990	0.020	0.575	0.404
DSM-5 Autism Level	-1.595	2.776	-0.574	93.603	1.000	0.261	0.223
Pre-treatment Despair	2.447	1.682	1.455	489.140	0.292	0.099	0.094
Pre-treatment Self-Blame	-2.430	1.330	-1.827	1789.452	0.165	0.050	0.048
Pre-treatment Acceptance	0.005	1.395	0.004	3206.084	1.000	0.037	0.036
Parent gender	2.330	6.682	0.349	4877.999	1.000	0.029	0.029
Despair*Parent gender	-2.127	2.145	-0.992	208.265	0.969	0.161	0.147
Self-Blame*Parent gender	0.740	2.167	0.341	84.117	1.000	0.279	0.236
Acceptance*Parent gender	-0.465	2.402	-0.194	67.447	1.000	0.322	0.265
Intercept~~Intercept|StudyID	53.418						
Residual~~Residual	24.241						
ICC|StudyID	0.681						

Table 37 - Pooled imputed model: Effect of pre-treatment adjustment on post-treatment SRS-2 Total with parent gender moderator.

Dependent variable: Post-treatment SRS-2 Total

Reference groups: parent gender = fathers

Please note: DSM-5 Autism Level was not included in a covariate for SRS-2 model because both SRS-2 Total and DSM-5 Autism Level are measures of level of autism features.

Predictor	Estimate	Std. Error	*t*	df	*p*	RIV	FMI
(Intercept)	31.495	17.941	1.755	70.827	0.083	0.312	0.258
Pre-treatment SRS-2 Total	0.594	0.109	5.468	59.906	0.000	0.348	0.282
Pre-treatment Despair	0.557	3.993	0.140	785.964	0.889	0.077	0.074
Pre-treatment Self-Blame	-3.377	3.274	-1.032	3062.555	0.302	0.037	0.037
Pre-treatment Acceptance	1.838	3.741	0.491	74.881	1.000	0.301	0.251
Parent gender	-5.244	16.923	-0.310	2965.813	1.000	0.038	0.037
Despair*Parent gender	0.377	5.332	0.071	191.764	1.000	0.169	1.153
Self-Blame*Parent gender	2.465	5.325	0.463	115.379	1.000	0.229	0.200
Acceptance*Parent gender	-1.063	5.623	-0.189	442.263	1.000	0.105	0.099
Intercept~~Intercept|StudyID	187.384						
Residual~~Residual	174.846						
ICC|StudyID	0.516						

Appendix 16 – Qualitative Semi-Structured Interview Guide

Questions that should be asked to all participants are in bold. Option follow-up questions are non-bolded. Each question does not need to be asked if the general focus of the question has been discussed in the answer to a previous question.

Introduction
To be read to the participant at the start of each interview.

Thank you for your time today. My name is Elysha, and I am a provisional psychologist and PhD student at the University of Sydney.
Today I'd like to ask you some questions about your experiences of the *ParentWorks Spectrum* program, as well as your journey with your child's autism, including your thoughts and feelings about your child's diagnosis of ASD. We are doing this research to get a better understanding of caregivers' experiences. There are no right or wrong answers to these questions - I am hoping to understand your experiences. If I ask a question that you don't want to answer, please tell me and we can move on to the next question. Please also let me know if you would like me to repeat any questions or if there's anything I say that you don't understand.

Section 1 - Timeline of Experiences

1.1 Could you please start by telling me about your journey with [CHILD]'s autism diagnosis. I'm going to use this to make a timeline of your experiences.

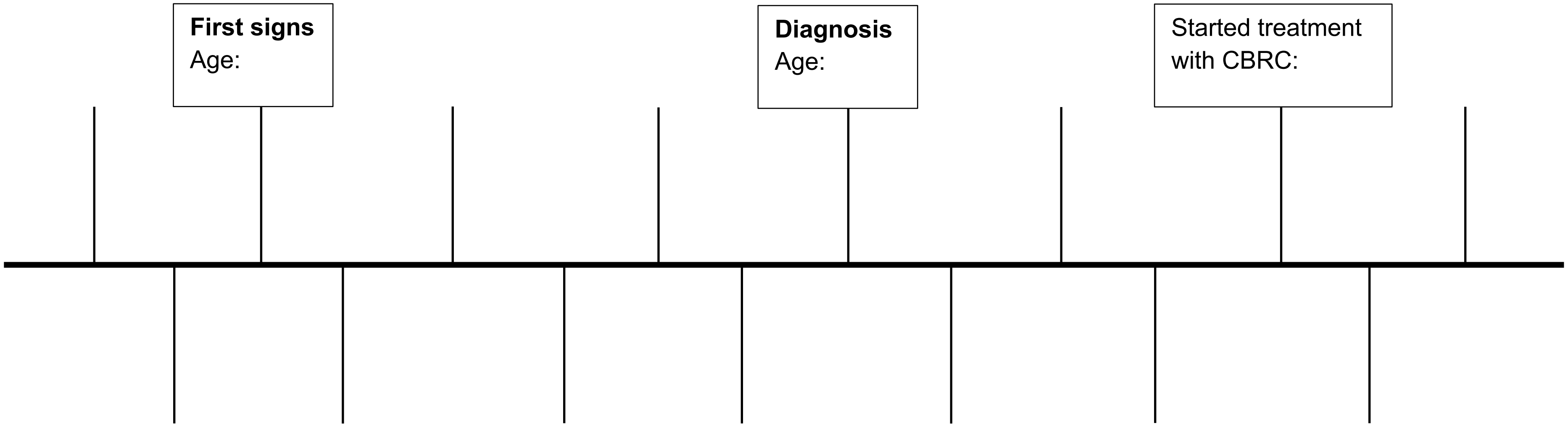
Plot the events the caregiver describes on timeline (See next page).

General prompt - If caregiver doesn't include any elements to be added to timeline:
What have been the major events from the time that you first noticed signs that your child may be developing differently through to now?

Specific prompts to add in missing elements:
Who first raised the idea that [CHILD] might be developing differently? When did this happen?
What were the first signs that [CHILD] might be developing differently? When did you notice these signs?
When was it first thought that [CHILD] might have autism? - *as compared to general developmental concerns - can exclude if caregiver describes that first concerns were ASD-specific*
What was the process of getting [CHILD]'s autism diagnosis? What professionals did you see? What tests were done? How long did the process take? How many visits?
When was the formal ASD diagnosis given? By who? - *answer in terms of date or child's age*
When did [CHILD] start receiving therapy? The *ParentWorks Spectrum* program specifically?
What major events have happened for your family since [CHILD]'s diagnosis? This could be things like the birth of a sibling, moving to a new house, [CHILD] starting school etc.

Present completed timeline to caregiver. Ask them to confirm accuracy, whether there is anything else important to add. Once timeline is finalised, stop sharing screen but note that we can refer back to the timeline throughout the interview as needed.

Thank you for working with me to put together this timeline. That will be really helpful to have some context as we now move to some other questions.


First signs
Age:
Diagnosis
Age:
Started treatment
with CBRC:

Section 2 - Program Experiences

In [months, year] you participated in the *ParentWorks Spectrum* intervention.

2.1 How would you describe your overall experience of participating in *ParentWorks Spectrum*.

2.2 Are there any particular aspects of the *ParentWorks Spectrum* program that you found most helpful?

2.3 Are there any particular aspects of the *ParentWorks Spectrum* program that you found were unhelpful or less helpful?

2.4 Are there any changes you would recommend to the *ParentWorks Spectrum* program?

2.5 Have there been any changes in your day-to-day life since participating in the program?

Section 3 - General Concept of Adjustment

Now I'm going to ask you some questions about your child and your experiences more generally.

3.1 Has your understanding of [CHILD]'s autism changed over time? How so/why not? At which point(s)?

3.2 Have your expectations for yourself as a parent changed over time? How so/why not? At which point(s)?

3.3 What does the word "adjustment" mean to you when thinking about autism diagnosis?
To be asked if the caregiver doesn't give a definition, or asks what "adjustment" means. If they give an answer but answer is vague or unclear, DO NOT give prompt:
Some people think of adjustment as meaning coming to accept their child's autism diagnosis, coming to understand the diagnosis, or moving through a process of grief about the diagnosis. Do any of these fit with your understanding of "adjustment" or do you have a different meaning that fits better for you?

If the caregiver talks about general experiences of adjustment and makes no reference to their own experience:
3.4 What has been your experience of adjusting to [CHILD]'s ASD diagnosis?
Ask about both practical and emotional aspects of adjustment if caregiver doesn't address both in their answer:

You've spoken about the emotional aspect of adjustment; for you has there been any practical adjustment? This might include changes to your day-to-day life.

You've spoken about the practical aspect of adjustment; for you has there been any emotional adjustment?

Adjustment is often understood to be an ongoing process. I'm going to ask some more questions about adjustment, so I want to be clear that when I ask about adjustment, I mean whatever you see as your experience of adjustment and no matter where you are in this adjustment process.

3.5 *Refer to the timeline* – **Do any of these points stand out when thinking about your experience of adjusting to [CHILD]'s ASD diagnosis?**

Section 4 - Factors that Influence Adjustment

For families in which two caregivers are participating, or in which there is another caregiver living in the home who is not participating

4.1 How do you think your experience of adjustment to [CHILD]'s diagnosis has compared to [OTHER CAREGIVER]'s?

4.2 How is autism understood by others around you, such as people in your family or your community?

4.3 Has others' understanding of autism changed your experience of adjustment? How so/why not?

4.4 What experiences had you had with autistic people prior to your child's diagnosis?

4.5 What, if anything (in addition to what you have already said), has helped you in the process of adjusting to your child's ASD diagnosis?
Ask regardless of prior responses in case there is anything to add.
Were there any resources or supports you used to help you in this process of adjustment? How were these helpful?
Referring to timeline - at which points did you use these resources/supports?

4.6 What, if anything, has made the process of adjusting to your child's ASD diagnosis difficult?
Ask regardless of prior responses in case there is anything to add
Referring to timeline - at which points did these challenges come up?
Why have these made it more difficult?

4.7 What extra support, if any, would have helped with your adjustment to your child's ASD diagnosis?
Ask regardless of prior responses in case there is anything to add
What stopped you from getting this support?
Referring to timeline - at what point(s) would this have been helpful?

4.8 Were there any changes to your adjustment to your child's ASD diagnosis while participating in the *ParentWorks-Spectrum* program?

Ask specifically about both practical and emotional aspects of adjustment
If yes
4.8.a Are there specific parts of the program that helped with your adjustment?
4.8.b Were there any interactions with your clinician that helped your adjustment to your child's diagnosis?
4.8.c Is there anything that you think could have been added to the program that would have better supported your adjustment?
4.8.d Was there anything that made it hard for you to do the program?
IF SO (*don't ask if they have stated that a clear external factor e.g., childcare difficulties interfered with participation)* - Do you think that your adjustment related to this difficulty?

4.9 Do you think your adjustment to [CHILD]'s autism diagnosis might change in the future? How so/why not?

4.10 If you could talk to your past self on the day of [CHILD]'s ASD diagnosis, what would you tell your past self?

4.11 We're coming towards the end of our interview. Is there anything you haven't yet been asked but would like to say about your experience of adjustment to [CHILD]'s ASD diagnosis?

Section 5 - Feedback and Debrief

5.1 What has this experience of talking about your adjustment to your child's ASD diagnosis been like for you?
Have you spoken previously with anyone about your experience of adjustment?
Has there been anything difficult or uncomfortable for you about talking about this topic?
Has there been anything that you have found helpful about talking about this topic?
Do you have any questions about anything we spoke about today?

Respond to any concerns, ensure caregivers are able to be contained and stable before ending the interview.

5.2 What supports are you currently linked in with? In addition to supports for your child, are you linked in with any supports for yourself and your wellbeing? Do you need any additional support for any of the issues we have talked about today?
Provide options for further support as available or offer to follow up with an email with additional resources.

Research debrief: Thank you for your time today. The goal of this interview was to get feedback that may help us improve the *ParentWorks-Spectrum* program, and to gain an understanding of what adjustment to autism diagnosis means to caregivers, what caregivers experiences of adjustment is, and what things make adjustment easier or harder. In particular, we are hoping to understand whether the ParentWorks-Spectrum program has any effect on adjustment, and how we may give caregivers better support.

Appendix 17 – Themes, Subthemes, and Clusters (Study 3)

<u>Theme 1 – Feeling out of control</u>

Subtheme 1a: An unwanted diagnosis.

- Diagnosis as a loss
- Situation is unfair
- Societal perceptions of autism

Subtheme 1b: Autism changed parents' entire life.

- Autism adds uncertainty about the future
- Autism is expected to bring lifelong challenges
- Autism makes life more complicated for parents and child
- Current challenges for child
- Impact of contextual factors on journey
- In the trenches
- Layers beyond typical parenting
- Things have been harder than expected

Subtheme 1c: Feeling lost in a minefield.

- Child is in control rather than parent
- Diagnosis was unexpected
- Feeling lost after diagnosis
- Ongoing gaps
- The journey to get the diagnosis was effortful
- We don't fit in

<u>Theme 2 – Becoming agents of change</u>

Subtheme 2a: Change in the parent

- Actively building understanding through learning
- Actively making choices in the process
- Feeling stuck
- Finding space for parents' own needs
- Parent is confident
- Parent putting pressure on themselves
- Parenting team
- There is always more to be done

Subtheme 2b: Change in the child

- Diagnosis was a relief
- Parent feels better as the child makes progress
- Putting in work for the child's benefit
- Support is available
- Ways the child does well

Subtheme 2c: Change in the world around them

- Working to find community amid exclusion
- Parent pushes for societal change
- Empowering child

<u>Theme 3 – Accepting that what will be will be</u>

- Adjustment takes time
- Attitudes towards the diagnosis have changed
- Benefit finding
- First steps in adjusting happened prior to diagnosis
- It is what it is
- Things work out by chance

<u>Adjustment as acceptance and change</u>

- Accepting the diagnosis is a challenging process
- Contradictions
- Reflecting on the adjustment journey

Appendix B1 - Articles Excluded at Full - Text Review

Table B1 - Articles excluded at full - text review.

Title	Authors	Published Y	Journal	Volume	Issue	Pages	DOI	Notes
Parent coaching intervention program based on the Early Start Denver Model for children with autism spectrum disorder: Feasibility and acceptability study	Abouzeid, N.; Rivard, M.; Mello, C.; Mestari, Z.; Boul√©, M.; Guay, C.	2020	Research in Developmental Disabilities	105			10.1016/j.ridd.2020.103747	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Finding Benefit and Feeling Strain in Parenting a Child with Autism Spectrum Disorder	Adams, Haley C.; Zlomke, Kimberly R.; Rossetti, Kristina G.	2022	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS				10.1007/s10803-022-05663-3	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effectiveness of happiness training on the pattern of parent-child relationships and the hope of parents with autistic children	Agha Mohammad Hasani, Parvin; Sheikh Fathollahi, Mahmood; Gerami Fard, Asal; Mokhtari, Mohammadreza	2020	Iranian Rehabilitation Journal	18	3	309-318	10.32598/irj.18.3.946.1	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Online Positive Thinking Training Intervention for Caregivers of Individuals with ASD: necessity, Acceptability and Feasibility	Ak, Bekhet	2017	Issues in mental health nursing	38	5	443-448	10.1080/01612840.2017.1279247	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parent, child, and family outcomes following Acceptance And Commitment Therapy for parents of autistic children: a randomized controlled trial	Al, Maughan; Y, Lunsky; J, Lake; Js, Mills; K, Fung; L, Steel; Ja, Weiss	2024	Autism	28	2	367-380		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Quality of life and coping strategies used by parents of children with autism spectrum disorder in Oman	ALBusaidi, A.M.S.; ALMasroori, S.A.S.; Awladthani, B.M.S.; ALKhaldi, S.A.; Al Alawi, N.; Al Salmani, A.A.	2022	Autism and Developmental Language Impairments	7			10.1177/23969415221142262	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effectiveness of Integrative Structural Family Therapy and Double ABCX Model on Marital Adjustment and Parenting Stress Among Parents of Children with Autism: Randomized Controlled Trial	AlHorany, A.K.; Hassan, S.A.; Juhari, R.; Aljaberi, M.A.	2024	Child and Family Behavior Therapy				10.1080/07317107.2024.2395296	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping strategies in parents of children with disabilities: A case-control study	Alos, Francisco J.; Garcia, Andres Garcia; Maldonado, Miguel A.	2022	Brain and Behavior	12	8	e2701	10.1002/brb3.2701	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parental coping as a buffer between child factors and emotion-related parenting in families of children with autism spectrum disorder	Alostaz, Jasmin; Baker, Jason K.; Fenning, Rachel M.; Neece, Cameron L.; Zeedyk, Sasha	2022	Journal of Family Psychology	36	1	153-158	10.1037/fam0000757	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Fostering awareness and acceptance of disability in Mexican mothers of autistic children	Amaya, Alfa Celene Rea; Tomasini, Guadalupe Acle	2014	Psychology	5	11	1355-1365	10.4236/psych.2014.511146	Exclusion reason: 3A) Not target population (not ASD);

Mental health disorder among children: Social adaptation and rehabilitation	Amirbekova, G.; Abdikerova, G.	2021	Journal of Human Behavior in the Social Environment	31	5	661-672	10.1080/10911359.2020.1811824	Exclusion reason: 4b) Not quantitative measurement;
Cognitive behavioural therapy and mindfulness for health-related quality of life: Comparing treatments for parents of children with chronic conditions - A pilot feasibility study	Anclair, M.; Hj√§rthag, F.; Hiltunen, A.J.	2017	Clinical Practice and Epidemiology in Mental Health	13			10.2174/1745017901713010001	Exclusion reason: 3A) Not target population (not ASD);
Mental Health and Coping in Parents of Children with Autism Spectrum Disorder (ASD) in Singapore: An Examination of Gender Role in Caring	Ang, Karen Qian Ping; Loh, Pek Ru	2019	Journal of Autism & Developmental Disorders	49	5	2129-2145	10.1007/s10803-019-03900-w	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Multidisciplinary parent education for caregivers of children with autism spectrum disorders	B, Ji; M, Sun; R, Yi; S, Tang	2014	Archives of psychiatric nursing	28	5	319-326	10.1016/j.apnu.2014.06.003	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Play brick therapy to aid the social skills of children and young people with autism spectrum disorder: the I-SOCIALISE cluster RCT	B, Wright; E, Kingsley; C, Cooper; K, Biggs; M, Bursnall; Hi, Wang; T, Chater; E, Coates; Teare; K, McKendrick; G, Gomez de la Cuesta; A, Barr; K, Solaiman; A, Packham; D, Marshall; D, Varley; R, Nekooi; S, Parrott; S, Ali; S, Gilbody; A, Le Couteur	2023	Public health research (southampton, england)	11	12	1-137		Exclusion reason: 2b) Full text not accessible;
Impact of autism in adolescents on parental quality of life	Baghdadli, A.; Pry, R.; Michelon, C.; Rattaz, C.	2014	Quality of Life Research	23	6	1859-1868	10.1007/s11136-014-0635-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Behavior disorders and social skills in adolescents with intellectual disability: Does co-morbid autism matter?	Baker, Bruce L.; Blacher, Jan	2021	Journal of Mental Health Research in Intellectual Disabilities	14	2	174-188	10.1080/19315864.2020.1871451	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Longitudinal effects of adaptability on behavior problems and maternal depression in families of adolescents with autism	Baker, Jason K.; Seltzer, Marsha Mailick; Greenberg, Jan S.	2011	Journal of Family Psychology	25	4	601-609	10.1037/a0024409	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Diving into the Resolution Process: Parent,Äôs Reactions to Child,Äôs Diagnosis	Barak-Levy, Y.; Paryente, B.	2023	International Journal of Environmental Research and Public Health	20	4		10.3390/ijerph20043295	Exclusion reason: 3A) Not target population (not ASD);
Factors Associated with Stress Among Parents of Children with Autism	Batool, Syeda Shahida; Khurshid, Sumaira	2015	Jcpsp, Journal of the College of Physicians & Surgeons - Pakistan	25	10	752-756	10.2015/JCPSP.752756	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Relationships Between Psychological Flexibility, Psychological Capital and Marital Quality Amongst Parents of Children With Autism Spectrum Disorder	Bayazy, YG; Gur, A	2024	CHILD & FAMILY SOCIAL WORK				10.1111/cfs.13237	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Toward an exportable parent training program for disruptive behaviors in autism spectrum disorder	Bearss, K.; Lecavalier, L.; Minshawi, N.; Johnson, C.; Smith, T.; Handen, B.; Sukhodolsky, D.G.; Aman, M.G.; Swiezy, N.; Butter, E.; Scahill, L.	2013	Neuropsychiatry	3	2	169-180	10.2217/npy.13.14	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parent and professional evaluations of family stress associated with characteristics of autism	Bebko, J. M.; Konstantareas, M. M.; Springer, J.	1987	Journal of Autism & Developmental Disorders	17	4	565-576		Exclusion reason: 3A) Not target population (not ASD);
Coping strategies and education of parents of autistic children in Bangladesh	Begum, F.; Islam, M.S.; Rahman, A.S.M.M.H.	2020	Bangladesh Journal of Medical Science	19	4	614-619	10.3329/bjms.v19i4.46615	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Positive Thinking Training Intervention for Caregivers of Persons with Autism: Establishing Fidelity	Bekhet, Abir K.	2017	Archives of Psychiatric Nursing	31	3	306-310	10.1016/j.apnu.2017.02.006	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The Mediating Effects of Positive Cognitions on Autism Caregivers' Depression and Their Children's Challenging Behaviors	Bekhet, Abir K.	2016	Archives of Psychiatric Nursing	30	1	13-18	10.1016/j.apnu.2015.11.001	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Self-assessed health in caregivers of persons with autism spectrum disorder: associations with depressive symptoms, positive cognitions, resourcefulness, and well-being	Bekhet, Abir K.	2014	Perspectives in Psychiatric Care	50	3	210-217	10.1111/ppc.12046	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Depression, positive thinking, personal and social resourcefulness among caregivers of persons with autism spectrum disorders	Bekhet, Abir K.; Garnier-Villarreal, Mauricio	2018	Archives of Psychiatric Nursing	32	6	823-827	10.1016/j.apnu.2018.06.006	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effects on resilience of caregivers of persons with autism spectrum disorder: the role of positive cognitions	Bekhet, Abir K.; Johnson, Norah L.; Zauszniewski, Jaclene A.	2012	Journal of the American Psychiatric Nurses Association	18	6	337-344	10.1177/1078390312467056	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mindful Self-Care for Caregivers: A Proof of Concept Study Investigating a Model for Embedded Caregiver Support in a Pediatric Setting	Bellone, K.M.; Elliott, S.C.; Hynan, L.S.; Warren, B.; Jarrett, R.B.	2023	Journal of Autism and Developmental Disorders	53	2	539-552	10.1007/s10803-021-05113-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping and psychological adjustment among mothers of children with ASD: An accelerated longitudinal study	Benson, P.R.	2014	Journal of Autism and Developmental Disorders	44	8	1793-1807	10.1007/s10803-014-2079-9	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Network characteristics, perceived social support, and psychological adjustment in mothers of children with autism spectrum disorder	Benson, P.R.	2012	Journal of Autism and Developmental Disorders	42	12	2597-2610	10.1007/s10803-012-1517-9	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A psychometric evaluation of the parental acceptance and action questionnaire (PAAQ) in parents of children with and without disabilities	Bergman, TH; Sandred, A; Lindstrom, T; Lappalainen, P; Ghaderi, A; Hirvikoski, T	2024	JOURNAL OF CONTEXTUAL BEHAVIORAL SCIENCE	32			10.1016/j.jcbs.2024.100757	Exclusion reason: 3A) Not target population (not ASD);
Routine measurement and feedback in support groups for parents of children with Autistic Spectrum Disorder	Bitan, D.T.; Zilcha-Mano, S.; Ganor, O.; Biran, L.; Bloch, Y.	2018	Psychotherapy	55	2	191-195	10.1037/pst0000140	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Collateral Effects of Youth Disruptive Behavior Disorders on Mothers‚Äô Psychological Distress: Adolescents with Autism Spectrum Disorder, Intellectual Disability, or Typical Development	Blacher, J.; Baker, B.L.	2019	Journal of Autism and Developmental Disorders	49	7	2810-2821	10.1007/s10803-017-3347-2	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Experience of Approbation of the Psychoeducational Program for Families of Children with Autism Spectrum Disorders	Bogacheva, Oksana I.; Ivanov, Mikhail V.; Simashkova, Natalya V.	2023	CLINICAL PSYCHOLOGY AND SPECIAL EDUCATION	12	1	126-149	10.17759/cpse.2023120106	Exclusion reason: 1) Not published in English;
Self-compassion: A Novel Predictor of Stress and Quality of Life in Parents of Children with Autism Spectrum Disorder	Bohadana, Gal; Morrissey, Shirley; Paynter, Jessica	2019	Journal of Autism & Developmental Disorders	49	10	4039-4052	10.1007/s10803-019-04121-x	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Efficacy of a Parent-Implemented Pivotal Response Treatment for Children with Autism Spectrum Disorder	Bozkus-Genc, Gulden; Yucesoy-Ozkan, Serife	2024	Journal of Autism & Developmental Disorders	54	11	3992-4005	10.1007/s10803-023-06113-4	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parenting a Child with Autism in India: Narratives Before and After a Parent,ÄìChild Intervention Program	Brezis, R.S.; Weisner, T.S.; Daley, T.C.; Singhal, N.; Barua, M.; Chollera, S.P.	2015	Culture, Medicine and Psychiatry	39	2	277-298	10.1007/s11013-015-9434-y	Exclusion reason: 4b) Not quantitative measurement;
Dyadic Effect of Coping on the Perceived Impact of ASD of Children on Parental Quality of Life: Report from the ELENA Cohort	Brillet, Leila; Peries, Marianne; Vernhet, Christelle; Rattaz, Cecile; Michelon, Cecile; Baghdadli, Amaria	2023	Journal of Autism & Developmental Disorders	53	1	38-49	10.1007/s10803-021-05414-w	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mothers of children with autism or communication disorders: successful adaptation and the double ABCX model	Bristol, M. M.	1987	Journal of Autism & Developmental Disorders	17	4	469-486		Exclusion reason: 3A) Not target population (not ASD);
The disclosure of a diagnosis of an autistic spectrum disorder: Determinants of satisfaction in a sample of Scottish parents	Brogan, C.A.; Knussen, C.	2003	Autism	7	1	31-46	10.1177/1362361303007001004	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Feasibility of Coping Effectiveness Training for Caregivers of Children with Autism Spectrum Disorder: a Genetic Counseling Intervention	C, Haakonsen Smith; E, Turbitt; J, Muschelli; L, Leonard; Kl, Lewis; B, Freedman; M, Muratori; Bb, Biesecker	2018	Journal of genetic counseling	27	1	252-262	10.1007/s10897-017-0144-1	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Telehealth for Family Guidance: Acceptance and Commitment Therapy, Parent-Focused Preference Assessment, and Activity-Based Instruction for the Support of Children with Autism Spectrum Disorder and Their Families. [Review]	Cameron, Michael J.; Moore, Tiffanie; Bogran, Carla; Leidt, Alexandria	2021	Behavior Analysis in Practice	14	4	1128-1134	10.1007/s40617-020-00443-w	Exclusion reason: 2c) Review paper;
A Comparison of Parent-Reported Severe Autism with Mild/Moderate Autism among US Children	Carbone, P.S.; Stipelman, C.H.; Villalobos, M.E.; Ellzey, A.; Stuart, A.; Stoddard, G.J.; Campbell, K.	2024	Journal of Developmental and Behavioral Pediatrics	45	5	e422-e430	10.1097/DBP.0000000000001306	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Using implementation science frameworks to explore barriers and facilitators for parents,Äô use of therapeutic strategies following a parent-mediated autism intervention	Carruthers, S.; Mleczko, N.; Page, S.; Ahuja, S.; Ellis, C.; Howlin, P.; Leadbitter, K.; Taylor, L.; Slonims, V.; Charman, T.	2023	Autism	27	4	1011-1025	10.1177/13623613221125630	Exclusion reason: 4b) Not quantitative measurement;
Relationship between stress levels and coping techniques in caregivers of children with autism spectrum disorder in Chile, 2021	Cerda-Aedo, B.	2024	Dementia e Neuropsychologia	18			10.1590/1980-5764-DN-2022-0112	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Autism: Diagnosis announcement and parents‚Äô experience	Ch√©rif, L.; Yaich, K.; Sahnoun, C.; Khemekhem, K.; Boudabbous, J.; HadjKacem, I.; Ayadi, H.; Moalla, Y.	2021	Annales Medico-Psychologiques	179	10	907-911	10.1016/j.amp.2020.12.019	Exclusion reason: 1) Not published in English;
Comparison of maternal beliefs about causes of autism spectrum disorder and association with utilization of services and treatments	Chaidez, V.; Fernandez y Garcia, E.; Wang, L.W.; Angkustsiri, K.; Krakowiak, P.; Hertz-Picciotto, I.; Hansen, R.L.	2018	Child: Care, Health and Development	44	6	916-925	10.1111/cch.12612	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The autism diagnostic experiences of French parents	Chamak, Brigitte; Bonniau, Beatrice; Oudaya, Lila; Ehrenberg, Alain	2011	Autism	15	1	83-97	10.1177/1362361309354756	Exclusion reason: 3A) Not target population (not ASD);
Trait Mindfulness Attenuates the Adverse Psychological Impact of Stigma on Parents of Children with Autism Spectrum Disorder	Chan, Kevin Ka Shing; Lam, Chun Bun	2017	MINDFULNESS	8	4	984-994	10.1007/s12671-016-0675-9	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Do maternal attributions play a role in the acceptability of behavioural interventions for problem behaviour in children with autism spectrum disorders?	Choi, K.Y.K.; Kovshoff, H.	2013	Research in Autism Spectrum Disorders	7	8	984-996	10.1016/j.rasd.2013.04.010	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Who participates in support groups for parents of children with autism spectrum disorders? The role of beliefs and coping style	Clifford, Tessen; Minnes, Patricia	2013	Journal of Autism & Developmental Disorders	43	1	179-187	10.1007/s10803-012-1561-5	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Acceptance and Commitment Therapy-Oriented Parent-Training for Parents of Children with Autism	Corti, C.; Pergolizzi, F.; Vanzin, L.; Cargasacchi, G.; Villa, L.; Pozzi, M.; Molteni, M.	2018	Journal of Child and Family Studies	27	9	2887-2900	10.1007/s10826-018-1123-3	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parents‚Äô views and experiences of talking about autism with their children	Crane, L.; Jones, L.; Prosser, R.; Taghrizi, M.; Pellicano, E.	2019	Autism	23	8	1969-1981	10.1177/1362361319836257	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parents' experiences of caring for children with autism and attending a touch therapy programme	Cullen, L.; Barlow, J.	2002	Child Care in Practice	8	1	35-45	10.1080/13575270220140452	Exclusion reason: 4b) Not quantitative measurement;
Virtual Mindfulness Workshops for Parents of Children on the Autism Spectrum	Curl, E.L.; Hampton, L.H.	2024	Journal of Early Intervention	46	3	323-337	10.1177/10538151231169950	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parents' views of the national autistic society's earlybird plus programme	Cutress, A.L.; Muncer, S.J.	2014	Autism	18	6	651-657	10.1177/1362361313495718	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Coping strategies and stress in mothers of children with autism spectrum condition and ADHD during the COVID 19 pandemic	Cvitkovifá, D.M.; Sto≈°ifá, J.M.; Jakab, A.V.W.	2024	Specijalna Edukacija i Rehabilitacija	23	2	95-111	10.5937/specedreh23-47035	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effects of written disclosure on psychophysiological stress among parents of children with autism: A randomized controlled pilot study	Da Paz, N.S.; Wallander, J.L.; Tiemensma, J.	2018	Research in Autism Spectrum Disorders	53		42917.00	10.1016/j.rasd.2018.05.007	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parents taking action adapted to parents of Black autistic children: Pilot results	Dababnah, S.; Kim, I.; Maga√±a, S.; Zhu, Y.	2023	Journal of Policy and Practice in Intellectual Disabilities	20	1	18-32	10.1111/jppi.12423	Exclusion reason: 3A) Not target population (not ASD);
Characterizing Accommodations by Parents of Young Children with Autism: A Mixed Methods Analysis	Dai, Y.G.; Carter, A.S.	2022	Journal of Autism and Developmental Disorders				10.1007/s10803-022-05652-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Characterizing Accommodations by Parents of Young Children with Autism: A Mixed Methods Analysis	Dai, Yael G.; Carter, Alice S.	2023	Journal of Autism & Developmental Disorders	53	9	3380-3393	10.1007/s10803-022-05652-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
From symptom recognition to diagnosis: children with autism in urban India	Daley, Tamara C.	2004	Social Science & Medicine	58	7	1323-1335		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parental Stress and Religious Coping by Mothers of Children With Autism	Davis, Richard F.; Kiang, Lisa	2020	PSYCHOLOGY OF RELIGION AND SPIRITUALITY	12	2	137-148	10.1037/rel0000183	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A comparative feasibility study of two parent education and training programmes for autism spectrum disorder in a low-resource South African setting	Dawson-Squibb, J.-J.; de Vries, P.J.	2020	Autism	24	8	2269-2284	10.1177/1362361320942988	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Teleconsultation, a promising technique for psychoeducational programs for parents of children with autism spectrum disorder	de Gaulmyn, A.; Boutteau, M.; Doyen, C.; Rousseau, M.; McKinnon, S.; Bourassa, J.; Cappe, E.	2024	Annales Medico-Psychologiques				10.1016/j.amp.2024.04.005	Exclusion reason: 1) Not published in English;
An ecological exploration of individual, family, and environmental contributions to parental quality of life in autism	Derguy, C.; Roux, S.; Portex, M.; M'bailara, K.	2018	Psychiatry Research	268		87-93	10.1016/j.psychres.2018.07.006	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Parental Attunement, Insightfulness, and Acceptance of Child Diagnosis in Parents of Children With Autism: Clinical Implications	Di Renzo, M.; Guerriero, V.; Zavattini, G.C.; Petrillo, M.; Racinaro, L.; Bianchi di Castelbianco, F.	2020	Frontiers in Psychology	11			10.3389/fpsyg.2020.01849	Exclusion reason: 3A) Not target population (not ASD);
Living with children diagnosed with autistic spectrum disorder: parental and professional views	Dillenburger, K.; Keenan, M.; Doherty, A.; Byrne, T.; Gallagher, S.	2010	British Journal of Special Education	37	1	13-23	10.1111/j.1467-8578.2010.00455.x	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Investigation of the relationship between the sense of coherence and the level of depression in mothers of children with autism	Durankus, Ferit; Erdogan, Firat; Durankus, Ramazan; Gulek, Ayse; Bas, Raif Kaan; Albayrak, Yakup; Yilmaz, Kubra	2024	International Journal of Developmental Neuroscience	84	6	605-610	10.1002/jdn.10359	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Factors impacting parental quality of life in preschool children on the autism spectrum	Eapen, Valsamma; Islam, Raisa; Azim, Syeda Ishra; Masi, Anne; Klein, Louis; Karlov, Lisa	2024	Journal of Autism and Developmental Disorders	54	3	943-954	10.1007/s10803-022-05848-w	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parent stress and coping trajectories in Hispanic and non-Hispanic families of children at risk of autism spectrum disorder	Ej, Hickey; M, Stransky; J, Kuhn; Je, Rosenberg; Hj, Cabral; C, Weitzman; S, Broder-Fingert; E, Feinberg	1694	Autism	25	6	1694-1708	10.1177/13623613211001611	Exclusion reason: 3A) Not target population (not ASD);
Religiosity, spirituality, and socioemotional functioning in mothers of 1children with autism spectrum disorder	Ekas, N.V.; Whitman, T.L.; Shivers, C.	2009	Journal of Autism and Developmental Disorders	39	5	706-719	10.1007/s10803-008-0673-4	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Hope, social relations, and depressive symptoms in mothers of children with autism spectrum disorder	Ekas, Naomi V.; Pruitt, Megan M.; McKay, Erin	2016	RESEARCH IN AUTISM SPECTRUM DISORDERS	29-30		43313.00	10.1016/j.rasd.2016.05.006	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Evaluation of a support group for fathers of children with autism spectrum disorder	Elfert, Miriam; Mirenda, Pat	2015	Canadian Journal of Counselling and Psychotherapy	49	2	115-138		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parental stress and dyadic adjustment among parents of children with ASD: Moderating effects of dyadic coping and perceived social support	Fallahchai, R.; Fallahi, M.	2022	Research in Developmental Disabilities	123			10.1016/j.ridd.2022.104192	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Self-efficacy as a mediator between involvement in intervention and quality of life in parents of children and adolescents with autism spectrum disorder	Fante, C.; Zagaria, A.; Dioni, B.; Raffin, C.; Capelli, F.; Manari, T.; Lenzo, V.; De Luca Picione, R.; Musetti, A.	2024	Research in Autism Spectrum Disorders	113			10.1016/j.rasd.2024.102351	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder	Faso, Daniel J.; Neal-Beevers, A. Rebecca; Carlson, Caryn L.	2013	RESEARCH IN AUTISM SPECTRUM DISORDERS	7	2	288-297	10.1016/j.rasd.2012.08.014	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Efficacy and Implementation of Stress-Reduction Interventions for Underserved Families of Autistic Preschoolers Across In-Person and Virtual Modalities	Fenning, R.M.; Neece, C.L.; Sanner, C.M.; Morrell, H.E.R.	2023	Mindfulness				10.1007/s12671-023-02250-0	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Family Functioning and Emotional Aspects of Children with Autism Spectrum Disorder in Southern Brazil	Flenik, T.M.N.; Bara, T.S.; Cordeiro, M.L.	2023	Journal of Autism and Developmental Disorders	53	6	2306-2313	10.1007/s10803-022-05497-z	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A preliminary exploration of different coping strategies used by Korean immigrant parents of autistic children in high versus low family quality of life ratings	Fong, V.C.; Shim, J.; Yoon, A.; Lee, B.S.; Iarocci, G.	2023	Autism	27	5	1307-1319	10.1177/13623613221133961	Exclusion reason: 4b) Not quantitative measurement;
"We are exhausted, worn out, and broken": Understanding the impact of service satisfaction on caregiver well-being	Fong, VC; Mclaughlin, J; Schneider, M	2023	AUTISM RESEARCH	16	11	2198-2207	10.1002/aur.3024	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Multilevel approach to gender differences in adaptation in father-mother dyads parenting individuals with Autism Spectrum Disorder	Garc√≠a-L√≥pez, C.; Sarri√°, E.; Pozo, P.	2016	Research in Autism Spectrum Disorders	28		42552.00	10.1016/j.rasd.2016.04.003	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Supportive Dyadic Coping and Psychological Adaptation in Couples Parenting Children with Autism Spectrum Disorder: The Role of Relationship Satisfaction	Garc√≠a-L√≥pez, C.; Sarri√°, E.; Pozo, P.; Recio, P.	2016	Journal of Autism and Developmental Disorders	46	11	3434-3447	10.1007/s10803-016-2883-5	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parental adjustment, marital relationship, and family function in families of children with autism	Gau, S.S.-F.; Chou, M.-C.; Chiang, H.-L.; Lee, J.-C.; Wong, C.-C.; Chou, W.-J.; Wu, Y.-Y.	2012	Research in Autism Spectrum Disorders	6	1	263-270	10.1016/j.rasd.2011.05.007	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coming to understand the child has autism: A process illustrating parents' evolving readiness for engaging in care	Gentles, Stephen J.; Nicholas, David B.; Jack, Susan M.; McKibbon, K. Ann; Szatmari, Peter	2020	Autism	24	2	470-483	10.1177/1362361319874647	Exclusion reason: 4b) Not quantitative measurement;
Parents of Autistic Children: Some Thoughts about Trauma, Dislocation, and Tragedy	Gombosi, P.G.	1998	Psychoanalytic Study of the Child	53		254-275	10.1080/00797308.1998.11822486	Exclusion reason: 2c) Review paper;

Dyadic coping and inflammation in the context of chronic stress	Gouin, J.-P.; Scarcello, S.; da Estrela, C.; Paquin, C.; Barker, E.T.	2016	Health Psychology	35	10	1081-1084	10.1037/hea0000395	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Evaluating the effects of Acceptance and Commitment Training on the overt behavior of parents of children with autism	Gould, E.R.; Tarbox, J.; Coyne, L.	2018	Journal of Contextual Behavioral Science	7		81-88	10.1016/j.jcbs.2017.06.003	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Resilience in families with an autistic child	Greeff, A.P.; Van Der Walt, K.-J.	2010	Education and Training in Autism and Developmental Disabilities	45	3	347-355		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Predictors of Change in Wellbeing and Mental Health of Parents of Autistic Pre-Schoolers	Green, CC; Smith, J; Bent, CA; Chetcuti, L; Uljarevic, M; Benson, PR; Hudry, K	2024	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS				10.1007/s10803-024-06471-7	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Using matched groups to explore child behavior problems and maternal well-being in children with down syndrome and autism	Griffith, G.M.; Hastings, R.P.; Nash, S.; Hill, C.	2010	Journal of Autism and Developmental Disorders	40	5	610-619	10.1007/s10803-009-0906-1	Exclusion reason: 3A) Not target population (not ASD);
Vaccine Hesitancy in the Autism Spectrum Disorder Context: Parental Vaccine Decision-Making and Coping with Stress Strategies	Gulle, Bugra Taygun; Yassibas, Ugur; Sarigedik, Enes	2024	Journal of Autism & Developmental Disorders	1			10.1007/s10803-024-06508-x	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Randomized controlled trial of a brief acceptance and commitment training for parents of individuals diagnosed with autism spectrum disorders	Hahs, A.D.; Dixon, M.R.; Paliliunas, D.	2019	Journal of Contextual Behavioral Science	12		154-159	10.1016/j.jcbs.2018.03.002	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Setting Families Up for Success: A Pilot Study of a Toolkit to Enhance the Autism Spectrum Disorder Diagnostic Evaluation Process	Haine-Schlagel, R.; Corsello, C.; Caplan, B.; Gould, H.; Brookman-Frazee, L.	2022	Journal of Autism and Developmental Disorders				10.1007/s10803-022-05601-3	Exclusion reason: 4b) Not quantitative measurement;
Families of children with autism: behaviors of children, community support and coping	Hall, Heather R.	2012	Issues in Comprehensive Pediatric Nursing	35	2	111-132	10.3109/01460862.2012.678263	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Perceived Social Support, Normalization, and Subjective Well-Being Among Family Members of a Child with Autism Spectrum Disorder	Hamama, Liat	2023	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS				10.1007/s10803-022-05857-9	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Perceived Social Support, Normalization, and Subjective Well-Being Among Family Members of a Child with Autism Spectrum Disorder	Hamama, Liat	2024	Journal of Autism & Developmental Disorders	54	4	1468-1481	10.1007/s10803-022-05857-9	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Caregiver Burden Varies by Sensory Subtypes and Sensory Dimension Scores of Children with Autism	Hand, Brittany N.; Lane, Alison E.; De Boeck, Paul; Basso, D. Michele; Nichols-Larsen, Deborah S.; Darragh, Amy R.	2018	Journal of Autism & Developmental Disorders	48	4	1133-1146	10.1007/s10803-017-3348-1	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Autism spectrum disorder in Latin American families: Experiences in Chile	Hartmann, Kathrin; Kozikowski, C. Teal; Urbano, Maria R.; Williams, Takeshia V.; Ba, Caroline Luong-Tran; Peterkin, Alexander	2018	Families, Systems, & Health	36	2	169-174	10.1037/fsh0000340	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism	Hastings, R. P.; Kovshoff, H.; Ward, N. J.; Espinosa, F. D.; Brown, T.; Remington, B.	2005	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS	35	5	635-644	10.1007/s10803-005-0007-8	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping strategies in mothers and fathers of preschool and school-age children with autism	Hastings, Richard P.; Kovshoff, Hanna; Brown, Tony; Ward, Nicholas J.; Espinosa, Francesca Degli; Remington, Bob	2005	Autism	9	4	377-391		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
'I bring her up with love:' Perspectives of caregivers of children with neurodevelopmental delays in western Kenya	Heng, Yi Yan; Nafiseh, Amira; Oyungu, Eren; Ombitsa, Ananda Roselyne; Cherop, Carolyne; McHenry, Megan S.	2023	CHILD CARE HEALTH AND DEVELOPMENT	49	1	201-209	10.1111/cch.13033	Exclusion reason: 3A) Not target population (not ASD);
Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice	Hennel, S.; Coates, C.; Symeonides, C.; Gulenc, A.; Smith, L.; Price, A.M.H.; Hiscock, H.	2016	Journal of Paediatrics and Child Health	52	5	506-511	10.1111/jpc.13157	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Pilot evaluation of the frankfurt social skills training for children and adolescents with autism spectrum disorder	Herbrecht, E.; Poustka, F.; Birnkammer, S.; Duketis, E.; Schlitt, S.; Schm√∂tzer, G.; B√∂lte, S.	2009	European Child and Adolescent Psychiatry	18	6	327-335	10.1007/s00787-008-0734-4	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Siblings of children with autism: Predictors of adjustment	Hesse, T.L.; Danko, C.M.; Budd, K.S.	2013	Research in Autism Spectrum Disorders	7	11	1323-1331	10.1016/j.rasd.2013.07.024	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Parent stress and coping trajectories in Hispanic and non-Hispanic families of children at risk of autism spectrum disorder	Hickey, Emily J.; Stransky, Michelle; Kuhn, Jocelyn; Rosenberg, Jessica E.; Cabral, Howard J.; Weitzman, Carol; Broder-Fingert, Sarabeth; Feinberg, Emily	2021	AUTISM	25	6	1694-1708	10.1177/13623613211001611	Exclusion reason: 3A) Not target population (not ASD);
Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder	Higgins, Daryl J.; Bailey, Susan R.; Pearce, Julian C.	2005	Autism	9	2	125-137		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Adaptation of Parents Raising a Child with ASD: The Role of Positive Perceptions, Coping, Self-efficacy, and Social Support	Higgins, L.; Mannion, A.; Chen, J.L.; Leader, G.	2023	Journal of Autism and Developmental Disorders	53	3	1224-1242	10.1007/s10803-022-05537-8	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Acceptance and Commitment Therapy Group Intervention for Parents of Children with Disabilities (Navigator ACT): An Open Feasibility Trial	Holmberg Bergman, T.; Renhorn, E.; Berg, B.; Lappalainen, P.; Ghaderi, A.; Hirvikoski, T.	2023	Journal of Autism and Developmental Disorders	53	5	1834-1849	10.1007/s10803-022-05490-6	Exclusion reason: 3A) Not target population (not ASD);
Mental Health in Mothers of Autistic Children with a Medical Home: The Potentially Mechanistic Roles of Coping and Social Support	Horan, Madeline R.; Latendresse, Shawn J.; Limbers, Christine A.	2024	Journal of Autism & Developmental Disorders	54	7	2682-2692	10.1007/s10803-023-05997-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mind the gap: An intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable	Iadarola, S.; Pellecchia, M.; Stahmer, A.; Lee, H.S.; Hauptman, L.; Hassrick, E.M.; Crabbe, S.; Vejnoska, S.; Morgan, E.; Nuske, H.; Luelmo, P.; Friedman, C.; Kasari, C.; Gulsrud, A.; Mandell, D.; Smith, T.	2020	Pilot and Feasibility Studies	6	1		10.1186/s40814-020-00662-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effectiveness of Online Parent Training for Vietnamese Parents of Children witAutism Spectrum Disorders	Inoue, M.; Yamaguchi, H.; Nakatani, K.; Nishimoto, A.; Namiki, K.; Kuroda, S.; Ha, T.T.V.; Thu, D.N.T.	2024	Yonago Acta Medica	67	3	213-224	10.33160/yam.2024.08.008	Exclusion reason: 3A) Not target population (not ASD);
Quality of Life Among Malaysian Parents with Autism Spectrum Disorder Child: The Double ABCX Model Approach	Ismail, Mohd Fahmi; Safii, Razitasham; Saimon, Rosalia; Rahman, Md Mizanur	2022	Journal of Autism & Developmental Disorders	52	1	113-123	10.1007/s10803-021-04929-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Examining the Efficacy of a Family Peer Advocate Model for Black and Hispanic Caregivers of Children with Autism Spectrum Disorder	Jamison, J.M.; Fourie, E.; Siper, P.M.; Trelles, M.P.; George-Jones, J.; Buxbaum Grice, A.; Krata, J.; Holl, E.; Shaoul, J.; Hernandez, B.; Mitchell, L.; McKay, M.M.; Buxbaum, J.D.; Kolevzon, A.	2017	Journal of Autism and Developmental Disorders	47	5	1314-1322	10.1007/s10803-017-3045-0	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Feedback from parents and carers attending the 'adjusting to the diagnosis of autism spectrum disorder' workshop	Jones, J.; Milne, J.; Coatham, S.; Wilkinson, A.	2017	Clinical Psychology Forum		292	19-23		Exclusion reason: 2b) Full text not accessible;
A mindfulness parent well-being course: evaluation of outcomes for parents of children with autism and related disabilities recruited through special schools	Jones, L.; Gold, E.; Totsika, V.; Hastings, R.P.; Jones, M.; Griffiths, A.; Silverton, S.	2018	European Journal of Special Needs Education	33	1	16-30	10.1080/08856257.2017.1297571	Exclusion reason: 3A) Not target population (not ASD);
Child behavior problems and parental well-being in families of children with autism: The mediating role of mindfulness and acceptance	Jones, L.; Hastings, R.P.; Totsika, V.; Keane, L.; Rhule, N.	2014	American Journal on Intellectual and Developmental Disabilities	119	2	171-185	10.1352/1944-7558-119.2.171	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Inclusion, Exclusion and Isolation of Autistic People: Community Attitudes and Autistic People‚Äôs Experiences	Jones, S.C.; Gordon, C.S.; Akram, M.; Murphy, N.; Sharkie, F.	2022	Journal of Autism and Developmental Disorders	52	3	1131-1142	10.1007/s10803-021-04998-7	Exclusion reason: 3B) Not target population (not caregivers);
The development, feasibility and acceptability of Empower-Autism: a new psychoeducational and psychotherapeutic programme for caregivers of children recently diagnosed with autism	K, Leadbitter; L, Harrison; S, Langhorne; C, Ellis; R, Smallman; A, Pearson; L, Hackett; L, Kroll; A, Dunkerley; H, Beach; J, Gilbert; A, van Gils; T, Hutton; J, Green; P, Bee	2024	Autism					Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A Transdiagnostic Prevention Support Group for Caregivers of Children With Autism Spectrum Disorder: A Case Example	Kangavary, A.; Halliday, E.R.; Durocher, J.; Ehrenreich-May, J.	2023	Clinical Case Studies	22	5	484-500	10.1177/15346501231198889	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Comparison between mothers and fathers in coping with autistic children: A multivariate model	Kaniel, S.; Siman-Tov, A.	2011	European Journal of Special Needs Education	26	4	479-493	10.1080/08856257.2011.597186	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Resiliency and the subjective evaluation of health in mothers of children with Asperger's syndrome	Kasprzak, Arleta; Basinska, Malgorzata A.; Lewandowska, Paulina	2013	HEALTH PSYCHOLOGY REPORT	1	1	34-41	10.5114/hpr.2013.40467	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

A Virtual Resiliency Intervention for Parents of Children with Autism: A Randomized Pilot Trial	Kuhlthau, K.A.; Luberto, C.M.; Traeger, L.; Millstein, R.A.; Perez, G.K.; Lindly, O.J.; Chad-Friedman, E.; Proszynski, J.; Park, E.R.	2020	Journal of Autism and Developmental Disorders	50	7	2513-2526	10.1007/s10803-019-03976-4	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Emotional availability in the mother-child relationship for families of young children with autism spectrum disorder in Australia: A cross-sectional survey	Kulasinghe, K.; Whittingham, K.; Mitchell, A.E.	2022	Research in Developmental Disabilities	131			10.1016/j.ridd.2022.104365	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mental health, broad autism phenotype and psychological inflexibility in mothers of young children with autism spectrum disorder in Australia: A cross-sectional survey	Kulasinghe, K.; Whittingham, K.; Mitchell, A.E.	2021	Autism	25	5	1187-1202	10.1177/1362361320984625	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Families With Children Diagnosed With Autism Implications for Counselors	Kurz, Isanely Guerrero	2018	FAMILY JOURNAL	26	4	455-461	10.1177/1066480718796256	Exclusion reason: 2c) Review paper;
Coping and Well-Being in Parents of Children with Autism Spectrum Disorders (ASD)	Lai, Wei Wei; Goh, Tze Jui; Oei, Tian P. S.; Sung, Min	2015	Journal of Autism & Developmental Disorders	45	8	2582-2593	10.1007/s10803-015-2430-9	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The experiences of family caregiver and clinician facilitators implementing a co-delivered acceptance and commitment training (ACT) intervention	Lake, J; Fung, KPL; Steel, L; Magnacca, C; Cardiff, K; Thomson, K; Bobbette, N; Redquest, B; Bailey, S; Lunsky, Y	2024	JOURNAL OF CONTEXTUAL BEHAVIORAL SCIENCE	33			10.1016/j.jcbs.2024.100780	Exclusion reason: 4b) Not quantitative measurement;
"The stress can be unbearable, but the good times are like finding gold": A phase one modelling survey to inform the development of a self-help positive reappraisal coping intervention for caregivers of those with autism spectrum disorder	Lancastle, Deborah; Hill, Joanna; Faulkner, Susan; Cousins, Alecia L.	2022	PLoS ONE [Electronic Resource]	17	3	e0264837	10.1371/journal.pone.0264837	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Predictors of Satisfaction with Life in Parents of Children with Autism Spectrum Disorder	Landon, Jason; Shepherd, Daniel; Goedeke, Sonja	2018	Journal of Autism & Developmental Disorders	48	5	1640-1650	10.1007/s10803-017-3423-7	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Adaptation and feasibility of the Mandarin version of PEERS for autistic adolescents	Lao, Uchong; Li, Yan; Bai, Wuxia; Wang, Yu; Li, Yongmei; Xie, Yixiang; Huang, Xiaoqian; Zhu, Huilin; Zou, Xiaobing	2024	Journal of Autism and Developmental Disorders	54	9	3387-3399	10.1007/s10803-023-06056-w	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Assessment of Acceptability, Usage, and Impact on Caregivers of Children With Autism's Stress and Mindfulness: Multiple-Method Feasibility Study of the 5Minutes4Myself App's Mindfulness Module	Larson, Elizabeth; Mattie, Rebecca L.; Riffkin, Sophia A.	2024	JMIR Human Factors	1		e54171	10.2196/54171	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The Autism Family Experience Questionnaire (AFEQ): An Ecologically-Valid, Parent-Nominated Measure of Family Experience, Quality of Life and Prioritised Outcomes for Early Intervention	Leadbitter, Kathy; Aldred, Catherine; McConachie, Helen; Le Couteur, Ann; Kapadia, Dharmi; Charman, Tony; Macdonald, Wendy; Salomone, Erica; Emsley, Richard; Green, Jonathan	2018	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS	48	4	1052-1062	10.1007/s10803-017-3350-7	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parents of children with high functioning autism: How well do they cope and adjust?	Lee, G.K.	2009	Journal of Developmental and Physical Disabilities	21	2	93-114	10.1007/s10882-008-9128-2	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Needs, strain, coping, and mental health among caregivers of individuals with autism spectrum disorder: A moderated mediation analysis	Lee, Gloria K.; Krizova, Katarina; Shivers, Carolyn M.	2019	Autism	23	8	1936-1947	10.1177/1362361319833678	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Health-Related Quality of Life of Parents of Children With High-Functioning Autism Spectrum Disorders	Lee, Gloria K.; Lopata, Christopher; Volker, Martin A.; Thomeer, Marcus L.; Nida, Robert E.; Toomey, Jennifer A.; Chow, Sabrina Y.; Smerbeck, Audrey M.	2009	FOCUS ON AUTISM AND OTHER DEVELOPMENTAL DISABILITIES	24	4	227-239	10.1177/1088357609347371	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Factors that affect the physical and mental health of caregivers of school-age children and transitioning young adults with autism spectrum disorder	Lee, Gloria K.; Shivers, Carolyn M.	2019	Journal of Applied Research in Intellectual Disabilities	32	3	622-634	10.1111/jar.12556	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mobile App-Assisted Parent Training Intervention for Behavioral Problems in Children With Autism Spectrum Disorder: Pilot Randomized Controlled Trial	Lee, JooHyun; Lim, JaeHyun; Kang, Soyeon; Kim, Sujin; Jung, So Yoon; Kim, Sujin; Hong, Soon-Beom; Park, Yu Rang	2024	JMIR Human Factors	1		e52295	10.2196/52295	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Emotionally Focused Couple Therapy for Parents Raising a Child with an Autism Spectrum Disorder: A Pilot Study	Lee, Nicholas A.; Furrow, James L.; Bradley, Brent A.	2017	JOURNAL OF MARITAL AND FAMILY THERAPY	43	4	662-673	10.1111/jmft.12225	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Social support and family quality of life in Chinese families of children with autism spectrum disorder: the mediating role of family cohesion and adaptability	Lei, X.; Kantor, J.	2022	International Journal of Developmental Disabilities	68	4	454-461	10.1080/20473869.2020.1803706	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Study on Family Cohesion and Adaptability of Caregivers of Children with ASD and Its Influencing Factors	Lei, Xianmei; Kantor, Jiri	2020	SOCIAL PSYCHOLOGY AND SOCIETY	11	3	70-85	10.17759/sps.2020110305	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The creator did not give me more than I can handle: Exploring coping in parents of Black autistic children	Lewis, Ericka M.; Dababnah, Sarah; Hollie, Kelley R.; Kim, Irang; Wang, Yao; Shaia, Wendy E.	2022	Autism	26	8	2015-2025	10.1177/13623613211070865	Exclusion reason: 4b) Not quantitative measurement;
Psychometric Properties of the Chinese Version of the Psy-Flex Among Parents of Children with Autism Spectrum Disorder	Li, S.N.; Chien, W.T.; Lam, S.K.K.; Chong, Y.Y.; Gloster, A.T.	2024	Journal of Autism and Developmental Disorders				10.1007/s10803-024-06610-0	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Child Behavioral Problems and Parental Adjustment: Family, Interparental, and Parent-Child Processes as Simultaneous Mediators	Li, XM; Lam, CB; Chung, KKH	2024	AMERICAN JOURNAL OF ORTHOPSYCHIATRY				10.1037/ort0000757	Exclusion reason: 3A) Not target population (not ASD);
Self-compassion, mental health, and parenting: Comparing parents of autistic and non-autistic children	Liang, Kaixin; Lai Lam, Kelly Ka; Huang, Liuyue; Lin, Xiuyun; Wang, Zhiyong; Liu, Honghai; Chi, Peilian	2024	Autism	1		########	10.1177/13623613241286683	Exclusion reason: 3A) Not target population (not ASD);
Feeling Good, Feeling Bad: Influences of Maternal Perceptions of the Child and Marital Adjustment on Well-being in Mothers of Children with an Autism Spectrum Disorder	Lickenbrock, Diane M.; Ekas, Naomi V.; Whitman, Thomas L.	2011	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS	41	7	848-858	10.1007/s10803-010-1105-9	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parenting stress in autism: Do children's characteristics still count more than stressors related to the COVID-19 pandemic?	Lievore, Rachele; Lanfranchi, Silvia; Mammarella, Irene C.	2024	Current Psychology: A Journal for Diverse Perspectives on Diverse Psychological Issues	43	3	2607-2617	10.1007/s12144-023-04441-3	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Moderating effect of child's autism spectrum disorder (ASD) diagnosis on benefit finding and negative affect of parents	Lim, Kit Kwan; Chong, Wan Har	2017	American Journal of Orthopsychiatry	87	3	357-364	10.1037/ort0000251	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

The efficacy of wechat-based parenting training on the psychological well-being of mothers with children with autism during the COVID-19 pandemic: Quasi-experimental study	Liu, G.; Wang, S.; Liao, J.; Ou, P.; Huang, L.; Xie, N.; He, Y.; Lin, J.; He, H.-G.; Hu, R.	2021	JMIR Mental Health	8	2		10.2196/23917	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parenting confidence and social support as predictors of coping strategies in parents of children newly diagnosed with autism spectrum disorder: A cross-sectional study	Liu, Shaofei; Deng, Tao; Chen, Miaoying; Ji, Yan; Dai, Yushen; Zhang, Tao; Zhang, Lifeng	2023	Journal of Advanced Nursing	79	10	3946-3955	10.1111/jan.15708	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Using a blended format (videoconference and face to face) to deliver a group psychosocial intervention to parents of autistic children	Lodder, Annemarie; Papadopoulos, Chris; Randhawa, Gurch	2020	INTERNET INTERVENTIONS-THE APPLICATION OF INFORMATION TECHNOLOGY IN MENTAL AND BEHAVIOURAL HEALTH	21		########	10.1016/j.invent.2020.100336	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The Impact of Parental Stress among the Qualitof Life of mothers of children with Autism Spectrum Disorder and Down Syndrome	Loux, A.	2023	International Journal of Special Education	38	3	95-106	10.52291/ijse.2023.38.42	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Social support mediates the relationship between dispositional gratitude and psychological distress in caregivers of autistic children	Lovell, B.; Wetherell, M.A.	2023	Psychology, Health and Medicine				10.1080/13548506.2022.2162939	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Acceptability of a Virtual Mind‚ÄìBody Intervention for Parents of Children With Autism or Learning Disabilities	Luberto, C.M.; Perez, G.K.; Finkelstein-Fox, L.; Millstein, R.A.; Fell, L.; Chad-Friedman, E.; Park, E.R.; Kuhlthau, K.A.	2021	Global Advances In Health and Medicine	10			10.1177/21649561211047804	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Evaluation of Acceptance and Commitment Therapy (ACT) for Mothers of Children and Youth with Autism SpectrumDisorder	Lunsky, Y.; Fung, K.; Lake, J.; Steel, L.; Bryce, K.	2018	Mindfulness	9	4	1110-1116	10.1007/s12671-017-0846-3	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The role of coping strategies and self-efficacy as predictors of life satisfaction in a sample of parents of children with autism spectrum disorder	Luque Salas, Barbara; Yanez Rodriguez, Virginia; Tabernero Urbieta, Carmen; Cuadrado, Esther	2017	Psicothema	29	1	55-60	10.7334/psicothema2016.96	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping and social support for parents of children with autism	Luther, Edith H.; Canham, Daryl L.; Young Cureton, Virginia	2005	Journal of School Nursing	21	1	40-47		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Parents Taking Action: A Psycho-Educational Intervention for Latino Parents of Children With Autism Spectrum Disorder	Maga√±a, S.; Lopez, K.; Machalicek, W.	2017	Family Process	56	1	59-74	10.1111/famp.12169	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Psychological distress and well-being of Latina and non-Latina White mothers of youth and adults with an autism spectrum disorder: cultural attitudes towards coresidence status	Magana, Sandra; Smith, Matthew J.	2006	American Journal of Orthopsychiatry	76	3	346-357	10.1037/0002-9432.76.3.346	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Sense of coherence, parenting attitudes and stress among mothers of children with autism in Hong Kong	Mak, W.W.S.; Ho, A.H.Y.; Law, R.W.	2007	Journal of Applied Research in Intellectual Disabilities	20	2	157-167	10.1111/j.1468-3148.2006.00315.x	Exclusion reason: 3A) Not target population (not ASD);
Who joins support groups among parents of children with autism?	Mandell, D.S.; Salzer, M.S.	2007	Autism	11	2	111-122	10.1177/1362361307077506	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The Double ABCX Model of Adaptation in Racially Diverse Families with a School-Age Child with Autism	Manning, Margaret M.; Wainwright, Laurel; Bennett, Jillian	2011	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS	41	3	320-331	10.1007/s10803-010-1056-1	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Brief Parent-Mediated Intervention for Children with Autism Spectrum Disorder: A Feasibility Study from South India	Manohar, H.; Kandasamy, P.; Chandrasekaran, V.; Rajkumar, R.P.	2019	Journal of Autism and Developmental Disorders	49	8	3146-3158	10.1007/s10803-019-04032-x	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Self-forgiveness, Guilt, Shame, and Parental Stress among Parents of Children with Autism Spectrum Disorder	Marcinechov√°, D.; Z√°horcov√°, L.; Lohazerov√°, K.	2023	Current Psychology				10.1007/s12144-023-04476-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Self-forgiveness, guilt, shame, and parental stress among parents of children with autism spectrum disorder	Marcinechova, Denisa; Zahorcova, Lucia; Lohazerova, Katarina	2024	Current Psychology: A Journal for Diverse Perspectives on Diverse Psychological Issues	43	3	2277-2292	10.1007/s12144-023-04476-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The effect of acceptance and commitment therapy for improving psychological well‚Äêbeing in parents of individuals with autism spectrum disorders: A randomized controlled trial	Marino, F.; Failla, C.; Chil√†, P.; Minutoli, R.; Puglisi, A.; Arnao, A.A.; Pignolo, L.; Presti, G.; Pergolizzi, F.; Moderato, P.; Tartarisco, G.; Ruta, L.; Vagni, D.; Cerasa, A.; Pioggia, G.	2021	Brain Sciences	11	7		10.3390/brainsci11070880	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

The ‚Äúmourning instead‚Äù: sensory differences and autistics‚Äô social trauma	Marinoudi, S.	2022	Greek Review of Social Research	159		33-56		Exclusion reason: 1) Not published in English;
Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden	Marsack-Topolewski, C.N.; Samuel, P.S.; Tarraf, W.	2021	PLoS ONE	16		1-Jan	10.1371/journal.pone.0244844	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Impact of Caregiver Burden on Quality of Life for Parents of Adult Children With Autism Spectrum Disorder	Marsack-Topolewski, Christina N.; Church, Heather L.	2019	American Journal on Intellectual & Developmental Disabilities	124	2	145-156	10.1352/1944-7558-124.2.145	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mediating Effects of Social Support on Quality of Life for Parents of Adults with Autism	Marsack, Christina N.; Samuel, Preethy S.	2017	Journal of Autism & Developmental Disorders	47	8	2378-2389	10.1007/s10803-017-3157-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parent, child, and family outcomes following Acceptance And Commitment Therapy for parents of autistic children: A randomized controlled trial	Maughan, A.L.; Lunsky, Y.; Lake, J.; Mills, J.S.; Fung, K.; Steel, L.; Weiss, J.A.	2023	Autism				10.1177/13623613231172241	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Fathers Raising Children on the Autism Spectrum: Lower Stress and Higher Self-Efficacy Following SMS (Text2dads) Intervention	May, Chris D.; St George, Jennifer M.; Lane, Shelly	2022	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS	52	1	306-315	10.1007/s10803-021-04925-w	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Modeling Relations among Coparenting Quality, Autism-Specific Parenting Self-Efficacy, and Parenting Stress in Mothers and Fathers of Children with ASD	May, Chris; Fletcher, Richard; Dempsey, Ian; Newman, Louise	2015	PARENTING-SCIENCE AND PRACTICE	15	2	119-133	10.1080/15295192.2015.1020145	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Quality of Life, Coping Styles, Stress Levels, and Time Use in Mothers of Children with Autism Spectrum Disorders: Comparing Single Versus Coupled Households	McAuliffe, T.; Cordier, R.; Vaz, S.; Thomas, Y.; Falkmer, T.	2017	Journal of Autism and Developmental Disorders	47	10	3189-3203	10.1007/s10803-017-3240-z	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The impact of mutual support on Iranian parents of children with an autism spectrum disorder: a longitudinal study	McConkey, Roy; Samadi, Sayyed Ali	2013	Disability & Rehabilitation	35	9	775-784	10.3109/09638288.2012.707744	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Caregiver stress during the first year after diagnosis of an Autism Spectrum Disorder	McGrew, J.H.; Keyes, M.L.	2014	Research in Autism Spectrum Disorders	8	10	1373-1385	10.1016/j.rasd.2014.07.011	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Examining the utilisation and usefulness of social support for mothers with young children with autism spectrum disorder	McIntyre, Laura Lee; Brown, Mallory	2018	Journal of Intellectual & Developmental Disability	43	1	93-101	10.3109/13668250.2016.1262534	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

The Family Adjustment Measure: Identifying Stress in Parents of Youth with Autism	McKee, S.L.; Liu, X.; Truong, D.M.; Meinert, A.C.; Daire, A.P.; Mire, S.S.	2020	Journal of Child and Family Studies	29	2	592-604	10.1007/s10826-019-01569-4	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
SAFE, a new therapeutic intervention for families of children with autism: A randomised controlled feasibility trial	McKenzie, R.; Dallos, R.; Stedmon, J.; Hancocks, H.; Vickery, P.J.; Barton, A.; Vassallo, T.; Myhill, C.; Chynoweth, J.; Ewings, P.	2020	BMJ Open	10	12		10.1136/bmjopen-2020-038411	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Predicting Internalizing and Externalizing Symptoms in Children with ASD: Evaluation of a Contextual Model of Parental Factors	McRae, E.M.; Stoppelbein, L.; O,ÄôKelley, S.E.; Fite, P.; Greening, L.	2018	Journal of Autism and Developmental Disorders	48	4	1261-1271	10.1007/s10803-017-3368-x	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model	McStay, Rebecca L.; Trembath, David; Dissanayake, Cheryl	2014	Journal of Autism and Developmental Disorders	44	12	3101-3118	10.1007/s10803-014-2178-7	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Family adaptation among parents of children on the autism spectrum without a comorbid intellectual disability: A test of the Double ABCX model	Meleady, Jane; Nearchou, Finiki; Bramham, Jessica; Carr, Alan	2020	RESEARCH IN AUTISM SPECTRUM DISORDERS	78		########	10.1016/j.rasd.2020.101637	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Association Between Neighborhood Support and Family Resilience in Households with Autistic Children	Menezes, Michelle; Soland, Jim; Mazurek, Micah O. O.	2023	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS				10.1007/s10803-023-05951-6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Exploring the profiles of children with autism spectrum disorder: association with family factors	Mira, √Å.; Berenguer, C.; Rosell√≥, B.; Baixauli, I.; Miranda, A.	2022	International Journal of Developmental Disabilities	68	1	14-24	10.1080/20473869.2019.1679459	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parent-to-Parent support perception and Parent-Child relationship in parents of children with special Needs: The mediating role of quality of life	Miray S√ºmer Dodur, H.; √áali≈ükan, B.	2024	Children and Youth Services Review	166			10.1016/j.childyouth.2024.107925	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Stress profiles for mothers and fathers of children with autism	Moes, D.; Koegel, R. L.; Schreibman, L.; Loos, L. M.	1992	Psychological Reports	1	3 Pt 2	1272-1274		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Psychological functioning and coping among mothers of children with autism: A population-based study	Montes, G.; Halterman, J.S.	2007	Pediatrics	119	5	e1040-e10	10.1542/peds.2006-2819	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Positive Family Intervention for Children with ASD: Impact on Parents' Cognitions and Stress	Mueller, Robert; Moskowitz, Lauren J.	2020	JOURNAL OF CHILD AND FAMILY STUDIES	29	12	3536-3551	10.1007/s10826-020-01830-1	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parental quality of life, child adjustment and adult attachment in parents of children and adolescents with Autism Spectrum Disorder	Musetti, A.; Zagaria, A.; Pezzi, M.; Fante, C.; Dioni, B.; Raffin, C.; Manari, T.; Lenzo, V.; De Luca Picione, R.	2024	Research in Developmental Disabilities	146			10.1016/j.ridd.2024.104684	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Development and Validation of the Participation Questionnaire for Preschoolers with Autism Spectrum Disorder: Structural Validity, Internal Consistency, and Construct Validity	Nakamura, T; Nagayama, H; Sasada, S	2024	PHYSICAL & OCCUPATIONAL THERAPY IN PEDIATRICS				10.1080/01942638.2024.2421856	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Self-Compassion and Well-Being in Parents of Children with Autism	Neff, K.D.; Faso, D.J.	2015	Mindfulness	6	4	938-947	10.1007/s12671-014-0359-2	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Exploring the Variables of the Psychological Well-Being of Mothers of Children with Autism Spectrum Disorder Through Self-Compassion and Psychological Hardiness	Nemati, Shahrooz; Shojaeian, Nazila; Bardel, Mohammad; Deetjen-Ruiz, Rukiya; Khani, Zahra; McHugh, Louise	2024	Journal of Autism & Developmental Disorders	54	10	3739-3744	10.1007/s10803-023-06077-5	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Autism Spectrum Disorder: The Parental Experience	Neupane, Kunta Gautam	2020	Journal of Psychosocial Nursing & Mental Health Services	58	2	14-19	10.3928/02793695-20191022-02	Exclusion reason: 2c) Review paper;
Caregiver strain and its predictors among parents of autistic children: a cross-sectional study	Nighat, A.; Ahmer, Z.; Ovais, M.; Athar, F.B.; Baig, L.A.	2024	Journal of Child and Adolescent Mental Health	34	1-Mar	70-82	10.2989/17280583.2023.2279637	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping Strategies in mothers of children with autism spectrum disorder and their relation to maternal stress and depression	Ntre, V.; Papanikolaou, Œö.; Amanaki, E.; Triantafyllou, K.; Tzavara, C.; Kolaitis, G.	2022	Psychiatrike = Psychiatriki	33	3	210-218	10.22365/jpsych.2022.068	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The effects of coping style, social support, and behavioral problems on the well-being of mothers of children with Autism Spectrum Disorders in Lebanon	Obeid, Rita; Daou, Nidal	2015	RESEARCH IN AUTISM SPECTRUM DISORDERS	10		59-70	10.1016/j.rasd.2014.11.003	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Are a Child's Autistic Traits, Behavioural Difficulties, Prosocial Behaviour and Temperament Predictors of Parental Self-Efficacy and Satisfaction? A Study on Parents of Autistic and Neurotypical Children Aged 7-11 Years	Omelanczuk, I; Pisula, E	2024	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS				10.1007/s10803-024-06517-w	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Cognitive behavior therapy for autistic adolescents, awareness and care for my autistic traits program: A multicenter randomized controlled trial	Oshima, Fumiyo; Mandy, William; Seto, Mikuko; Hongo, Minako; Tsuchiyagaito, Aki; Hirano, Yoshiyuki; Sutoh, Chihiro; Guan, Siqing; Nitta, Yusuke; Ozawa, Yoshihito; Kawasaki, Yohei; Ohtani, Toshiyuki; Masuya, Jiro; Takahashi, Noriko; Sato, Noriyuki; Nakamura, Shizuka; Nakagawa, Akiko; Shimizu, Eiji	2023	BMC Psychiatry	23	1		10.1186/s12888-023-05075-2	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment	Pakenham, K. I.; Samios, C.; Sofronoff, K.	2005	AUTISM	9	2	191-212	10.1177/1362361305049033	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Spirituality to build resilience in primary caregiver parents of children with autism spectrum disorders: a cross-country experiment	Pandya, S.P.	2018	International Journal of Developmental Disabilities	64	1	53-64	10.1080/20473869.2016.1222722	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Growing up with autism: challenges and opportunities of parenting young adult children with autism spectrum disorders	Parsi, Kayhan; Elster, Nanette	2012	Narrative Inquiry in Bioethics	2	3	207-211	10.1353/nib.2012.0058	Exclusion reason: 2c) Review paper;
Psychological mindedness as a mediator in the relationship between dysfunctional coping styles and depressive symptoms in caregivers of children with autism spectrum disorder	Ping Pang, Nicholas Tze; Masiran, Ruziana; Tan, Kit-Aun; Kassim, Aminah	2020	Perspectives in Psychiatric Care	56	3	649-656	10.1111/ppc.12481	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Cross-cultural adaptation and validation of the Autism Family Experience Questionnaire to an Indian context	Pinto, C.F.; Lakshmi, V.R.; Tiwari, S.	2023	International Journal of Developmental Disabilities				10.1080/20473869.2023.2280808	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Empowerment in Polish fathers of children with autism and Down syndrome: the role of social support and coping with stress - a preliminary report	Pisula, E.; Banasiak, A.	2020	Journal of Intellectual Disability Research	64	6	434-441	10.1111/jir.12681	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Sense of coherence and coping with stress among mothers and fathers of children with autism	Pisula, E.; Kossakowska, Z.	2010	Journal of Autism and Developmental Disorders	40	12	1485-1494	10.1007/s10803-010-1001-3	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome	Pisula, Ewa; Porebowicz-Dorsmann, Anna	2017	PLoS ONE	12	10	e0186536	10.1371/journal.pone.0186536	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parent adjustment and family stress as factors in behavioral parent training for young autistic children	Plienis, A.J.; Robbins, F.R.; Dunlap, G.	1988	Journal of the Multihandicapped Person	1	1	31-52	10.1007/BF01110554	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Quality of life of mothers of children with autism spectrum disorder attending special classes in primary or secondary education	Poirier, N.; Belzil, A.; Cappe, √â.	2018	Journal de Therapie Comportementale et Cognitive	28	3	141-151	10.1016/j.jtcc.2018.06.006	Exclusion reason: 1) Not published in English;
Economic impacts of the COVID-19 pandemic on families of children with autism and other developmental disabilities	Pokoski, Olivia M.; Crain, Hayley; DiGuiseppi, Carolyn; Furnier, Sarah M.; Moody, Eric J.; Nadler, Cy; Pazol, Karen; Sanders, Jessica; Wiggins, Lisa D.; Durkin, Maureen S.	2024	Frontiers in psychiatry Frontiers Research Foundation	1		########	10.3389/fpsyt.2024.1342504	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Music therapy for children and adolescents with behavioural and emotional problems: a randomised controlled trial	Porter, S.; McConnell, T.; McLaughlin, K.; Lynn, F.; Cardwell, C.; Braiden, H.-J.; Boylan, J.; Holmes, V.; Rogan, S.; Clinician, L.; Diamond, K.; Allen, J.; Reilly, C.; Davidson, F.; McDowell, C.; Boyd, R.; Oldfield, A.; Mullowney, M.; Downes, C.; Jack, K.; Cresswell, M.; Wilson, J.; Gardner, C.; Patterson, F.; Gboloo-Teye, D.; McClatchey, L.; Gribbon, M.; Kamat, M.; Kehoe, A.; Slack, T.; Welsh, J.; Nelson, J.; Lawlor, K.; McKenna, A.; O'Rawe, A.; Rowan, V.; Sharvin, M.; Bann, B.; McQuillan, M.; Spratt, A.; Gill, P.; Rankin, G.; Lehmann, K.; Boyd, H.; Kierans, A.; Carney, J.; Haridas, M.; Cormack, E.; Morrow, A.; Browne, H.; McShane, C.; Hurley, S.; McGurgan, M.; O'Neill, S.; Campbell, M.; Corrigan, N.; Maxwell, L.; Fitzsimmons, L.; McMahon, E.; McGibbon, A.; Short, M.; Cummings, J.; McGuire, C.; Fulton, K.; McKenna, S.; Mercer, F.; Mullin, A.; Heale, A.	2017	Journal of Child Psychology and Psychiatry and Allied Disciplines	58	5	586-594	10.1111/jcpp.12656	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Still stressed but feeling better: Well-being in autism spectrum disorder families as children become adults	Pozo, P.; Sarri√°, E.	2015	Autism	19	7	805-813	10.1177/1362361315583191	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Prediction of stress in mothers of children with autism spectrum disorders	Pozo, P.; Sarri√°, E.	2014	Spanish Journal of Psychology	17	2		10.1017/sjp.2014.6	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Family quality of life and psychological well-being in parents of children with autism spectrum disorders: a double ABCX model	Pozo, P.; Sarria, E.; Brioso, A.	2014	Journal of Intellectual Disability Research	58	5	442-458	10.1111/jir.12042	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Use and Benefit of Dyadic Coping for Couple Relationship Satisfaction in Parents of Children with Autism	Putney, Jennifer M.; Greenlee, Jessica L.; Hartley, Sigan L.	2021	Family Process	60	4	1331-1346	10.1111/famp.12617	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effectiveness of on-line and off-line Acceptance and Commitment Therapy in developing psychological flexibility, self-compassion and ego-resiliency in parents of children with autism spectrum disorder	Pyszkowska, A.; G√≥rnik-Durose, M.E.	2023	Polish Psychological Bulletin	54	2	156-167	10.24425/ppb.2023.146587	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Self-stigma and cognitive fusion in parents of children with autism spectrum disorder. The moderating role of self-compassion	Pyszkowska, A.; Roznawski, K.; Farny, Z.	2021	PeerJ	9			10.7717/peerj.12591	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A parent-to-parent approach to strengthening family relationships after a child is diagnosed with autism spectrum disorder	R, Hock; N, Nelson; A, Shacklock; M, Yingling	2016	Journal of intellectual disability research	60	7-Aug			Exclusion reason: 2) Grey literature;
Fostering resilience among couples coparenting a young child with autism: An evaluation of Together We Are Stronger	Raffaele Mendez, Linda M.; Berkman, Karen; Lam, Gary Yu Hin; Dawkins, Charisse	2019	American Journal of Family Therapy	47	3	165-182	10.1080/01926187.2019.1624225	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Determining the relationship between over-care burden and coping styles, and resilience in mothers of children with autism spectrum disorder	Rasoulpoor, S.; Salari, N.; Shiani, A.; Khaledi-Paveh, B.; Mohammadi, M.	2023	Italian Journal of Pediatrics	49	1		10.1186/s13052-023-01465-0	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Changes in mothers‚Äô and fathers‚Äô stress level, mental health and coping strategies during the 3 years following ASD diagnosis	Rattaz, C.; Loubersac, J.; Michelon, C.; Picot, M.-C.; Baghdadli, A.	2023	Research in Developmental Disabilities	137			10.1016/j.ridd.2023.104497	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Changes in mothers' and fathers' stress level, mental health and coping strategies during the 3 years following ASD diagnosis	Rattaz, Cecile; Loubersac, Julie; Michelon, Cecile; Picot, Marie-Christine; Baghdadli, Amaria	2023	Research in Developmental Disabilities	1		########	10.1016/j.ridd.2023.104497	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder	Rayan, A.; Ahmad, M.	2016	Research in Developmental Disabilities	55		185-196	10.1016/j.ridd.2016.04.002	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Psychological Distress in Jordanian Parents of Children with Autism Spectrum Disorder: The Role of Positive Reappraisal Coping	Rayan, Ahmad; Ahmad, Muayyad	2017	Archives of Psychiatric Nursing	31	1	38-42	10.1016/j.apnu.2016.07.017	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Child behaviour problems moderate effectiveness of coping strategies except for reframing for mothers of children with ASD	Reed, P.	2020	Research in Autism Spectrum Disorders	76			10.1016/j.rasd.2020.101589	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
‚ÄúSet in Stone,Äù or ‚ÄúRay of Hope,Äù: Parents‚Äô Beliefs About Cause and Prognosis After Genomic Testing of Children Diagnosed with ASD	Reiff, M.; Bugos, E.; Giarelli, E.; Bernhardt, B.A.; Spinner, N.B.; Sankar, P.L.; Mulchandani, S.	2017	Journal of Autism and Developmental Disorders	47	5	1453-1463	10.1007/s10803-017-3067-7	Exclusion reason: 4b) Not quantitative measurement;
Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents	Renty, J.; Roeyers, H.	2006	Child: Care, Health and Development	32	3	371-385	10.1111/j.1365-2214.2006.00584.x	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Determining the effectiveness of a modulated parenting skills program on reducing autistic symptoms in children and improvement of parental adjustment	Rezaee, H.; Younesi, D.; Farahbod, M.; Ranjbar, M.	2018	Iranian Rehabilitation Journal	16	1	35-44	10.29252/nrip.irj.16.1.35	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Brief transition-focused education for families of autistic youth: preliminary mixed-methods investigation	Rispoli, Kristin M.; Curtiss, Sarah L.; Naguib, Suzi	2024	Disability & Rehabilitation	1		45536.00	10.1080/09638288.2024.2365415	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The Diagnostic Period for Autism: Risk and Protective Factors for Family Quality of Life in Early Childhood	Rivard, Melina; Morin, Diane; Coulombe, Patrick; Morin, Marjorie; Mello, Catherine	2023	Journal of Autism & Developmental Disorders	53	10	3755-3769	10.1007/s10803-022-05686-w	Exclusion reason: 3A) Not target population (not ASD);
Resilience in Families of Children With Autism and Sleep Problems Using Mixed Methods	Roberts, Cristine A.; Hunter, Jennifer; Cheng, An-Lin	2017	Journal of Pediatric Nursing	1		e2-e9	10.1016/j.pedn.2017.08.030	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Psychosocial adaptation of fathers of children with autism, Down syndrome, and normal development	Rodrigue, J. R.; Morgan, S. B.; Geffken, G. R.	1992	Journal of Autism & Developmental Disorders	22	2	249-263		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Fathers of children with autism spectrum disorder: Their perceptions of paternal role a predictor of caregiving satisfaction, self-efficacy and burden	Rudelli, N.; Straccia, C.; Petitpierre, G.	2021	Research in Autism Spectrum Disorders	83			10.1016/j.rasd.2021.101744	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Single Session Psychology Clinic for Parents of Children with Autism Spectrum Disorder: A Feasibility Study	Ryan, C.; O‚ÄôConnor, S.	2017	Journal of Child and Family Studies	26	6	1614-1621	10.1007/s10826-017-0681-0	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Pilot Randomized Controlled Trial of the WHO Caregiver Skills Training in Public Health Services in Italy	Salomone, E.; Settanni, M.; McConachie, H.; Suma, K.; Ferrara, F.; Foletti, G.; Salandin, A.; Brown, F.L.; Pacione, L.; Shire, S.; Servili, C.; Adamson, L.B.	2022	Journal of Autism and Developmental Disorders	52	10	4286-4300	10.1007/s10803-021-05297-x	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parental beliefs and feelings about autism spectrum disorder in Iran	Samadi, S.A.	2020	International Journal of Environmental Research and Public Health	17	3		10.3390/ijerph17030828	Exclusion reason: 4b) Not quantitative measurement;
Enhancing parental well-being and coping through a family-centred short course for Iranian parents of children with an autism spectrum disorder	Samadi, Sayyed Ali; McConkey, Roy; Kelly, Greg	2013	Autism	17	1	27-43	10.1177/1362361311435156	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Family stress and adjustment as perceived by parents of children with autism or down syndrome: Implications for intervention	Sanders, J.L.; Morgan, S.B.	1997	Child and Family Behavior Therapy	19	4	15-32	10.1300/J019v19n04_02	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Marital satisfaction and attribution style in parents of children with Autism Spectrum Disorder, Down Syndrome and non-disabled children	Santamaria, F.; Cuzzocrea, F.; Gugliandolo, M.C.; Larcan, R.	2012	Life Span and Disability	15	1	19-37		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
"Maybe at birth there was an injury": Drivers and implications of caretaker explanatory models of autistic characteristics in Kerala, India	Sarrett, Jennifer C.	2015	Culture, Medicine, and Psychiatry: An International Journal of Cross-Cultural Health Research	39	1	62-74	10.1007/s11013-015-9440-0	Exclusion reason: 3A) Not target population (not ASD);
Supporting caregivers of children with developmental disabilities: Findings from a brief caregiver well-being programme in South Africa	Schlebusch, Liezl; Chambers, Nola; Rosenstein, David; Erasmus, Petro; de Vries, Petrus J.	2024	Autism	28	1	199-214	10.1177/13623613221133182	Exclusion reason: 3A) Not target population (not ASD);
Positive and negative cognitive appraisal of the impact of children with autism spectrum disorder on the family	Schlebusch, Liezl; Dada, Shakila	2018	RESEARCH IN AUTISM SPECTRUM DISORDERS	51		86-93	10.1016/j.rasd.2018.04.005	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Resilience Intervention for Parents of Children with Autism: Findings from a Randomized Controlled Trial of the AMOR Method	Schwartzman, J.M.; Millan, M.E.; Uljarevic, M.; Gengoux, G.W.	2022	Journal of Autism and Developmental Disorders	52	2	738-757	10.1007/s10803-021-04977-y	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Predictors of self-reported resilience in parents of autistic children	Schwartzman, Jessica M.; Millan, Maria Estefania; Gengoux, Grace W.	2022	RESEARCH IN AUTISM SPECTRUM DISORDERS	94		########	10.1016/j.rasd.2022.101954	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The psychological and physical health of fathers of children with Autism Spectrum Disorder compared to fathers of children with long-term disabilities and fathers of children without disabilities	Seymour, Monique; Giallo, Rebecca; Wood, Catherine E.	2017	Research in Developmental Disabilities	1		42948.00	10.1016/j.ridd.2017.07.018	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Fatigue, stress and coping in mothers of children with an autism spectrum disorder	Seymour, Monique; Wood, Catherine; Giallo, Rebecca; Jellett, Rachel	2013	Journal of Autism & Developmental Disorders	43	7	1547-1554	10.1007/s10803-012-1701-y	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A Personal Construct Approach to Understanding Stress in Mothers of Children Diagnosed with Autism Spectrum Disorders	Sharma, S.; Winter, D.; McCarthy, M.	2013	Journal of Constructivist Psychology	26	1	50-61	10.1080/10720537.2013.732534	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping and care-related stress in parents of a child with autism spectrum disorder	Shepherd, Daniel; Landon, Jason; Taylor, Steve; Goedeke, Sonja	2018	Anxiety, Stress, & Coping	31	3	277-290	10.1080/10615806.2018.1442614	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The reaction to diagnosis questionnaire: a preliminary validation of a new self-report measure to assess parents' resolution of their child's diagnosis	Sher-Censor, Efrat; Ram-On, Tali Dan; Rudstein-Sabbag, Liron; Watemberg, Merav; Oppenheim, David	2020	ATTACHMENT & HUMAN DEVELOPMENT	22	4	409-424	10.1080/14616734.2019.1628081	Exclusion reason: 3A) Not target population (not ASD);
A therapeutic counseling for parents of mentally handicapped children	Shimizu, T.; Oda, K.	1980	Japanese Journal of National Medical Services	34	4	379-381	10.11261/iryo1946.34.379	Exclusion reason: 1) Not published in English;
Types of strain among family members of individuals with autism spectrum disorder across the lifespan	Shivers, Carolyn M.; Krizova, Katarina; Lee, Gloria K.	2017	Research in Developmental Disabilities	1		42-51	10.1016/j.ridd.2017.07.003	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Quality of life of family caregivers of children with autism: The mother's perspective	Shu, Bih-Ching	2009	Autism	13	1	81-91	10.1177/1362361307098517	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model	Siman-Tov, A.; Kaniel, S.	2011	Journal of Autism and Developmental Disorders	41	7	879-890	10.1007/s10803-010-1112-x	Exclusion reason: 3A) Not target population (not ASD);
Family system and coping behaviors: a comparison between parents of children with autistic spectrum disorders and parents with non-autistic children	Sivberg, Bengt	2002	Autism	6	4	397-409		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD	Smith, Leann E.; Seltzer, Marsha Mailick; Tager-Flusberg, Helen; Greenberg, Jan S.; Carter, Alice S.	2008	Journal of Autism & Developmental Disorders	38	5	876-889		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Caregiver burden after receiving a diagnosis of an autism spectrum disorder	Stuart, Melissa; McGrew, John H.	2009	RESEARCH IN AUTISM SPECTRUM DISORDERS	3	1	86-97	10.1016/j.rasd.2008.04.006	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A failure to confirm the effectiveness of a brief group psychoeducational program for mothers of children with high-functioning pervasive developmental disorders: A randomized controlled pilot trial	Suzuki, M.; Yamada, A.; Watanabe, N.; Akechi, T.; Katsuki, F.; Nishiyama, T.; Imaeda, M.; Miyachi, T.; Otaki, K.; Mitsuda, Y.; Ota, A.; Furukawa, T.A.	2014	Neuropsychiatric Disease and Treatment	10		1141-1153	10.2147/NDT.S60058	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Association of Child and Family Attributes With Outcomes in Children With Autism	Szatmari, Peter; Cost, Katherine Tombeau; Duku, Eric; Bennett, Teresa; Elsabbagh, Mayada; Georgiades, Stelios; Kerns, Connor; Mirenda, Pat; Smith, Isabel M.; Ungar, Wendy J.; Vaillancourt, Tracy; Waddell, Charlotte; Zaidman-Zait, Anat; Zwaigenbaum, Lonnie	2021	JAMA Network Open	4	3	e212530	10.1001/jamanetworkopen.2021.2530	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Acceptance and Commitment Therapy Group Intervention for Parents of Children with Disabilities (Navigator ACT): an Open Feasibility Trial	T, Holmberg Bergman; E, Renhorn; B, Berg; P, Lappalainen; A, Ghaderi; T, Hirvikoski	1834	Journal of autism and developmental disorders	53	5	1834-1849		Exclusion reason: 3A) Not target population (not ASD);
The impact of a child with autism on the Bruneian family system	Tait, K.J.; Mundia, L.	2012	International Journal of Special Education	27	3	199-212		Exclusion reason: 4b) Not quantitative measurement;

Religious Coping in Families of Children with Autism	Tarakeshwar, N.; Pargament, K.I.	2001	Focus on Autism and Other Developmental Disabilities	16	4	247-260	10.1177/108835760101600408	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Associations between autism traits and family functioning over time in autistic and non-autistic children	ten Hoopen, L.W.; de Nijs, P.F.A.; Slappendel, G.; van der Ende, J.; Bastiaansen, D.; Greaves-Lord, K.; Hakkaart-van Roijen, L.; Hillegers, M.H.J.	2023	Autism				10.1177/13623613231151784	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Cognitive vulnerability and adjustment to having a child with a disability in parents of children with Autistic Spectrum disorder	Tiba, A.; Johnson, C.; Vadineanu, A.	2012	Journal of Cognitive and Behavioral Psychotherapies	12	2	209-218		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Treatment for Sleep Problems in Children with Autism and Caregiver Spillover Effects	Tilford, J.M.; Payakachat, N.; Kuhlthau, K.A.; Pyne, J.M.; Kovacs, E.; Bellando, J.; Williams, D.K.; Brouwer, W.B.F.; Frye, R.E.	2015	Journal of Autism and Developmental Disorders	45	11	3613-3623	10.1007/s10803-015-2507-5	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Stress in Parents of Children with Autism Spectrum Disorder: an Exploration of Demands and Resources	Tm, Krakovich; Jh, McGrew; Y, Yu; La, Ruble	2042	Journal of autism and developmental disorders	46	6	2042-2053	10.1007/s10803-016-2728-2	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Effects on parental mental health of an education and skills training program for parents of young children with autism: A randomized controlled trial	Tonge, B.; Brereton, A.; Kiomall, M.; Mackinnon, A.; King, N.; Rinehart, N.	2006	Journal of the American Academy of Child and Adolescent Psychiatry	45	5	561-569	10.1097/01.chi.0000205701.48324.26	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Influences on the psychosocial adjustment of siblings of children with autism spectrum disorder in Taiwan and the United Kingdom	Tsai, H.-W.J.; Cebula, K.; Fletcher-Watson, S.	2016	Research in Autism Spectrum Disorders	32		115-129	10.1016/j.rasd.2016.09.007	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A Model of Family and Child Functioning in Siblings of Youth with Autism Spectrum Disorder	Tudor, M.E.; Rankin, J.; Lerner, M.D.	2018	Journal of Autism and Developmental Disorders	48	4	1210-1227	10.1007/s10803-017-3352-5	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping by redefinition: Cognitive appraisals in mothers of children with autism and children without autism	Tunali, B.; Power, T. G.	2002	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS	32	1	25-34	10.1023/A:1017999906420	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Coping strategies used by parents of children with autism	Twoy, Richard; Connolly, Phyllis M.; Novak, Jean M.	2007	Journal of the American Academy of Nurse Practitioners	19	5	251-260		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Building Parental Capacity: Outcomes of a Therapeutic Parent Group Run Concurrently with a Social Skills Group for Their Young Person	van Mourik, M.; Marshall, J.-M.; Hopkins, L.; Kehoe, M.; Whitehead, R.	2024	Adolescents	4	3	375-385	10.3390/adolescents4030026	Exclusion reason: 3A) Not target population (not ASD);
Match or mismatch? Influence of parental and offspring ASD and ADHD symptoms on the parent-child relationship	Van Steijn, D.J.; Oerlemans, A.M.; Van Aken, M.A.G.; Buitelaar, J.K.; Rommelse, N.N.J.	2013	Journal of Autism and Developmental Disorders	43	8	1935-1945	10.1007/s10803-012-1746-y	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coherence of Parental Representations Following Therapy for Autistic Children	Vashi, Nisha; Ibrahim, Alaa; Pouyandeh, Ava; Weiss, Jonathan A.	2024	Journal of Autism & Developmental Disorders	1			10.1007/s10803-024-06252-2	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
A pre-experimental evaluation of a 9-session training program with Latinx parents of children with autism	Vela, Javier Cavazos; Ramos, Noe; Perez, Susana	2024	Counseling Outcome Research and Evaluation	15	1	43831.00	10.1080/21501378.2023.2243324	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Daily experiences and well-being of Chinese parents of children with autism	Wang, H.; Liu, S.; Xu, J.; Hu, X.; Han, Z.R.	2023	Autism	27	6	1560-1574	10.1177/13623613221144191	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mental health issues in parents of children with autism spectrum disorder: A multi-time-point study related to COVID-19 pandemic	Wang, L.; Zhang, H.; Shang, C.; Liang, H.; Liu, W.; Han, B.; Xia, W.; Zou, M.; Sun, C.	2022	Autism Research	15	12	2346-2358	10.1002/aur.2836	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment	Weiss, J.A.; Cappadocia, M.C.; MacMullin, J.A.; Viecili, M.; Lunsky, Y.	2012	Autism	16	3	261-274	10.1177/1362361311422708	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The Brief Family Distress Scale: A Measure of Crisis in Caregivers of Individuals with Autism Spectrum Disorders	Weiss, J.A.; Lunsky, Y.	2011	Journal of Child and Family Studies	20	4	521-528	10.1007/s10826-010-9419-y	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Empowerment and Parent Gain as Mediators and Moderators of Distress in Mothers of Children with Autism Spectrum Disorders	Weiss, J.A.; MacMullin, J.A.; Lunsky, Y.	2015	Journal of Child and Family Studies	24	7	2038-2045	10.1007/s10826-014-0004-7	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Direct and indirect psychosocial outcomes for children with autism spectrum disorder and their parents following a parent-involved social skills group intervention	Weiss, J.A.; Viecili, M.A.; Sloman, L.; Lunsky, Y.	2013	Journal of the Canadian Academy of Child and Adolescent Psychiatry	22	4	303-309		Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Exploring Family Adjustment Among Parents of a Child With a Disability Attending Relationship Education	Wheeler, NJ; Allen, L; Man, JL; Pointer, A	2024	FAMILY JOURNAL	32	3	471-480	10.1177/10664807241235680	Exclusion reason: 3A) Not target population (not ASD);
Psychological Adjustment in Families Affected by Autism Spectrum Disorder	Whitehead, K.; Dorstyn, D.; Ward, L.	2015	Journal of Developmental and Physical Disabilities	27	5	703-717	10.1007/s10882-015-9446-0	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Stepping Stones Triple P: A pilot study to evaluate acceptability of the program by parents of a child diagnosed with an Autism Spectrum Disorder	Whittingham, K.; Sofronoff, K.; Sheffield, J.K.	2006	Research in Developmental Disabilities	27	4	364-380	10.1016/j.ridd.2005.05.003	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Life After an Autism Spectrum Disorder Diagnosis: A Comparison of Stress and Coping Profiles of African American and Euro-American Caregivers	Williams, Takeshia V.; Hartmann, Kathrin; Paulson, James F.; Raffaele, C. Teal; Urbano, Maria R.	2019	Journal of Autism & Developmental Disorders	49	3	1024-1034	10.1007/s10803-018-3802-8	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The Relationship Between Optimism, Coping, and Depressive Symptoms in Hispanic Mothers and Fathers of Children with Autism Spectrum Disorder	Willis, Kelcie; Timmons, Lisa; Pruitt, Megan; Schneider, Hoa Lam; Alessandri, Michael; Ekas, Naomi V.	2016	Journal of Autism & Developmental Disorders	46	7	2427-2440	10.1007/s10803-016-2776-7	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Mental health impact of autism on families of children with intellectual and developmental disabilities of genetic origin	Wolstencroft, J.; Srinivasan, R.; Hall, J.; van den Bree, M.B.M.; Owen, M.J.; Raymond, F.L.; Skuse, D.	2023	JCPP Advances	3	1		10.1002/jcv2.12128	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Vicarious futurity in autism and childhood dementia	Wong, M.G.; Heriot, S.A.	2007	Journal of Autism and Developmental Disorders	37	10	1833-1841	10.1007/s10803-006-0317-5	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Predicting the Outcomes of Parents of Transition-Age Youth or Young Adults with ASD	Wong, Venus; McGrew, John; Ruble, Lisa	2020	Journal of Autism & Developmental Disorders	50	8	2723-2739	10.1007/s10803-020-04362-1	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Family functioning in Asian families raising children with autism spectrum disorders: The role of capabilities and positive meanings	Xue, J.; Ooh, J.; Magiati, I.	2014	Journal of Intellectual Disability Research	58	5	406-420	10.1111/jir.12034	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The effect of parental burnout on psychological adjustment among Chinese children with developmental disabilities: the roles of parental autonomy support and psychological control	Yan, T.; Hou, Y.; Deng, M.	2024	International Journal of Developmental Disabilities				10.1080/20473869.2024.2331830	Exclusion reason: 3A) Not target population (not ASD);
Examining the Views of Teachers and Parents About Autism Awareness in a Rural Inclusive Elementary School	Yazƒ±cƒ±, M.S.	2023	Advances in Neurodevelopmental Disorders				10.1007/s41252-023-00376-9	Exclusion reason: 3B) Not target population (not caregivers);
Effectiveness of online responsive teaching in young children with developmental disabilities: a pilot study	Yeom, Jung Sook; Kim, Jeongmee	2024	Clinical and Experimental Pediatrics	67	6	303-311	10.3345/cep.2023.01662	Exclusion reason: 3A) Not target population (not ASD);
Using a model of family adaptation to examine outcomes of caregivers of individuals with autism spectrum disorder transitioning into adulthood	Yu, Yue; McGrew, John H.; Rand, Kevin L.; Mosher, Catherine E.	2018	Research in Autism Spectrum Disorders			37-50	10.1016/j.rasd.2018.06.007	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders	Zablotsky, B.; Bradshaw, C.P.; Stuart, E.A.	2013	Journal of Autism and Developmental Disorders	43	6	1380-1393	10.1007/s10803-012-1693-7	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder	Zaidman-Zait, Anat; Mirenda, Pat; Duku, Eric; Vaillancourt, Tracy; Smith, Isabel M.; Szatmari, Peter; Bryson, Susan; Fombonne, Eric; Volden, Joanne; Waddell, Charlotte; Zwaigenbaum, Lonnie; Georgiades, Stelios; Bennett, Teresa; Elsabaggh, Mayada; Thompson, Ann	2017	AUTISM	21	2	155-166	10.1177/1362361316633033	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Profiles of Social and Coping Resources in Families of Children with Autism Spectrum Disorder: Relations to Parent and Child Outcomes	Zaidman-Zait, Anat; Mirenda, Pat; Szatmari, Peter; Duku, Eric; Smith, Isabel M.; Vaillancourt, Tracy; Volden, Joanne; Waddell, Charlotte; Bennett, Teresa; Zwaigenbaum, Lonnie; Elsabaggh, Mayada; Georgiades, Stelios	2018	JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS	48	6	2064-2076	10.1007/s10803-018-3467-3	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Coping strategies and parenting skills of parents of children with autism spectrum disorder	Zebdi, R.; Amalric, H.; Viod√©, C.; Lignier, B.	2018	Neuropsychiatrie de l'Enfance et de l'Adolescence	66	5	323-329	10.1016/j.neurenf.2018.01.008	Exclusion reason: 1) Not published in English;
The path to an autism spectrum disorders diagnosis in Ethiopia: Parent perspective	Zeleke, W.A.; Hughes, T.; Chitiyo, M.	2018	American Journal of Orthopsychiatry	88	3	316-327	10.1037/ort0000249	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Caregivers and interventionists: Developing a Dual Role Behaviors Scale for parents of children with autism spectrum disorders	Zhou, T.; Zhang, C.; Yi, C.	2022	Family Process				10.1111/famp.12831	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);
Parenting stress, coping strategies and social support for mothers of preschool children with autism spectrum disorder in the Republic of Croatia	Zovko, Matea; Simlesa, Sanja; Olujic Tomazin, Marina	2024	Clinical Child Psychology & Psychiatry	29	2	674-686	10.1177/13591045231191802	Exclusion reason: 4) Not target outcomes (adjustment to ASD diagnosis);

Table B2. Articles identified in systematic review.

Reference	**Abbeduto et al., 2004**	**Abd Latif et al., 2023**
Title	Psychological well-being and coping in mothers of youths with autism, Down Syndrome, or Fragile X Syndrome	Factors influencing despair, self-blame, and acceptance among parents of children with Autism Spectrum Disorder (ASD): A Malaysian perspective
MMAT rating %	100	60
Demographics*		
Sample size	174	111
Child age mean (SD)	16.32 years (3.00)	13.18 years
Child age range	10-23 years	Not reported
Child gender	73.6% male, 26.4% female	79.3% male, 20.7% female
Caregiver gender	100% female	67.6% female, 32.4% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	USA	Malaysia
Ethnicity	Not reported	Parents 73.9% Malay, 18.9% Chinese, 2.7% Indian, 4.5% other
Child reported autism features	Autism Behaviour Checklist: Mean 53.44 (SD 26.64)	Not reported
Child other reported features	Excluded Down syndrome, Fragile X syndrome, Rett's Disorder, Childhood Disintegrative Disorder, or tuberous sclerosis	9% other psychiatric illness, 12.6% medical illness
	*Where study includes multiple groups, demographics are reported here for the autism group only	
Name of adjustment measure	**Questionnaire on Resources and Stress; Pessimism subscale**	**Adjustment to the Diagnosis of Autism Questionnaire**
Reference of adjustment measure	Friedrich et al., 1983	Da Paz et al., 2018
Adaptations from original measure	No	Translated into Malay

Reference	Al-Kandari et al., 2017	Alon, 2019
Title	Brief report: Social support and coping strategies of mothers of children suffering from ASD in Kuwait	Social support and post-crisis growth among mothers of children with autism spectrum disorder and mothers of children with down syndrome
MMAT rating %	40	50
Demographics*		
Sample size	198	99
Child age mean (SD)	Not reported	Not reported for autism group
Child age range	Not reported	Not reported for autism group
Child gender	79.6% male, 20.4% female	72.7% male, 27.3% female
Caregiver gender	100% female	100% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	40.4% less than 2 years, 37.8% 2.1-3 years, 21.8% greater than 3.1 years	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	Kuwait	Israel
Ethnicity	Parents 68.4% Kuwaiti, 31.6% non-Kuwaiti	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	Not reported	Not reported
Name of adjustment measure	**Unnamed measure of changes to relationships and behaviour following diagnosis**	**Stress-Related Growth Scale**
Reference of adjustment measure	Current study - Al-Kandari et al., 2017	Park et al., 1996
Adaptations from original measure	N/A	No

Reference	Anderberg & South, 2021	Ayyash et al., 2023
Title	Predicting parent reactions at diagnostic disclosure sessions for autism	A comparison of the experiences, challenges and coping strategies for parents of children with autism residing in the United States and The Arab World
MMAT rating %	80	50
Demographics*		
Sample size	189	USA = 235; Arab = 165
Child age mean (SD)	Not reported	MEDIAN USA = 9 years; MEDIAN Arab = 7 years
Child age range	Not reported	Q1-Q3 USA = 5-10; Q1-Q3 Arab = 5-14
Child gender	77% male, 23% female	USA = 72.8% MALE, 21.8% Female; Arab = 80.5% male, 19.5% female
Caregiver gender	90.5% female, 6.9% male, 2.6% unknown	USA = 93.6% female, 3.8% male, 2.6% unknown; Arab = 69.8% female, 24.7% male, 5.6% unknown
Child age at diagnosis mean (SD)	6.23 years (5.12)	MEDIAN USA = 3.5 years; MEDIAN Arab = 3 years
Child age at diagnosis range	1-28 years	Interquartile range USA = 2.5-5; Interquartile range Arab = 2-4 years
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Maximum 3 years	Not reported
Country conducted	USA	USA; 15 Arab countries including Iraq, Egypt, Jordan, Lebanon, Palestine and Syria
Ethnicity	Children 85.7% White, 1.1% Black/African-American, 4.8% Asian, 1.1% American Indian/Alaska Native, 0.5% Native Hawaiian/Pacific Islander, 6.9% Other	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	Not reported	Not reported
Name of adjustment measure	**Unnamed measure of parent reaction post diagnostic feedback session**	**Unnamed measure of coping strategies used following diagnosis**
Reference of adjustment measure	Current study - Anderberg & South, 2021	Current study - Ayyash et al., 2023
Adaptations from original measure	N/A	N/A

Reference	**Anthony et al., 2020**	
Title	Increasing autism acceptance: The impact of the Sesame Street "See Amazing in All Children" initiative	
MMAT rating %	80	
Demographics*		
Sample size	312 baseline; 176 1-week follow-up; 182 1-month follow-up	
Child age mean (SD)	4.46 years (1.08)	
Child age range	6 years or younger	
Child gender	73.7% male, 26.0% female, 0.3% other	
Caregiver gender	84.0% female, 15.7% male, 0.3% other	
Child age at diagnosis mean (SD)	Not reported	
Child age at diagnosis range	Not reported	
Time since diagnosis mean (SD)	Not reported	
Time since diagnosis range	Not reported	
Country conducted	USA	
Ethnicity	Parents 73.9% White, 9.1% Black/African-American, 6.2% Asian, 1.6% American Indian/Alaska Native, 0.3% Middle Eastern or Northern African, 0.3% Native Hawaiian or Other Pacific Islander, 2.9% Other, 5.5% two or more races	
Child reported autism features	Not reported	
Child other reported features	Not reported	
Name of adjustment measure	**Acceptance of Children with Autism**	**Affiliate Stigma Scale**
Reference of adjustment measure	Harnum et al., 2007	Mak & Cheung, 2008; Werner & Shulman, 2015
Adaptations from original measure	No	Yes, specific adaptations not reported

Reference	**Bravo-Benítez et al., 2024**	
Title	Grief intervention program for caregivers to individuals with autism spectrum disorder (ASD): A randomized preliminary trial	
MMAT rating %	0	
Demographics*		
Sample size	28	
Child age mean (SD)	Not reported	
Child age range	6-12 years	
Child gender	Not reported	
Caregiver gender	85.7% female, 14.3% male	
Child age at diagnosis mean (SD)	Not reported	
Child age at diagnosis range	18-132 months	
Time since diagnosis mean (SD)	Not reported	
Time since diagnosis range	Not reported	
Country conducted	Spain	
Ethnicity	Not reported	
Child reported autism features	Not reported	
Child other reported features	"All had behavioural problems"	
Name of adjustment measure	**Caregiver Grief Scale**	**The Post-Traumatic Growth Inventory Short Form**
Reference of adjustment measure	Meichsner et al., 2016	Tedeschi & Calhoun, 1996
Adaptations from original measure	Translated into Spanish	Adapted by Castro et al., 2015

Reference	Cappe et al., 2011	Cappe et al., 2024
Title	Quality of life: A key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes	Parental involvement and adjustment during the diagnostic evaluation of autism spectrum disorder at two diagnostic centers
MMAT rating %	60	60
Demographics*		
Sample size	160 parents including 41 dyads; 118 children	49
Child age mean (SD)	14.25 years (8)	4.58 years
Child age range	Not reported	Not reported
Child gender	79.66% male, 20.34% female	79.6% male, 20.4% female
Caregiver gender	70.6% female, 29.4% male	75.5% female, 24.5% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	2-4 weeks
Country conducted	France	France
Ethnicity	Not reported	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	56.78% speech language disorder; 90.9% behaviour disorder	14% no spoken language, 84% disruptive behaviours
Name of adjustment measure	**Cancer Locus of Control Scale**	**Cancer Locus of Control Scale (CLCS)**
Reference of adjustment measure	Cousson-Gélie et al., 2005; French adaptation Koleck, 2000	Pruyn et al., 1988
Adaptations from original measure	Reworded to be autism-specific; items removed	As adapted in Cappe et al., 2011

Reference	**Cappe et al., 2018**	
Title	Quality of life of French Canadian parents raising a child with autism spectrum disorder and effects of psychosocial factors	
MMAT rating %	60	
Demographics*		
Sample size	77	
Child age mean (SD)	9.62 years (3.47)	
Child age range	2.16-18.17 years	
Child gender	87% male, 13% female	
Caregiver gender	92% female, 6% male, 2% not specified	
Child age at diagnosis mean (SD)	4.36 years (2.06)	
Child age at diagnosis range	1.58 - 12.33 years	
Time since diagnosis mean (SD)	Not reported	
Time since diagnosis range	Not reported	
Country conducted	Canada	
Ethnicity	Not reported	
Child reported autism features	Not reported	
Child other reported features	61% presented with "associated disorders", 87% use oral language	
Name of adjustment measure	**Cancer Locus of Control Scale**	**Ways of Coping Checklist - Revised**
Reference of adjustment measure	Cousson-Gélie et al., 2005; French adaptation Koleck, 2000	Vitaliano et al., 1985; French adaptation Cousson et al., 1996
Adaptations from original measure	As adapted in Cappé et al., 2011	Reworded to be autism-specific

Reference	Cetinbakis et al., 2020	Cheung et al., 2019
Title	Factors contributing to higher caregiving burden in Turkish mothers of children with autism spectrum disorders	Role of mindful parenting, affiliate stigma, and parents' well-being in the behavioral adjustment of children with Autism Spectrum Disorder: Testing parenting stress as a mediator
MMAT rating %	50	80
Demographics*		
Sample size	60	136
Child age mean (SD)	11.53 years (5.14)	9.39 years (5.24)
Child age range	Not reported	Not reported
Child gender	83.9% male, 16.1% female	81.62% male, 18.38% female
Caregiver gender	100% female	81.62% female, 18.38% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	8.02 years (4.82)	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	Turkey	Hong Kong
Ethnicity	Not reported	Not reported
Child reported autism features	Autism Behaviour Checklist: Mean 60.69 (SD 3.22)	Not reported
Child other reported features	Mean disability percentage 78.53 (SD 17.28)	33.82% intellectual disability; comorbid disorders including attention deficit/hyperactivity disorder and dyslexia were excluded from this study
Name of adjustment measure	**Post-Traumatic Growth Inventory**	**Affiliate Stigma Scale**
Reference of adjustment measure	Tedeschi & Calhoun, 1996	Mak & Cheung, 2008
Adaptations from original measure	Translated into Turkish	No

Reference	**Chan & Lam, 2018**	
Title	Self-stigma among parents of children with autism spectrum disorder	
MMAT rating %	80	
Demographics*		
Sample size	424	
Child age mean (SD)	10. 41 years (6.68)	
Child age range	Not reported	
Child gender	83.3% male, 16.7% female	
Caregiver gender	86.1% female, 13.9% male	
Child age at diagnosis mean (SD)	Not reported	
Child age at diagnosis range	Not reported	
Time since diagnosis mean (SD)	7.24 years (6.67)	
Time since diagnosis range	Not reported	
Country conducted	Hong Kong	
Ethnicity	Not reported	
Child reported autism features	Not reported	
Child other reported features	60.4% intellectual disability	
Name of adjustment measure	**Self-stigmatizing Thinking's Automaticity and Repetition Scale**	**Affiliate Stigma Scale**
Reference of adjustment measure	Chan & Mak, 2017	Mak & Cheung, 2008
Adaptations from original measure	Reworded to be autism-specific	Reworded to be autism-specific

Reference	Chu et al., 2020	Da Paz et al., 2018
Title	Self-stigma and its associations with stress and quality of life among Malaysian parents of children with autism	Acceptance or despair? Maternal adjustment to having a child diagnosed with autism
MMAT rating %	80	100
Demographics*		
Sample size	110	90
Child age mean (SD)	Not reported	Not reported
Child age range	2-18 years	Not reported
Child gender	Not reported	Not reported
Caregiver gender	72.2% female, 27.3% male	100% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	Malaysia	USA
Ethnicity	Parents 93.6% Malay, 5.5% Chinese, 0.9% Indian	Parents 84% White, 12% Asian, 4% Black or African American
Child reported autism features	Not reported	Childhood Autism Rating Scales: means not included but correlated with 2 out of 3 adjustment subscales
Child other reported features	Not reported	Not reported
Name of adjustment measure	**Affiliate Stigma Scale**	**Adjustment to the Diagnosis of Autism Scale**
Reference of adjustment measure	Mak & Cheung, 2008	Current study - Da Paz et al., 2018
Adaptations from original measure	No	N/A

Reference	Dolev et al., 2016	Downes et al., 2022
Title	Resolution of the child's ASD diagnosis among Arab-Israeli mothers: Associations with maternal sensitivity and wellbeing	Dyadic coping and coparenting among couples after their child's recent autism diagnosis
MMAT rating %	80	100
Demographics*		
Sample size	46	140 parents of 70 children (dyads)
Child age mean (SD)	Resolved: 59.32 months (22.42); Unresolved 64.08 months (27.76)	55 months (21)
Child age range	2-8 years	25-119 months
Child gender	100% male	80% male, 20% female
Caregiver gender	100% female	50% female, 50% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Resolved: 28.50 months (19.14); Unresolved: 33.38 months (24.23)	21 months (17.3)
Time since diagnosis range	At least 6 months	1-36 months
Country conducted	Israel	France
Ethnicity	Parents 87% Muslim, 10.9% Christian, 2.2% Druze	Not reported
Child reported autism features	Social Communication Questionnaire: fewer autism features reported by resolved as compared to unresolved mothers	Not reported
Child other reported features	Adaptive behaviour Vineland: no significant differences between resolved and unresolved mothers	Not reported
Name of adjustment measure	**Reaction to Diagnosis Interview**	**Appraisal of Life Events Scale**
Reference of adjustment measure	Marvin & Pianta, 1996	Ferguson et al., 1999
Adaptations from original measure	No	Adapted in Cappé et al., 2017

Reference	Ebrahim & Alothman, 2021	Ekas et al., 2015
Title	Resilience and social support as predictors of post-traumatic growth in mothers of children with autism spectrum disorder in Saudi Arabia	The power of positivity: Predictors of relationship satisfaction for parents of children with Autism Spectrum Disorder
MMAT rating %	100	80
Demographics*		
Sample size	88	134 parents of 67 children - dyads
Child age mean (SD)	7.34 years (1.89)	78.09 months (26.24)
Child age range	3-12 years	Not reported
Child gender	68.1% male, 31.9% female	82.6% male, 16.4% female
Caregiver gender	100% female	50% female, 50% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	30-66 months	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	At least 6 months	Not reported
Country conducted	Saudi Arabia	USA
Ethnicity	All Saudi nationals	Parents 55.2% Hispanic or Latino, 35.8% White/Caucasian, 1.5% African-American, 3% Caribbean-American, 4.5% mixed ethnicity/other
Child reported autism features	Not reported	Not reported
Child other reported features	WISC-IV: All had IQ below 70	Not reported
Name of adjustment measure	**Post-traumatic Growth Inventory**	**Benefit Finding Scale**
Reference of adjustment measure	Tedeschi & Calhoun, 1996	Carver & Antoni, 2004
Adaptations from original measure	No	Reworded to be autism-specific

Reference	Ekas et al., 2016	Ekas et al., 2019
Title	The role of family cohesion in the psychological adjustment of non-Hispanic White and Hispanic mothers of children with autism spectrum disorder	Religiosity/spirituality and mental health outcomes in mothers of children with Autism Spectrum Disorder: The mediating role of positive thinking
MMAT rating %	75	60
Demographics*		
Sample size	106	73
Child age mean (SD)	Hispanic 6.49 years (2.38); non-Hispanic White 6.75 years (2.28)	9.14 years (3.97)
Child age range	2.6-10.8 years	2-17 years
Child gender	Hispanic 82.2% male 17.8% female; non-Hispanic White 84.1% male 15.9% female	89% male, 11% female
Caregiver gender	100% female	100% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	USA	USA
Ethnicity	Parents 62.4% Hispanic, 37.6% non-Hispanic White	Parents 76.7% White/Caucasian, 2.7% African-American, 1.4% Asian or Pacific Islander, 13.7% Hispanic or Latino, 5.5% multiracial
Child reported autism features	Not reported	Social Responsiveness Scale: Mean 105.16 (SD 32.36)
Child other reported features	Not reported	Not reported
Name of adjustment measure	**Benefit Finding Scale**	**Benefit Finding Scale**
Reference of adjustment measure	Carver & Antoni, 2004	Carver & Antoni, 2004
Adaptations from original measure	As adapted in Ekas et al., 2015	As adapted in Ekas et al., 2015

Reference	Feng et al., 2022	Feng et al., 2022
Title	Symptom severity and posttraumatic growth in parents of children with autism spectrum disorder: The moderating role of social support	Posttraumatic growth and rumination among parents of children with autism spectrum disorder: The mediating role of social support
MMAT rating %	100	100
Demographics*		
Sample size	385	385
Child age mean (SD)	3.66 years (1.48)	3.66 years (1.40)
Child age range	2-14.4 years	2-14 years
Child gender	80.5% male, 19.5% female	80.5% male, 19.5% female
Caregiver gender	55.3% female, 44.7% male	55.3% female, 44.7% male
Child age at diagnosis mean (SD)	3.18 years (1.22)	3.18 years (1.22)
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	5.87 months (10.66)	5.87 months (10.66)
Time since diagnosis range	Minimum 1 month	Not reported
Country conducted	China	China
Ethnicity	Not reported	Not reported
Child reported autism features	Chinese Autism Behaviour Checklist: Mean 64.52 (SD 20.27)	Not reported
Child other reported features	Not reported	Not reported
Name of adjustment measure	**Posttraumatic Growth Inventory**	**Post-traumatic Growth Inventory**
Reference of adjustment measure	Tedeschi & Calhoun, 1996	Tedeschi & Calhoun, 2004
Adaptations from original measure	Translated into Chinese in Wang et al, 2011	Unspecified modifications

Reference	Feng et al., 2023	Ferenc et al., 2023
Title	Predictors of posttraumatic growth in 475 Chinese parents of children newly diagnosed with autism spectrum disorder	The spectrum of attitudes towards the spectrum of autism and its relationship to psychological distress in mothers of children with autism
MMAT rating %	100	60
Demographics*		
Sample size	475	371
Child age mean (SD)	Not reported	8.43 years (3.77)
Child age range	2-14 years	2-18 years
Child gender	80.4% male, 19.6% female	Not reported
Caregiver gender	55.4% female, 44.6% male	100% female
Child age at diagnosis mean (SD)	3.21 years (1.17)	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	5.56 months (10.11)	3.74 years (3.11)
Time since diagnosis range	Not reported	0-16 years
Country conducted	China	Poland
Ethnicity	Not reported	Not reported
Child reported autism features	Chinese Autism Behaviour Checklist: Mean 19.90 (SD 4.36)	Autism Spectrum Rating Scales: Mean 71.32 (SD 9.34)
Child other reported features	Not reported	15.6% intellectual disability
Name of adjustment measure	**Chinese Posttraumatic Growth Inventory**	**Attitudes Towards Autism Questionnaire**
Reference of adjustment measure	Tedeschi & Calhoun, 1996	Current study - Ferenc et al., 2023
Adaptations from original measure	Translated into Chinese in Wang et al., 2011	N/A

Reference	Grebe et al., 2022	Grogan et al., 2023
Title	Comparing fathers' and mothers' perspectives about their child's Autism Spectrum Disorder	Parent resolution of diagnosis and intervention fidelity in a parent-delivered intervention for pre-school children with autism: A mixed methods study
MMAT rating %	50	100
Demographics*		
Sample size	361 parents, including 27 parent dyads; 334 children	31
Child age mean (SD)	Not reported	49.91 months (10.38)
Child age range	7-23 years	37.26-75.20 months
Child gender	86.7% male, 13.3% female	58% male, 42% female
Caregiver gender	81.4% female, 18.6% male	90% female, 3% male, 7% not specified
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Resolved = 15.57 months (14.28); Unresolved = 17.04 months (12.25)
Time since diagnosis range	Not reported	Not reported
Country conducted	USA	Australia
Ethnicity	Not reported	Parents 77% Central and South-East Asian; other not specified
Child reported autism features	Not reported	ADOS-2 CSS: no significant difference between resolved and unresolved parents
Child other reported features	Not reported	Not reported
Name of adjustment measure	**Revised Illness Perception Questionnaire for ASD**	**Reaction to Diagnosis Interview**
Reference of adjustment measure	Moss-Morris et al., 2002	Marvin & Pianta, 1996
Adaptations from original measure	As adapted in Mire et al., 2018	No

Reference	Hall & Graff, 2011	Hutman et al., 2009
Title	The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping	Mothers' narratives regarding their child with autism predict maternal synchronous behavior during play
MMAT rating %	20	80
Demographics*		
Sample size	75	67
Child age mean (SD)	8.00 years (4.00)	53.8 months (12.5)
Child age range	Not reported	29-78 months
Child gender	82.7% male, 17.3% female	92.5% male, 7.5% female
Caregiver gender	68% female, 32% male	100% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	USA	USA
Ethnicity	Parents 84% Caucasian, 12% African-American, 2.7% Hispanic, 1.3% American Indian	Parents 52.2% Hispanic, 21% non-Hispanic White, 18% Asian, 6% Black
Child reported autism features	Not reported	ADOS-G and ADI-R, means not included
Child other reported features	28% described as being in poor health	Language less than phrase speech
Name of adjustment measure	**Coping Health Inventory for Parents: Coping Pattern III (understanding the health situation)**	**Reaction to Diagnosis Interview**
Reference of adjustment measure	McCubbin et al., 1981	Pianta & Marvin, 1992
Adaptations from original measure	No	No

Reference	Jose et al., 2021	Kheir et al., 2012
Title	Buffering effect of spousal support on stress levels in mothers of children with a diagnosis of Autism Spectrum Disorder in Kerala, India	Concerns and considerations among caregivers of a child with autism in Qatar
MMAT rating %	80	40
Demographics*		
Sample size	99	56
Child age mean (SD)	Not reported	Not reported
Child age range	1-18 years	3-17 years
Child gender	78.7% male, 22.3% female	Not reported
Caregiver gender	100% female	57.40% female, 42.59% male - missing gender for two caregivers
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	India	Qatar
Ethnicity	Not reported	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	72% diagnosed with mixed disabilities	13% other health conditions
Name of adjustment measure	**COPE**	**Unnamed measure of caregiver acceptance of having an autistic child**
Reference of adjustment measure	Carver et al., 1989	Current study - Kheir et al., 2012
Adaptations from original measure	Items removed; administered as interview	N/A

Reference	**Leccisco et al., 2013**	**Lovell & Wetherell, 2020**
Title	The association between maternal resolution of the diagnosis of autism, maternal mental representations of the relationship with the child, and children's attachment	Exploring the moderating role of benefit finding on the relationship between child problematic behaviours and psychological distress in caregivers of children with ASD
MMAT rating %	100	100
Demographics*		
Sample size	21	152
Child age mean (SD)	7 years 9 months (2 years 4 months)	10.1 years
Child age range	5-13 years	1-22 years
Child gender	90.47% male, 9.52% female	Not reported
Caregiver gender	100% female	95% female, 5% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	2 years 3 months (2 years 3 months)	Not reported
Time since diagnosis range	4 months - 10 years	Not reported
Country conducted	Italy	UK; also recruited participants from USA and Australia
Ethnicity	Not reported	Parents 93% White
Child reported autism features	Not reported	73% described as high functioning
Child other reported features	IQ > 70, age of language production > 4 years, excluded neurologic, genetic, infectious, metabolic or seizure disorders	Not reported
Name of adjustment measure	**Reaction to Diagnosis Interview**	**Benefit Finding Scale**
Reference of adjustment measure	Marvin & Pianta, 1996	Carver & Antoni, 2004
Adaptations from original measure	Translated into Italian	Reworded to be autism-specific

Reference	**Lodder et al., 2020**	
Title	SOLACE: A psychosocial stigma protection intervention to improve the mental health of parents of autistic children—A feasibility randomised controlled trial	
MMAT rating %	80	
Demographics*		
Sample size	17	
Child age mean (SD)	5.91 years (2.59)	
Child age range	2-10 years	
Child gender	76.5% male, 23.5% female	
Caregiver gender	94.1% female, 4.9% male	
Child age at diagnosis mean (SD)	Not reported	
Child age at diagnosis range	Not reported	
Time since diagnosis mean (SD)	Not reported	
Time since diagnosis range	Not reported	
Country conducted	UK	
Ethnicity	Parents 82% White British, 6% Black British, 6% Pakistani, 6% Maori	
Child reported autism features	Not reported	
Child other reported features	12% ADHD, 18% global developmental delay, 18% speech and language delay, 6% dysphraxia, 6% Down syndrome, 6% dyslexia	
Name of adjustment measure	**Affiliate Stigma Scale**	**Self-Blame and Responsibility scale**
Reference of adjustment measure	Mak & Cheung, 2008	Mak & Kwok, 2008
Adaptations from original measure	Reworded to be autism-specific; translated into English; items removed	Translated into English; reworded to suit UK population; items removed

Reference	Lunsky et al., 2021	Milshtein et al., 2010
Title	Group virtual mindfulness-based intervention for parents of autistic adolescents and adults	Resolution of the diagnosis among parents of children with Autism Spectrum Disorder: Associations with child and parent characteristics
MMAT rating %	20	100
Demographics*		
Sample size	39 parents of 40 children	122 parents of 61 children - dyads
Child age mean (SD)	20.92 years (5.32)	Boys: 7 years 8 months (3 years 1 month). Girls: 8 years 3 months (3 years 3 months).
Child age range	16-39 years	2 years 1 month - 17 years 1 month
Child gender	75% male, 25% female	55.7% male, 53.3% female
Caregiver gender	89.7% female, 10.3% male	50% female, 50% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Boys: 4 years 5 months (2 years 8 months). Girls: 4 years 2 months (2 years 11 months).
Time since diagnosis range	Not reported	6 months - 10 years 8 months
Country conducted	Canada	Israel
Ethnicity	Not reported	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	55% additional psychiatric disorder, 5% genetic disorder	Excluded medical conditions related to autism; 49% high functioning, 51% low functioning based on Vineland and IQ.
Name of adjustment measure	**Positive Gain Scale**	**Reaction to Diagnosis Interview**
Reference of adjustment measure	Jess et al., 2020	Marvin & Pianta, 1992
Adaptations from original measure	Reworded to be autism-specific	No

Reference	Mire et al., 2018	Mohammad et al., 2022
Title	Validating the Revised Illness Perception Questionnaire as a measure of parent perceptions of Autism Spectrum Disorder	Care burden, coping styles and involvement in care in mothers of autistic children in pandemic of COVID-19
MMAT rating %	100	100
Demographics*		
Sample size	361	110
Child age mean (SD)	13.3 years (3.5 years)	Not reported
Child age range	Not reported	6-14 years
Child gender	87.7% male, 12.3% female	70.90% male, 29.10% female
Caregiver gender	88% female, 12% male	100% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	USA, Canada	Iran
Ethnicity	Not reported	Not reported
Child reported autism features	ADOS CSS: Mean 7.4 (SD 1.6)	Not reported
Child other reported features	Mean full scale IQ in the low average range	Excluded other physical, cognitive-developmental or mental disorders
Name of adjustment measure	**Illness Perception Questionnaire - Revised for autism spectrum disorder**	**Burden Assessment Scale**
Reference of adjustment measure	Moss-Morris et al., 2002	Reinhardt & Horowitz, 1984
Adaptations from original measure	Reworded to be autism-specific	No

Reference	Montoya et al., 2024	Naicker et al., 2024
Title	"Glimmers of hope and good things": Positive aspects of caregiving to autistic adolescents and young adults	Does hope mediate the relationship between parent's resolution of their child's autism diagnosis of parental stress
MMAT rating %	80	60
Demographics*		
Sample size	174	73
Child age mean (SD)	20.93 years (3.66)	11.5 years (4.56)
Child age range	16-30	Not reported
Child gender	71.8% male	67.1% male, 32.9% female
Caregiver gender	91% female	97.3% female, 2.7% male
Child age at diagnosis mean (SD)	6.25 years (4.98)	5.5 years (3.45)
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	United States	Australia
Ethnicity	Not reported	Parents 83.6% Australian, 1.4% Indigenous Australian or Torres Strait Islander, 1.4% Asian, 4.2% Middle Eastern, 6.8% European, 1.4% other
Child reported autism features	Not reported	Confirmed support level 13.0% Level 1, 66.7% Level 2, 20.4% Level 3; perceived support level 21.1% Level 1, 63.2% Level 2, 15.8% Level 3
Child other reported features	Approximately 61% diagnosed with another mental health condition, 27% intellectual disability, 24% serious medical issue	Not reported
Name of adjustment measure	**Brief Coping Orientation to Problems Experienced Inventory (Brief COPE)**	**Reaction to Diagnosis Questionnaire (RDQ)**
Reference of adjustment measure	Carver, 1997	Sher-Censor et al., 2020
Adaptations from original measure	Used only a subset of scales	Items removed

Reference	Nguyen et al., 2016	Norozi et al., 2023
Title	Problem-solving skills training for mothers of children recently diagnosed with autism spectrum disorder: A pilot feasability study	Psychometric properties of the Revised Illness Perception Questionnaire among Iranian parents of children with autism spectrum disorder
MMAT rating %	40	60
Demographics*		
Sample size	24	18
Child age mean (SD)	Not reported	Not reported
Child age range	2-5 years	Not reported
Child gender	Not reported	76.3% male, 23.7% female
Caregiver gender	100% female	90.4% female, 9.6% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	8-24 weeks	Not reported
Country conducted	USA	Iran
Ethnicity	Parents 25% Black not Hispanic, 4% American Indian, 13% Asian/Pacific Islander, 58% White not Hispanic	Parents 100% Iranian
Child reported autism features	Not reported	Not reported
Child other reported features	Excluded genetic conditions	Not reported
Name of adjustment measure	**Impact of Event Scale - Revised**	**The Illness Perception Questionnaire-Revised for autism spectrum disorder**
Reference of adjustment measure	Creamer et al., 2003	Mire et al., 2018
Adaptations from original measure	No	As adapted in Mire et al., 2018; translated into Persian

Reference	O'Brien 2016	Oppenheim et al., 2009
Title	Families of adolescents with autism: Facing the future	Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders
MMAT rating %	80	80
Demographics*		
Sample size	103	45
Child age mean (SD)	16.2 years (2.70)	49.35 months (9.56)
Child age range	13-22	32-69 months
Child gender	84.5% male, 15.5% female	100% male
Caregiver gender	91.3% female, 8.7% male	100% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	21.07 months (9.42)
Time since diagnosis range	Not reported	9-38 months
Country conducted	USA	Israel
Ethnicity	Parents 91.2% White, 4.9% Latino, 2.0% Asian, 1.0% African American, 1.0% mixed ethnicity, 1.0% South Asian	Parents 100% Jewish
Child reported autism features	Not reported	Not reported
Child other reported features	64.1% had other medical conditions such as ADHD, epilepsy and other neurological conditoins	24.4% high functioning, 75.5% low functioning based on cognitive testing and Vineland
Name of adjustment measure	**Parents' Perception of Uncertainty in Illness Scale**	**Reaction to Diagnosis Interview**
Reference of adjustment measure	Mishel & Epstein, 1990	Marvin & Pianta, 1992
Adaptations from original measure	No	No

Reference	Oppenheim et al., 2024	Poslawsky et al., 2014
Title	Maternal and paternal insightfulness and reaction to the diagnosis in families of preschoolers with Autism spectrum disorder: Associations with observed parental sensitivity and inter-parent interaction	Parental reaction to early diagnosis for their children's autism spectrum disorder: An exploratory study
MMAT rating %	80	80
Demographics*		
Sample size	160 parents of 80 children - dyads	77
Child age mean (SD)	49.45 months	42.87 months (9.99)
Child age range	29-68 months	16-61 months
Child gender	100% male	86% male, 14% female
Caregiver gender	50% female, 50% male	90% female, 10% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	5.19 weeks (4.14)
Time since diagnosis range	Not reported	Not reported
Country conducted	Israel	Netherlands
Ethnicity	Not reported	90% of primary caregivers were Dutch, other nationalities were Chinese, Colombian, Israeli, Irish, French, Moroccan, Nigerian, Russian, Somali, Turkish
Child reported autism features	ADOS CSS: Mean 7.01 (SD 1.58)	ADOS-G total sum score: Mean 26.12 (SD 9.80)
Child other reported features	IQ WPPSI-III: Mean 68.01 (SD 25.01)	36% received comorbid somatic diagnosis
Name of adjustment measure	**Reaction to Diagnosis Interview**	**Reaction to Diagnosis Interview**
Reference of adjustment measure	Marvin & Pianta, 1996	Pianta & Marvin, 1992
Adaptations from original measure	As adapted in Wachtel & Carter, 2008	Reworded to be autism-specific; translated into Dutch

Reference	**Pakenham et al., 2004**	
Title	Finding meaning in parenting a child with Asperger syndrome: Correlates of sense making and benefit finding	
MMAT rating %	80	
Demographics*		
Sample size	59	
Child age mean (SD)	Children of mothers: 10.77 years (0.98). Children of fathers: 10.67 years (1.15).	
Child age range	10-12 years	
Child gender	84.7% male, 15.3% female	
Caregiver gender	79.7% female, 20.3% male	
Child age at diagnosis mean (SD)	Not reported	
Child age at diagnosis range	Not reported	
Time since diagnosis mean (SD)	Not reported	
Time since diagnosis range	Not reported	
Country conducted	Australia	
Ethnicity	Not reported	
Child reported autism features	Not reported	
Child other reported features	Not reported	
Name of adjustment measure	**Benefit Finding**	**Sense making**
Reference of adjustment measure	Current study - Pakenham et al., 2004	Current study - Pakenham et al., 2004
Adaptations from original measure	N/A	N/A

Reference	Qin et al., 2021	Reed et al., 2019
Title	Posttraumatic growth among parents of children with Autism Spectrum Disorder in China and its relationship to family function and mental resilience: A cross-sectional study	Actual and perceived speedy diagnoses are associated with mothers' unresolved reactions to a diagnosis of autism spectrum disorder for a child
MMAT rating %	100	80
Demographics*		
Sample size	205	67
Child age mean (SD)	3.63 years (1.30)	6.08 years (3.17)
Child age range	1-8 years	2-14 years
Child gender	85.85% male, 14.15% female	78% male, 22% female
Caregiver gender	57.56% female, 42.44% male	100% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	6.62 months (9.05)	N/A - diagnosed during the study
Time since diagnosis range	Not reported	Within 1 week
Country conducted	China	UK
Ethnicity	Not reported	Parents 69% White, 5% mixed/multiple, 15% Asian, 9% Black/African/Caribbean, 2% Other
Child reported autism features	Not reported	ADOS CSS: Mean 6.53 (SD 1.41)
Child other reported features	Not reported	Nonverbal functioning Leiter-R: Mean 72.33 (SD 13.34); Verbal functioning BPVS: Mean 67.66 (SD 16.58); Adaptive functioning Vineland: Mean 58.69 (SD 17.34)
Name of adjustment measure	**Posttraumatic Growth Inventory**	**Reaction to Diagnosis Interview**
Reference of adjustment measure	Tedeschi & Calhoun, 1996	Marvin & Pianta, 1992
Adaptations from original measure	Translated into Chinese in Liu et al., 2014	No

Reference	Reed & Osborne, 2019	Roselló et al., 2022
Title	Reaction to diagnosis and subsequent health in mothers of children with autism spectrum disorder	Personal and family childhood predictors of functional outcomes of adolescents with autism spectrum disorder
MMAT rating %	75	80
Demographics*		
Sample size	84	52
Child age mean (SD)	Not reported	8.56 years (1.38)
Child age range	Not reported	7-11 years
Child gender	85% male, 15% female	92.3% male, 7.7% female
Caregiver gender	100% female	Not reported
Child age at diagnosis mean (SD)	5.41 years, 4.00 years	Not reported
Child age at diagnosis range	1-25 years	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	0-3 months	Not reported
Country conducted	UK	Spain
Ethnicity	Parents 80% White, 2% mixed/multiple, 10% Asian, 4% Black/African/Caribbean, 4% Other	Not reported
Child reported autism features	ADOS CSS: Mean 7.70 (SD 0.98)	All Level 1
Child other reported features	Not reported	Intellectual functioning K-BITL: all > 80, Mean 101.41 (SD 12.65)
Name of adjustment measure	**Reaction to Diagnosis Interview**	**Brief COPE, engagement scale**
Reference of adjustment measure	Marvin & Pianta, 1992	Carver 1997
Adaptations from original measure	No	Translated into Spanish in Moran et al., 2011

Reference	**Rosenbrock et al., 2021**	**Salami & Alhalal, 2024**
Title	Exploring sociodemographic predictors of parents' perceptions about their children's autism and their families' adjustment	Gender differences in predictors of quality of life for parents of children with Autism Spectrum disorder in Saudi Arabia
MMAT rating %	100	75
Demographics*		
Sample size	363	376
Child age mean (SD)	13.65 years (3.41)	Children of mothers = 9.31 years (3.94). Children of fathers = 9.74 years (3.99)
Child age range	Not reported	3-18 years
Child gender	Not reported	Children of mothers = 69.5% male, 30.5% female; children of fathers = 87.2% male, 12.8% female
Caregiver gender	Not reported	58.6% female, 41.4% male
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	USA	Saudi Arabia
Ethnicity	Children 82.1% Caucasian, 3.2% African American, 2.8% Asian American, 6.1% more than one race, 5% other/not specified; 8.8% Hispanic or Latino	Mothers 92.3% Saudi, 7.7% non-Saudi; Fathers 93.6% Saudi, 6.4% non-Saudi
Child reported autism features	Caregiver perceived symptom severity: Mean 3.91 (SD 1.29)	CARS-2: Mother-rated mean 38.77 (SD 9.48); Father-rated mean 38.75 (SD 9.42)
Child other reported features	IQ measure not specified: Mean 82.32 (SD 28.19)	Not reported
Name of adjustment measure	**The Illness Perception Questionnaire-Revised for autism spectrum disorder**	**Adapted affiliate stigma scale**
Reference of adjustment measure	Original IPQ - Weinman et al., 1996	Mak & Cheung, 2008
Adaptations from original measure	As adapted in Mire et al., 2018	Adapted in Ting et al., 2018

Reference	Samios et al., 2008	Samios et al., 2009
Title	The nature of sense making in parenting a child with Asperger syndrome	The nature of benefit finding in parents of a child with Asperger syndrome
MMAT rating %	80	80
Demographics*		
Sample size	218	220
Child age mean (SD)	Children of mothers: 10.72 years (2.37). Children of fathers: 10.68 years (2.47).	Children of mothers: 10.72 years (2.37). Children of fathers: 10.65 years (2.47).
Child age range	5-18 years	5-18 years
Child gender	Children of mothers: 83% male, 15% female. Children of fathers: 85% male, 15% female.	Children of mothers: 82% male, 15% female. Children of fathers: 85% male, 15% female.
Caregiver gender	59.6% female, 40.1% male, 0.3% unknown gender	59.5% female, 40% male, 0.5% unknown gender
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Children of mothers: 49.67 months (27.07). Children of fathers: 50.80 months (27.46).	Children of mothers: 46.97 months (27.07). Children of fathers: 49.78 months (27.44).
Time since diagnosis range	1-144 months	1-144 months
Country conducted	Australia	Australia
Ethnicity	Not reported	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	Not reported	Not reported
Name of adjustment measure	**Sense Making Scale for Parents of Children with AS**	**Benefit Finding Scale for Parents of a Child with AS**
Reference of adjustment measure	Current study - Samios et al., 2008	Current study - Samios et al., 2009
Adaptations from original measure	N/A	N/A

Reference	Samios et al., 2012	
Title	Sense making and benefit finding in couples who have a child with Asperger syndrome: An application of the Actor Partner Interdependence Model	
MMAT rating %	80	
Demographics*		
Sample size	168 parents of 84 children - dyads	
Child age mean (SD)	Children of mothers: 10.63 years (2.52). Children of fathers: 10.54 years (2.52).	
Child age range	5-16 years	
Child gender	85% male, 16% female	
Caregiver gender	50% female, 50% male	
Child age at diagnosis mean (SD)	Not reported	
Child age at diagnosis range	Not reported	
Time since diagnosis mean (SD)	Children of mothers: 50.39 months (28.27). Children of fathers: 50.00 months (27.28).	
Time since diagnosis range	1-144 months	
Country conducted	Australia	
Ethnicity	Not reported	
Child reported autism features	CAST: Mean 20.20 (SD 3.89)	
Child other reported features	Not reported	
Name of adjustment measure	**Sense Making Scale for Parents of Children with AS**	**Benefit Finding Scale for Parents of a Child with AS**
Reference of adjustment measure	Samios et al., 2008	Samios et al., 2009
Adaptations from original measure	No	No

Reference	Sher-Censor et al., 2017	Su et al., 2013
Title	Coherence of representations regarding the child, resolution of the child's diagnosis and emotional availability: A study of Arab-Israeli mothers of children with ASD	Early intervention for children with autism spectrum disorders in China: A family perspective
MMAT rating %	80	60
Demographics*		
Sample size	46	156
Child age mean (SD)	61.80 months (25.18)	6 years 3 months
Child age range	2-8 years	1-12 years
Child gender	100% male	82.1% male, 17.9% female
Caregiver gender	100% female	Not reported
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	31.04 months (21.84)	Not reported
Time since diagnosis range	Minimum 6 months	Not reported
Country conducted	Israel	China
Ethnicity	Parents 87.0% Muslim, 10.9% Muslim, 2.2% Druze	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	Adaptive behaviour Vineland: 97.8% had a low level of adaptive behaviour, Mean 39.85 (SD 10.79)	Not reported
Name of adjustment measure	**Reaction to Diagnosis Interview**	**Unnamed measure of family beliefs regarding ASD**
Reference of adjustment measure	Marvin & Pianta, 1992	Current study - Su et al., 2013
Adaptations from original measure	No	N/A

Reference	Vitale et al., 2022	Wang et al., 2024
Title	Challenging behavior and parental depression: The effects of everyday stressors and benefit finding for parents of children with Autism Spectrum Disorder	Relationship between mindfulness and affiliate stigma in parents of children with Autism Spectrum Disorder in China: The mediating role of coping styles
MMAT rating %	60	80
Demographics*		
Sample size	408	345
Child age mean (SD)	Children of mothers: 79.28 months (29.66). Children of fathers: 80.54 months (30.67).	Not reported
Child age range	25-154 months	Not reported
Child gender	Children of mothers: 83.6% male, 16.4% female. Children of fathers: 81.0% male, 19.0% female	50.4% male, 49.6% female
Caregiver gender	61% female, 39% male	50.2% female, 49.8% male
Child age at diagnosis mean (SD)	Children of mothers: 38.74 months (17.76). Children of fathers: 38.15 months (17.45).	Not reported
Child age at diagnosis range	14-109 months	Not reported
Time since diagnosis mean (SD)	Children of mothers: 42.35 months (31.33). Children of fathers: 40.54 months (30.52).	Not reported
Time since diagnosis range	0-140 months	Not reported
Country conducted	USA	China
Ethnicity	Not reported	Not reported
Child reported autism features	Not reported	Not reported
Child other reported features	Not reported	Children with malignant tumors, organic diseases, or those in unstable or critical condition were excluded.
Name of adjustment measure	**Benefit Finding Scale**	**Affiliate stigma scale, Chinese version**
Reference of adjustment measure	Carver & Antoni, 2004	Mak & Cheung, 2008
Adaptations from original measure	As adapted in Ekas et al., 2015	Adapted in Yin Qunming et al., 2021

Reference	**Wachtel & Carter, 2008**
Title	Reaction to diagnosis and parenting styles among mothers of young children with ASDs
MMAT rating %	100
Demographics*	
Sample size	63
Child age mean (SD)	32 months (7.1)
Child age range	20-50 months
Child gender	76% male, 24% female
Caregiver gender	100% female
Child age at diagnosis mean (SD)	23 months (4.81)
Child age at diagnosis range	11-32 months
Time since diagnosis mean (SD)	9.9 months (7.1)
Time since diagnosis range	2-28 months
Country conducted	USA
Ethnicity	Parents 87.3% White, 4.8% Asian, 3.2% Hispanic, 4.8% more than one race; Children 84.1% White, 3.2% Asian, 4.8% Hispanic, 7.9% more than one race
Child reported autism features	ADOS-G communication: Mean 4.41 (SD 1.72); social interaction: Mean 10.21 (SD 3.11); stereotyped behaviour: Mean 3.73 (SD 1.53); ADI-R social behaviour: Mean 16.89 (SD 4.79); communication: Mean 11.44 (SD 3.12); repetitive behaviour: Mean 4.80 (SD 2.07).
Child other reported features	Not reported
Name of adjustment measure	**Reaction to Diagnosis Interview**
Reference of adjustment measure	Marvin & Pianta, 1992
Adaptations from original measure	Added a coding system to allow for continuous measurement of resolution of diagnosis

Reference	**Wayment & Brookshire, 2018**	
Title	Mothers' reactions to their child's ASD diagnosis: Predictors that discriminate grief from distress	
MMAT rating %	80	
Demographics*		
Sample size	362	
Child age mean (SD)	11.63 years (4.08)	
Child age range	2-18 years	
Child gender	81% male, 19% female	
Caregiver gender	100% female	
Child age at diagnosis mean (SD)	4.14 years (3.07)	
Child age at diagnosis range	1-26 years	**Unnamed measure of perception of autism diagnosis as a loss**
Time since diagnosis mean (SD)	7.70 years (3.93)	Current study - Wayment & Brookshire, 2018
Time since diagnosis range	Not reported	N/A
Country conducted	USA	
Ethnicity	Parents 85% Caucasian, 6.2% Latina, 3.4% Asian, 2.5% Afrian-American, 2.3% Native American, 3% not specified	**Unnamed measure of perceived injustice of autism diagnosis**
Child reported autism features	Novel ASD index: Mean 4.17 (SD 1.5)	Lepore et al., 1996
Child other reported features	Not reported	Reworded to be autism-specific

Name of adjustment measure	**Illness Perception Questionnaire (Impact on Parent subscale)**	**Health Specific Locus of Control measure; parent control subscale**
Reference of adjustment measure	Weinman et al., 1996	Rau & Ware, 1981
Adaptations from original measure	No	Reworded to be autism-specific

Reference	**Wayment et al., 2019**	
Title	Challenged and changed: Quiet ego and posttraumatic growth in mothers raising children with autism spectrum disorder	
MMAT rating %	100	
Demographics*		
Sample size	364	
Child age mean (SD)	11.63 years (4.08)	
Child age range	2-18 years	
Child gender	81% male, 19% female	
Caregiver gender	100% female	
Child age at diagnosis mean (SD)	4.14 years (3.07)	
Child age at diagnosis range	Not reported	
Time since diagnosis mean (SD)	7.7 years (3.9)	
Time since diagnosis range	Not reported	
Country conducted	USA	
Ethnicity	Parents 85% White, 6.2% Latina, 3.4% Asian, 2.5% African-American, 2.3% Native American	
Child reported autism features	Not reported	
Child other reported features	Mean 1.47 comorbid health issues (SD 1.50), most commonly ADHD, anxiety-related issues, and apraxia.	
Name of adjustment measure	**Posttraumatic Growth Inventory**	**Unnamed measure of ASD-related rumination**
Reference of adjustment measure	Tedeschi & Calhoun, 1996	Current study - Wayment et al., 2019
Adaptations from original measure	No	Items combined from several other measures; reworded to be autism-specific

Reference	White, 2009	Wynn et al., 2024
Title	The influence of religiosity on well-being and acceptance in parents of children with Autism Spectrum Disorder	Impact of a genetic diagnosis for a child's autism on parental perceptions
MMAT rating %	60	60
Demographics*		
Sample size	177	1174
Child age mean (SD)	9 years	13 years (6.5)
Child age range	2-31 years	3-43 years
Child gender	89% male, 11% female	81.3% male, 18.6% female
Caregiver gender	87% female, 13% male	74.1% male, 25.7% female, 0.1% transgender
Child age at diagnosis mean (SD)	Not reported	4.1 years (2.9)
Child age at diagnosis range	Not reported	1-33
Time since diagnosis mean (SD)	Not reported	Not reported
Time since diagnosis range	Not reported	Not reported
Country conducted	USA	United States
Ethnicity	"10% were members of visible minority ethnic groups"	Parents 83.6% White, 0.8% Native American, 2.8% Asian, 2.6% Black, 0.2% Pacific Islander/Hawaiian, 0.6% Middle Eastern/Mediterranean, 6.5% Unknown, 2.8% multiple races; 8.0% Hispanic/Latino, 92.0% not-Hispanic/Latino
Child reported autism features	Not reported	Not reported
Child other reported features	24% had comorbid diagnoses including ADHD, OCD, epilepsy/seizure disorder, intellectual disability, Tourette's syndrome, and anxiety disorder	IQ: Mean 77.8 (SD 18.1)
Name of adjustment measure	**Autism Acceptance Scale**	**Unnamed measure of perceived cause of autism**
Reference of adjustment measure	Current study - White et al., 2009	Current study - Wynn et al., 2024
Adaptations from original measure	Adapted from Parental Attitude Research Instrument (Zuk et al., 1961)	N/A

Reference	**Yang et al., 2024**
Title	Development and evaluation of a family-child reading picture book on reducing autism spectrum disorder caregivers’ psychological stress: A mixed method study
MMAT rating %	60
Demographics*	
Sample size	39
Child age mean (SD)	Not reported
Child age range	Not reported
Child gender	Not reported
Caregiver gender	92.3% female, 7.7% male
Child age at diagnosis mean (SD)	Not reported
Child age at diagnosis range	Not reported
Time since diagnosis mean (SD)	Not reported
Time since diagnosis range	Not reported
Country conducted	China
Ethnicity	Not reported
Child reported autism features	Not reported
Child other reported features	Not reported
Name of adjustment measure	**Affilitate stigma scale**
Reference of adjustment measure	Mak & Cheung, 2008
Adaptations from original measure	No

Reference	Yirmiya et al., 2015	Zhang et al., 2023
Title	Stability and change in resolution of diagnosis among parents of children with autism spectrum disorder: Child and parental contributions	Social support and parenting self-efficacy in parents of children with ASD: The mediating role of post-traumatic growth and the moderating role of self-esteem
MMAT rating %	100	80
Demographics*		
Sample size	78 parents of 39 children - dyads	208
Child age mean (SD)	Boys: 141.25 months (41.18). Girls: 133.06 months (43.15).	Not reported
Child age range	Boys: 74-245 months. Girls: 64-196 months.	Not reported
Child gender	56.4% male, 43.6% female	78.3% male, 27.7% female
Caregiver gender	50% female, 50% male	85.1% female, 14.9% female
Child age at diagnosis mean (SD)	Not reported	Not reported
Child age at diagnosis range	Not reported	Not reported
Time since diagnosis mean (SD)	Boys: 94.84 months, 35.61 months. Girls: 77.41 months, 37.08 months.	Not reported
Time since diagnosis range	Boys: 152-152 months. Girls: 36-155 months.	Not reported
Country conducted	Israel	China
Ethnicity	Not reported	Not reported
Child reported autism features	ADOS CSS: Boys Mean 8.59 (SD 1.44); Girls Mean 7.06 (SD 1.56)	Not reported
Child other reported features	Excluded medical conditions associated with autism (e.g., Fragile X and tuberous sclerosis); adaptive behaviour Vineland: Boys Mean 52.77 (SD 18.78); Girls Mean 54.76 (SD 13.50).	Not reported
Name of adjustment measure	**Reaction to Diagnosis Interview**	**Post-traumatic Growth Inventory**
Reference of adjustment measure	Marvin & Pianta, 1992	Tedeschi & Calhoun, 1996
Adaptations from original measure	No	Added introductory sentence to make the measure autism-specific

Check for updates

autism

Review

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Systematic review of measures and interventions for caregiver adjustment to child autism diagnosis

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Abstract

Caregivers' adjustment to their child's autism diagnosis has important implications for child and caregiver outcomes. However, there has been substantial variability in definitions and measurement of caregiver adjustment to autism diagnosis. This study reports a systematic review of measures of caregivers' adjustment to their child's autism diagnosis, and the effectiveness of intervention for caregiver adjustment. A systematic review (PROSPERO CRD42023463196) was conducted according to PRISMA guidelines. Adjustment was defined as caregivers' psychological response to their child's autism diagnosis. Database searches yielded 6345 unique articles, which were title and abstract screened. Full text screening was completed for 428 articles. Mixed Methods Appraisal Tool (MMAT) was used to assess study quality. The review identified 78 articles, which included 42 measures of adjustment and eight interventions targeting adjustment, four of which produced significant improvement in adjustment. Study quality was mostly adequate. The review identified a need for consensus on defining and measuring caregiver adjustment. The review also identified the need for fathers, caregivers who are autistic, and caregivers of adults to be more included in adjustment research. There is preliminary evidence for interventions supporting adjustment, but further research is needed.

Lay abstract

The process of understanding and accepting a child's diagnosis of autism, known as adjustment, is important for the ongoing well-being of autistic people and their caregivers. The way that researchers have defined and measured adjustment has not been consistent. This article reports a systematic review aiming to identify how adjustment has been defined and measured in published research. The review also aimed to identify interventions that have targeted caregiver adjustment and see whether they are effective. The review identified 78 articles, which included 42 measures of adjustment and eight interventions. Four of the interventions demonstrated significant benefits for adjustment. There is a need for further research to develop a consensus regarding definition and measurement of adjustment, so that adjustment can be measured more consistently across studies. There is also a need for research looking at whether existing interventions for autism have benefits for caregiver adjustment, and to conduct more rigorous evaluations of any new adjustment interventions that are developed.

Keywords

adjustment, autism, measurement, parents, systematic review

Worldwide prevalence estimates of autism range from 1% to 3% (Bradshaw et al., 2024; Nielsen et al., 2023; Wallis et al., 2023; Yang et al., 2023). While autism can be reliably diagnosed from 18 months in children with high levels of autistic traits (Benedetto et al., 2021), the global mean age of diagnosis is 5 years (van't Hof et al., 2020).

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The journey from caregivers' first concerns regarding a child's development to receiving an official autism diagnosis takes an average of 12 to 26 months, which can delay access to services and lead to confusion and stress for caregivers (Bent et al., 2020; Rivard et al., 2021). Then, in the period immediately after their child's diagnosis, caregivers report experiencing a complex range of emotions such as shock, grief at the loss of the future they had envisioned for their child and worry about what the child's future will hold (Fernández-Alcántara et al., 2016; Mansell & Morris, 2004). Some caregivers also report more positive emotions such as a sense of relief at the increased understanding of the child that can come with diagnosis (Mulligan et al., 2012).

Over time, caregivers then go through a process known as adjustment to the diagnosis. Caregiver adjustment has been considered across a range of diagnoses, including cerebral palsy (Rentinck et al., 2007), Down syndrome (e.g. Clark et al., 2020; Poehlmann et al., 2005) and cancer (Long & Marsland, 2011). However, aspects of adjustment to an autism diagnosis may be distinct from adjustment to these other conditions. In particular, uncertainty regarding the cause of autism, the diagnosis of autism through clinical judgement rather than objective medical testing, and difficulty predicting long-term outcomes can make adjustment to an autism diagnosis particularly complex (M. O'Brien, 2007). There is therefore a substantial body of literature aiming to understand the process of parent adjustment to child autism diagnosis specifically. There are also a range of autism-specific measures of adjustment to diagnosis, either adapted from measures addressing adjustment to other diagnoses, or developed specifically to assess adjustment to autism diagnosis.

Across this body of research evaluating caregiver adjustment to autism diagnosis, definitions of adjustment span a range of constructs, including more practical adjustments such as managing daily hassles and changes to daily routines (e.g. Dai & Carter, 2023), as well as psychological aspects of adjustment. Even within research focusing on psychological adjustment, definitions of adjustment range from more general caregiver mental health outcomes such as stress and mood (e.g. Benson, 2012; Gau et al., 2012), to those which look more specifically at caregivers' attitudes and emotions regarding their child's autism diagnosis (e.g. Da Paz et al., 2018; Dolev et al., 2016). In an effort to make the current review as focused as possible, adjustment was defined here as caregivers' psychological response to their child's diagnosis of autism. Adjustment is discussed interchangeably in the literature as both a process and an outcome – while theoretical discussions frame adjustment as an ongoing psychological process (Negri & Castorina, 2014), measurement typically captures a snapshot of adjustment outcomes at a particular timepoint. Within the current review, the term 'higher adjustment' will be used to refer to more optimal adjustment outcomes (operationalised in quantitative research as higher scores on measures of adjustment) as compared to 'lower adjustment'. However, it is important to note that adjustment does not necessarily fall on a linear scale, and that what is conceptualised as 'higher adjustment' may vary depending on how adjustment is defined, and indeed how autism is understood within a given study. For example, research applying a neurodiversity lens may define optimal adjustment differently as compared to research that conceptualises autism through the medical model (Kapp et al., 2013).

The variability in definitions of adjustment to autism diagnosis is likely underscored by the range of theoretical models that have been applied to understanding adjustment. Broadly, researchers have applied process models of trauma and grief, as well as cognitive models of coping. Considering the application of models of trauma and grief, it is important to acknowledge that caregivers may be adjusting not only to the day-to-day reality of parenting an autistic child but also to their assumptions about what an autism diagnosis will mean for their child and family, and to the perceived loss of the neurotypical child and the idealised future they had imagined (Gentles et al., 2020; Sinclair, 1993). For example, caregivers may assume that an autism diagnosis means that their child will never live on their own or get married, which may or may not be accurate for their child. Researchers have therefore understood adjustment as the process of working through these initial beliefs about autism and associated feelings. Some research has conceptualised the child's diagnosis as a traumatic event (Casey et al., 2012; W. Zhang et al., 2015) and associated research has therefore utilised post-traumatic outcome measures to measure caregiver adjustment on a continuum from post-traumatic stress or post-traumatic growth. Alternatively, Kübler-Ross' (1969) staged model of grief has been applied to conceptualise the process of adjusting as that of grieving the life parents had expected for their child. While the majority of research on caregiver adjustment to autism diagnosis has not included autistic perspectives, neurodiversity advocate Jim Sinclair emphasised that it is important for caregivers to adjust by working through their grief for the neurotypical child they expected to have, so that they can accept and value the autistic child they do have (Sinclair, 1993). In line with a grief model of adjustment, researchers have used measures which capture some, or all, of the stages of grief, such as denial, despair and acceptance (e.g. Da Paz et al., 2018; Wayment & Brookshire, 2018). However, more recent research has emphasised that adjustment is generally nonlinear and does not have a finite endpoint, as caregivers continue to adjust throughout the child's life (Negri & Castorina, 2014). In particular, caregivers' adjustment may fluctuate as they experience intermittent reminders of their child's difficulties, for example during major life transitions such as the child starting school or reaching adolescence; thus, caregiver adjustment to child autism diagnosis has been conceptualised as an ongoing process of *chronic sorrow* (Copley & Bodensteiner, 1987; Olshansky, 1962). Researchers have also applied the theory of *ambiguous loss*, noting that the process of adjustment is complicated by the fact that autistic individuals can have a vast range of outcomes, which means that the future that caregivers are adjusting to is more unclear as compared to a finite loss such as bereavement (Boss, 1999; Bravo-Benitez et al., 2019; M. O'Brien, 2007).

Distinct from these more process-oriented models, another body of research has focused on adjustment from the perspective of caregivers' cognitive appraisal of their child's autism diagnosis (Lazarus & Folkman, 1984; Rasmussen et al., 2020). Researchers have therefore measured various aspects of parental cognitions such as self-blame (Lodder et al., 2020; Mak & Kwok, 2010), perceived injustice (Wayment & Brookshire, 2018), use of coping strategies (Ayyash et al., 2023) and rumination (Wayment et al., 2019). This cognitive approach can also include understanding caregiver attitudes and beliefs. For instance, caregivers' stigmatising beliefs about autism and towards themselves as a parent of an autistic child, have been measured as a facet of adjustment to diagnosis (Anthony et al., 2020; Chan & Lam, 2018). However, longitudinal research exploring processes of change in these cognitive aspects of adjustment has been notably limited.

Given that adjustment has been understood through many different definitions and conceptual frameworks, it is challenging to compare findings across studies of adjustment. This limits researchers' ability to clearly identify factors that benefit or hinder adjustment, as well as adjustment's caregiver- and child-level sequelae. Research suggests that child-level factors such as level of autism features, as well as caregiver-level factors such as cultural background and access to informal supports, may influence caregivers' adjustment (see Naicker et al., 2023, for a review). However, findings regarding predictors of adjustment have been notably inconsistent across studies (e.g. Dolev et al., 2016; Ferenc et al., 2023; Mohammad et al., 2022; Rosenbrock et al., 2021; Wayment & Brookshire, 2018). Caregivers with greater prior knowledge of and experience with autism generally experience fewer challenges with adjustment (Gentles et al., 2020). The experience of adjustment to a child's autism diagnosis therefore likely differs for parents who are autistic themselves, though research has yet to assess this. Adjustment appears to be important for family functioning following a child's autism diagnosis, including caregivers' own mental health and well-being (Da Paz et al., 2018; Dolev et al., 2016; Jones et al., 2014; Vitale et al., 2023), as well as their ability to engage sensitively with the child (Di Renzo et al., 2020; Oppenheim et al., 2007, 2024; Wachtel & Carter, 2008). However, our ability to develop a thorough understanding of adjustment and its relation to other aspects of family functioning has been hampered by inconsistencies in how adjustment has been defined and measured. Accordingly, the first aim of the current systematic review was (1a) to identify measures of caregiver adjustment to autism diagnosis, including (1b) documenting the constructs these claim to measure as well as (1c) the reported psychometric properties of the measures.

Second, while higher adjustment appears to contribute to positive caregiver mental health and caregiver–child relationship outcomes (Di Renzo et al., 2020; Dolev et al., 2016; Vitale et al., 2023), our understanding of how best to support caregivers' adjustment is limited. There is an increasing emphasis on the involvement of caregivers in intervention for autistic individuals, especially early intervention for young children (Maglione et al., 2012). Through this caregiver involvement in intervention, the caregiver learns strategies to develop their child's skills and/or manage the child's challenges, such as externalising behaviour (Schreibman & Anderson, 2001; Schultz et al., 2011; Swain et al., 2025). While some studies suggest that improvements in child functioning can have flow-on benefits for caregivers, the research examining caregiver outcomes in autism intervention remains in its early stages; several reviews have failed to find a consistent effect on caregiver outcomes and have highlighted limitations of the evidence base (Conrad et al., 2021; Factor et al., 2019; Schultz et al., 2011). Augmenting caregiver training with components focused more directly on the caregiver themselves, such as training in mindfulness or acceptance-based strategies, may improve caregiver outcomes (Li et al., 2024). However, prior reviews have tended to adopt a broad focus across multiple aspects of caregiver functioning, and so are not able to offer insights into intervention effects for caregiver adjustment specifically. For researchers and clinicians to best support families along their journey of adjustment, it is important to understand what interventions are already being provided aimed at supporting caregiver adjustment, and their effects. The second aim of the current review was therefore (2a) to identify interventions for which caregiver adjustment has been evaluated as an outcome, and (2b) their effects on caregiver adjustment.

Method

The current systematic review adhered to PRISMA guidelines (Liberati et al., 2009). The protocol for this systematic review was registered on PROSPERO (CRD42023463196).

Search strategy

An electronic search was conducted by the first author on August 30, 2023, of the following databases: PsycINFO, Medline, Scopus, Web of Science, and the Cochrane Central Register of Controlled Trials. The keywords used were (adjust* OR accept* OR resol* OR grief OR 'respon* to diagnosis' OR 'react* to diagnosis') AND (parent* OR caregiver*) AND (autis* OR asperg* OR ASD). Subsequent searches were conducted on November 15, 2024, and October 3, 2025, to capture articles published since the initial search date. The searches were limited to peer reviewed articles published in English and to papers classified as using quantitative methods; not all databases allowed for automatic limiting by these criteria, so some articles outside of these limits were excluded manually through later screening. No limits on publication date were applied, given that the review aimed to capture how adjustment to autism diagnosis has been measured across a changing theoretical landscape. The current review did not include grey literature searching or searching of article reference lists. Articles identified through this search were uploaded into Covidence, a web-based collaboration software platform that streamlines the production of systematic and other literature reviews (Covidence Systematic Review Software, 2023). Duplicates were automatically removed by Covidence.

Screening

Covidence software was used to screen identified articles according to the following eligibility criteria: (1) Study sample is primary or secondary caregivers of care recipient with a confirmed diagnosis of autism spectrum disorder; (2) Study includes quantitative measurement of caregivers' psychological response to their child's autism diagnosis; (3) Original research articles published in peer reviewed journals in English. See Supplemental Material for complete inclusion and exclusion criteria including a list of concepts included under 'adjustment'. At each stage of screening, the first author (E.C.W.) screened 100% of articles. Four other authors (L.T., A.T., B.L., and E.M.) completed secondary screening, resulting in a total of 30% of articles double screened at each stage. Agreement for inclusion/exclusion at the title and abstract screening stage was 93%, and for full text inclusion/exclusion was 84%. For disagreements on inclusion at title and abstract screening, the article was included through to full text screening to allow for thorough evaluation. Disagreements at full text review were resolved through discussion between the two reviewers. Where the information provided in the article was insufficient to determine inclusion at full text screening (e.g. description of outcome measure was unclear), the corresponding author was contacted via email once with the request for the relevant information. Studies were subsequently excluded if no response was received within 1 month. Any duplicates that had not been automatically removed by Covidence were manually marked as duplicates and removed during screening.

Data extraction and quality appraisal

Data extraction was completed by the first author (E.C.W.). Extracted data were organised into the following sections: Demographics, Measure information and psychometric properties (Aim 1), and Intervention design and results (Aim 2). Multiple measures of adjustment included in the same study were extracted separately where relevant.

Article quality was assessed by the first author using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). Articles were classified as quantitative randomised controlled trials, quantitative non-randomised studies or quantitative descriptive studies and assessed for the five criteria for the relevant study type. For each criterion, a response of 'Yes', 'No', or 'Can't tell' was selected, with the percentage of 'Yes' responses calculated to determine the overall article quality out of 100%.

Results

Study selection

See Figure 1 for PRISMA flowchart. A total of 3189 articles from the initial search were screened after removal of duplicates; a further 2615 and 541 were screened following the updated searches in November 2024 and October 2025, respectively. Following title and abstract screening, the full text of 428 studies was reviewed. During full text review, the authors of five articles were contacted to request for a copy of the full outcome measure to assess eligibility. One author provided a copy of the outcome measure, which was determined not to meet inclusion criteria upon review; the remaining authors did not respond and so the relevant articles were excluded due to the outcome measure as described in the article not meeting inclusion criteria. The most common reason for exclusion at full text review was that the outcome measure did not measure caregiver adjustment to the child's autism diagnosis ($n=278$ articles). A final sample of 78 articles was included to address Aim 1, with a subsample of eight articles with an intervention component included to address Aim 2. All articles included to address Aim 2 were also included in the sample of studies addressing Aim 1. Articles were published between 2004 and 2025. See Supplemental Table 1 for a list of included articles.

Study quality

Study quality according to the MMAT ranged from 0% to 100%, with an average study quality of 78.03%. Study quality for each included article is reported in Supplemental Table 1. The most common reason for lower study quality was that the sample was not representative of the target

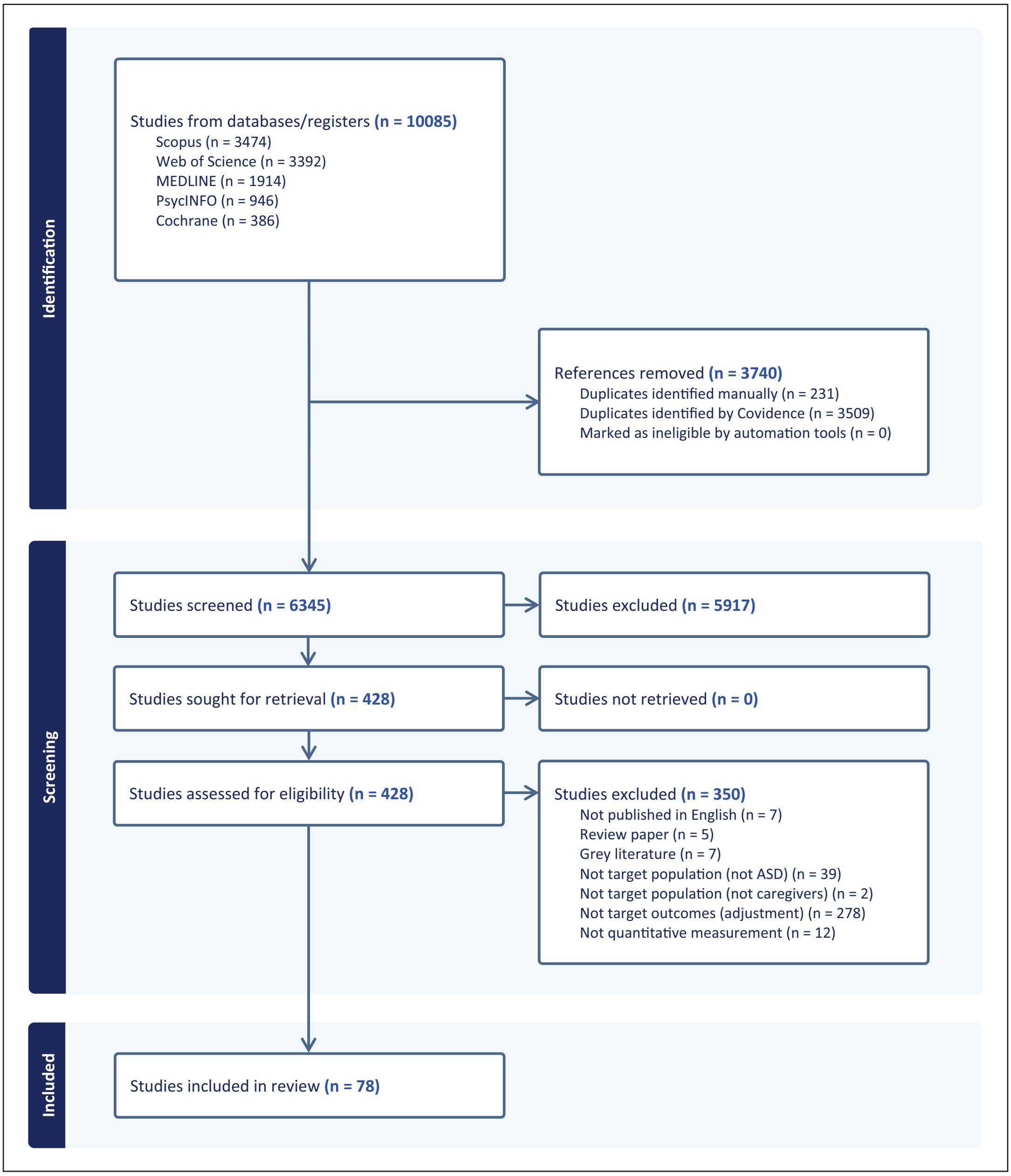

Figure 1. PRISMA flowchart. (Generated using Covidence).

population or representativeness could not be determined; this was due to articles failing to report study inclusion and exclusion criteria or providing insufficient information regarding how a diagnosis of autism spectrum disorder was confirmed in their study.

Participant characteristics

Participant characteristics, reported in Supplemental Table 1, were excluded from analysis when not reported in an article or associated supplementary materials. Studies were conducted across 24 countries, with the highest number of studies conducted in the United States (31%). The overall sample size across 78 studies was 14,163 caregivers; however, it is important to note that articles using the same sample as another article were not excluded, and some articles utilised large autism research databases such as the Simons Simplex Collection (Fischbach & Lord, 2010). Thus, it is likely that the articles do not include 14,163 unique participants. The sample size per article ranged from 17 to 1174. Overall, 81.81% of caregivers were mothers, with 22 studies including only mothers. Seven studies included mother–father dyads of the same child. In no studies did fathers comprise the majority of the sample. Four studies reported on caregiver neurodivergence – two (Lee et al., 2024, 2025) reported whether parents were diagnosed autistic (10%–27%), self-identified autistic (5%), or questioning whether they are autistic (15%–27%), while two studies assessed parent autistic traits using a continuous measure but did not assess parent autism diagnosis (Leadbitter et al., 2025; Milshtein et al., 2010).

Children of caregivers included in the extracted articles were 79.95% male and ranged in age from 1 to 43 years. Nearly half (44%) of the included articles ($n=34$) had a mean child age within the school age range (ages 6–12 years). No articles exclusively included adult offspring, though two studies (Lunsky et al., 2021; Montoya et al., 2024) focused on older adolescents and adults. The average child age at diagnosis across the 17 articles that reported this was 4.09 years, and the mean interval between diagnosis and completion of the measure of adjustment across the 24 articles that reported this was 40.60 months. About half of the included articles ($n=36$, 46.15%) failed to report information about the race or ethnicity of children or parents. Twenty-nine articles included information characterising the autism traits of the sample (such as diagnosis level or mean scores on a measure of autism traits), and 41 articles included other clinical information about the children such as intellectual functioning or medical conditions.

Aim 1 – measures of adjustment

Across the 78 studies included, 42 unique measures of adjustment were used (Aim 1a). See Supplemental Table 2 for full information regarding the included measures. All measures were questionnaires except the Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1993), which is a semi-structured interview with a coding scheme that allows for the classification of caregivers' reaction to the child's diagnosis as resolved or unresolved. The RDI was the most commonly used measure of adjustment, used in 13 studies. The most commonly used questionnaire measures were the Affiliate Stigma Scale (10 studies; Mak & Cheung, 2008), the Illness Perception Questionnaire Revised for ASD (7 studies; Mire et al., 2018), and the Post-Traumatic Growth Scale (7 studies; Tedeschi & Calhoun, 2004). There were 30 measures each used only in one included study. Regarding Aim (1b), the included measures spanned 22 constructs, the most common of which was perceived positive contributions of autism to the caregiver's life. The construct assessed by each measure is listed in Supplemental Table 2. Mapping onto the broad theoretical approaches to understanding adjustment, most of these constructs focused either on the process of adjustment, or on caregivers' cognitive appraisal of autism. Process focused measures included measures of resolution (e.g. Reaction to the Diagnosis Questionnaire; Sher-Censor et al., 2020), grief (e.g. Caregiver Grief Scale; Meichsner et al., 2016), and post-traumatic growth (e.g. Post-Traumatic Growth Scale; Tedeschi & Calhoun, 2004). Measures assessing appraisal of autism included measures of initial reaction to diagnosis (e.g. Anderberg & South, 2001), beliefs about or perceptions of autism (e.g. Attitudes Towards Autism Questionnaire; Ferenc et al., 2023) and measures of caregivers' self-perception as a caregiver of an autistic child (e.g. Affiliate Stigma Scale; Mak & Cheung, 2008; Self-Blame & Responsibility Scale; Mak & Kwok, 2010).

Psychometric properties of included measures (Aim 1c) are included in Supplemental Table 1. The majority of measures had acceptable internal consistency (Cronbach's $\alpha > 0.70$); however, this was not reported for nine measures. Factor analysis was conducted for 11 of the measures. Only six measures were assessed for validity and six for test–retest reliability, with one of these six demonstrating non-significant correlations between Time 1 and 2 scores (Samios et al., 2009). Fifteen measures were used to evaluate change in adjustment over time, with 11 of these demonstrating significant changes over time.

Aim 2 – interventions

Eight identified articles included an intervention targeting caregivers' adjustment to their child's autism diagnosis (Aim 2a). See Supplemental Table 3 for information regarding interventions and outcomes. Four intervention studies (Bravo-Benítez et al., 2024; Leadbitter et al., 2025; Lee et al., 2025; Lodder et al., 2020) used a randomised controlled trial design, while other studies used a single group design without a control group. Interventions were delivered to caregivers only (i.e. without any involvement of the child), aside from the picture book intervention (Yang et al., 2024), which briefly included children at the end of the session and required caregivers to engage children in home practice. Most interventions were delivered in group format. The majority of interventions included psychoeducation about autism and/or the adjustment process. Other intervention content included cognitive therapy strategies (Bravo-Benítez et al., 2024; Lunsky et al., 2021), Acceptance and Commitment Therapy (Leadbitter et al., 2025; Lee et al., 2025), mindfulness and acceptance-based strategies (Lodder et al., 2020; Lunsky et al., 2021) and problem-solving training (Nguyen et al., 2016). Regarding Aim (2b), the SOLACE (Lodder et al., 2020), Problem-Solving Skills Training (Nguyen et al., 2016) and caregiver grief (Bravo-Benítez et al., 2024) interventions evidenced statistically significant improvements in caregiver adjustment, which were maintained in those studies which included a follow-up timepoint. The Empower-Autism intervention (Leadbitter et al., 2025) also supported higher adjustment at 52-week follow-up as compared to treatment as usual; however, there was no measure of adjustment immediately post-intervention for this study. Medium to large effect sizes were reported for the complicated grief intervention (Bravo-Benítez et al., 2024), and a small effect size was reported for Empower-Autism (Leadbitter et al., 2025). None of the studies reported clinical significance of change.

Discussion

This systematic review identified measures of caregivers' adjustment to their child's diagnosis of autism. The review's second aim involved identifying interventions for caregiver adjustment and examining their effectiveness. The review identified 42 measures of caregiver adjustment used across 78 studies. These measures spanned 22 constructs, which spanned the main theoretical models that have been applied to understanding adjustment. The review identified eight interventions, four of which demonstrated statistically significant changes in caregiver adjustment (three compared to a control) with effect sizes ranging from small to large.

Measurement

The included measures spanned several conceptualisations of adjustment, such as acceptance, positive contributions of the diagnosis to the caregiver's life and post-traumatic growth. This substantial variability in how adjustment has been defined and measured was present despite this review's specific focus on caregivers' psychological response to their child's autism diagnosis, excluding measures of practical adjustment or broader caregiver well-being. Amid the shifting theoretical conceptualisation of caregiver adjustment (Negri & Castorina, 2014), it is clear that the field has yet to agree on a clear definition of adjustment. This is a core limitation of the research in this area; it is not possible to validate whether a measure is accurately capturing a construct without first having a clear definition of what the construct is (Wacker, 2004). Furthermore, without clear consensus regarding what *does* and *does not* fall into a construct, researchers may fall into concept stretching, whereby related but distinct constructs blur together (Wacker, 2004). Indeed, the number of constructs assessed by the measures identified here suggests that concept stretching has likely occurred in the absence of a clear definition of adjustment to diagnosis. Inadequate definition of a construct, and concept stretching, can in turn confound researchers' ability to identify consistent effects and draw clear conclusions, as studies that appear to measure the same construct may not be. It is therefore imperative that the next step in research investigating caregiver adjustment to child autism diagnosis is the development of a clear definition. Ideally, a consensus definition should be co-produced with autistic people and parents of autistic people, including autistic parents, and using Delphi methodology to seek expert consensus among those who work with parents of autistic children (Dalkey & Helmer, 1963).

Once adjustment is more clearly defined, further research will be needed to validate the proposed theoretical models of adjustment, and ideally to identify a model that best explains adjustment to diagnosis. While it was beyond the scope of the current study to formally identify the theoretical underpinning of each included study, a range of theoretical constructs were present, which likely contributed to variability in how adjustment was defined and measured across studies. Defining a clear theoretical model which accurately explains adjustment will support greater consistency in how adjustment is conceptualised. It was also beyond the scope of the current study to assess whether each study conceptualised autism through a medical or neurodiversity lens. This distinction will be important to explore in future adjustment research, given that the way autism itself is conceptualised in a given study will likely impact the way that adjustment to the diagnosis is understood.

The current study identified a range of measures of adjustment. In fact, nearly half the measures identified were only used in a single study, making it difficult to compare the results of those studies. It is important to note that these novel measures were often developed for studies conducted in countries that are typically underrepresented in autism research, such as Kuwait (Al-Kandari et al., 2017) and Qatar (Kheir et al., 2012). Such measures were likely developed with a goal of culturally sensitive measurement, which may indicate a need for cross-cultural validation of more commonly used measures of adjustment.

Many of the measured constructs appear to assess only part of the construct of adjustment. For example, grief measures may focus only on negative emotional reactions to diagnosis, whereas benefit-finding measures may focus only on caregivers' positive emotions. While it is challenging to make specific recommendations before first clearly defining adjustment, it seems important that measures of adjustment should aim to capture both positive and negative reactions to diagnosis. It is not sufficient to assume that the absence of a positive reaction constitutes a negative reaction, or vice versa, given that caregivers commonly report experiencing mixed emotions in response to their child's autism diagnosis (Anderberg & South, 2021; Makino et al., 2021). Where studies have captured multiple facets of adjustment through the use of subscales, these have shown differential relations to other outcomes (e.g. Da Paz et al., 2018; Lee et al., 2025). This suggests a need for further research to confirm whether these subsumed concepts are indeed components of adjustment. If so, adjustment may be best understood as a multidimensional construct that includes both positive and negative feelings towards a child's autism diagnosis, and the process by which these feelings change over time.

Overall, the available information regarding the psychometric properties of adjustment measures was lacking. Very few studies reported psychometric properties beyond internal consistency. It is therefore unclear whether existing measures of adjustment have adequate test–retest reliability or can be used to identify changes in adjustment over time. This limits the utility of these measures for longitudinal or intervention research, which is particularly problematic given that adjustment is conceptualised as a dynamic construct. In addition, very few studies examined measures' construct validity, either by comparing them to existing adjustment measures or using divergent validity to confirm that the measure is not tapping into a construct other than adjustment. This limited validation of adjustment measures likely follows from the lack of a clear definition, as discussed above. Following agreement on a definition of adjustment, further research evaluating the measurement properties of relevant measures would then allow for the recommendation of gold-standard measurement tools through rigorous assessment using a system such as PRISMA-COSMIN (Elsman et al., 2024).

While a clear conceptual definition of adjustment is clearly needed, the current review nevertheless offers some insight into currently available measures of adjustment. The most commonly used measure of adjustment was the Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1993). It is important to note that this measure was originally developed and validated with parents reacting to their child's diagnosis of cerebral palsy. Despite its extensive use in autism research, the RDI is yet to be formally validated in caregivers of autistic children, though some studies in this population have demonstrated associations of RDI resolution status with conceptually related variables such as quality of caregivers' interactions with the child (e.g. Dolev et al., 2016; Wachtel & Carter, 2008). The RDI has been shown to be suitable for use soon after diagnosis, as well as months to years after, and has demonstrated sensitivity to change over time with caregivers of autistic children (Poslawsky et al., 2014). It is, however, notable that the RDI asks about caregivers' reaction to the child's 'diagnosed condition' without focusing specifically on the diagnosis of autism; therefore caregivers' responses may confound adjustment to autism diagnosis with adjustment to co-occurring conditions such as intellectual disability or Attention-Deficit Hyperactivity Disorder. It is also important to note that use of the RDI requires training of interviewers and coders. There is also an additional time burden for caregivers associated with completing an interview as compared to a questionnaire. As such, the RDI may not be suitable for use in larger-scale studies. The Reaction to Diagnosis Questionnaire (Sher-Censor et al., 2020) was developed based on the RDI to address the limitations of an interview format. This measure was used in four studies identified through this review, and demonstrated sensitivity to change through the Empower-Autism intervention (Leadbitter et al., 2025), however has yet to be formally validated with caregivers of autistic people.

Of the three most commonly used questionnaire measures, the Affiliate Stigma Questionnaire (Mak & Cheung, 2008) demonstrated adequate test–retest reliability, as well as sensitivity to intervention impact (Lodder et al., 2020). The Illness Perception Questionnaire Revised for ASD (Mire et al., 2018) has not been used to assess change over time, and demonstrates adequate test–retest reliability for most but not all subscales (Norozi et al., 2023). Test–retest reliability has not been reported for the Post-Traumatic Growth Scale (Tedeschi & Calhoun, 2004). Furthermore, intervention effects as assessed by this measure were non-significant (Bravo-Benítez et al., 2024) despite significant intervention benefits as measured by the Caregiver Grief Scale (Meischner et al., 2016), calling into question whether the Post-Traumatic Growth Scale is sensitive to intervention effects in this population. Therefore, the Affiliate Stigma Questionnaire may tentatively be recommended for use in future studies. However, it is important to note that it only captures one aspect of adjustment: the extent to which caregivers feel stigmatised as a result of their child's autism diagnosis. Other studies have suggested that adjustment may have multiple facets, each with unique relations to other aspects of caregiver and child functioning. For example, the Adjustment to the Diagnosis of Autism Questionnaire (ADAQ; Da Paz et al., 2018) contains three subscales – despair, self-blame and acceptance – which were identified using factor analysis. These subscales demonstrated different concurrent and longitudinal associations with other aspects of caregiver mental health and well-being (Da Paz et al., 2018). Use of a more nuanced measure such as the ADAQ may therefore be recommended for studies aiming to measure adjustment. However, it is important to note that the ADAQ has, to date, only been used in two studies and has only been formally validated with mothers. Further research demonstrating replicable psychometric properties of the ADAQ, especially in fathers, would therefore be warranted before this, or another measure, can be recommended for widespread use in research and clinical practice.

While the quality of the included studies was generally acceptable, there are notable gaps in the identified research. First, many studies failed to report on the criteria used to confirm the child's autism diagnosis. This limits the conclusions that can be drawn about the similarity of samples across studies. The current review also identified that research into caregiver adjustment is lacking for caregivers of autistic adults. In caregivers of adults who were diagnosed with autism as children, investigating adjustment many years after diagnosis could enrich our understanding of the long-term trajectories of adjustment. This is particularly important to understand in the context of the significant variability in outcomes for adults with autism (Simonoff et al., 2020). It is also important to recognise that the lack of research into adjustment among caregivers of autistic adults is positioned within a context in which research about autism in adults is more limited overall as compared to that in children. In fact, research focusing on adults has been identified by stakeholders as a priority for ongoing autism research (Frazier et al., 2018). There is also increasing interest in understanding autistic adults' own adjustment to their diagnosis (de Broize et al., 2022); however, this was outside the scope of the current review. Only two of the included studies assessed whether caregivers themselves were autistic. Given that autism is a highly heritable condition, many caregivers of autistic children are autistic themselves (Tick et al., 2016). Research is yet to examine how parents who are diagnosed autistic, or who may be questioning whether they are autistic but not yet diagnosed, adjust to their child's autism diagnosis, which represents a notable gap in this body of research.

Fathers were also notably underrepresented across articles identified in the current review. In fact, over a quarter of the included articles focused exclusively on mothers. This same lack of father inclusion is evident across research with caregivers of autistic children (Brown et al., 2021) and parenting research more generally (Parent et al., 2017). Fathers may experience challenges with distinct aspects of caring for an autistic child (Ornstein Davis & Carter, 2008; Vernhet et al., 2022). It would therefore be misguided to assume that research focusing predominantly on mothers' adjustment to their child's autism diagnosis can be applied to fathers. This necessitates validation of adjustment measures specifically with fathers and a focus on prioritising father inclusion in subsequent research.

Intervention

The current review identified a small number of interventions targeting caregiver adjustment to their child's autism diagnosis, which demonstrated mixed effectiveness. There is insufficient evidence on the basis of the included interventions to recommend any specific intervention modality. Psychoeducation was the most commonly-included element across interventions, however not all interventions demonstrated significant benefits of psychoeducation. Some, but not all, of the cognitive therapy and mindfulness-acceptance based programmes showed benefits. This finding aligns with a recent review showing promise for mindfulness-acceptance based programmes to support other mental health outcomes in caregivers of autistic people (Li et al., 2024). The problem-solving skills training intervention (Nguyen et al., 2016) also demonstrated significant change in adjustment; however, there was no control group for comparison. It is also important to note that the problem-solving skills training was the only individually administered intervention, and so it is not clear whether providing caregivers with one-on-one clinician support may have facilitated improvements regardless of the programme content (Baier et al., 2020). Overall, it is promising that the small body of interventions included here suggest that caregiver adjustment challenges may be amenable to change through a relatively brief targeted intervention. Further research is needed to better understand which intervention modalities or components reliably support adjustment, and to more rigorously evaluate intervention effects.

Importantly, though, evaluating the effectiveness of any intervention requires the use of an outcome measure that is appropriately validated with this population, reliable, and sensitive to change over time. Given the limitations of current measurement identified through Aim 1, it is clear that validation of a gold-standard measure of caregiver adjustment to autism diagnosis is required before interventions can be appropriately evaluated.

It is important to note that almost all of the included intervention studies specifically targeted caregiver adjustment or other aspects of caregiver mental health. The exception to this is the AutInsight intervention (Lee et al., 2025), which aimed to improve caregivers' understanding of their autistic child and the parent-child relationship. However, AutInsight did not support significant improvements in adjustment, despite significant benefits for child conduct problems and prosocial behaviour. There were no studies identified which evaluated changes to caregiver adjustment through caregiver-mediated intervention focused on child behaviour or skills. Indeed, the potential for caregiver-mediated intervention to support adjustment should be viewed cautiously given limited evidence of benefits for other aspects of caregiver mental health (Conrad et al., 2021; Factor et al., 2019; Schultz et al., 2011). Nevertheless, it may be premature to develop targeted adjustment interventions without first exploring whether there are benefits to adjustment from the child-focused interventions that many caregivers of autistic individuals already engage in. In such interventions, caregivers are provided with psychoeducation about autism and are trained in skills that can help them manage day-to-day challenges such as their child's tantrums and non-compliance, and to build their child's skills (Schreibman et al., 2015). It is therefore possible that engaging in such interventions may facilitate caregivers' adjustment by way of increasing caregivers' knowledge and skills in relating effectively to their child, and reducing daily stressors (Dawson-Squibb et al., 2019). In line with this, caregivers engaged in qualitative research have described taking practical steps to support their child's development, such as engaging in intervention, to have benefits for their adjustment to their child's diagnosis (Downes et al., 2022; Rabba et al., 2019). By exploring how caregiver-mediated interventions might already be supporting caregiver adjustment, researchers can better understand whether there is a remaining need to augment such programmes with targeted content or to develop standalone interventions for caregiver adjustment.

In line with this, it is important to recognise that the majority of caregivers do successfully adjust to their child's autism diagnosis (Gentles et al., 2020; Poslawsky et al., 2014). This points to the potential appropriateness of a stepped-care approach whereby basic support for caregiver adjustment could be integrated within existing diagnostic and early support services, with caregivers showing greater adjustment challenges then stepped up to increasingly more intensive supports such as the interventions identified in this review. A stepped-care plan for adjustment support could be easily embedded within the broader stepped-care approach to autism support recommended by the Lancet Commission (Lord et al., 2022). It may also be important to identify predictors of adjustment challenges, to understand whether preventive support for adjustment can improve families' outcomes. Critically, applying a stepped approach to supporting adjustment requires use of a valid and reliable measure of adjustment to identify when caregivers need to be stepped up or down the levels of support, again highlighting the identification of a gold standard measure of caregiver adjustment as the necessary next step.

Conclusion

The current review has identified a series of next steps that are needed to improve research on caregiver adjustment to autism diagnosis. It is imperative that researchers first agree on a clear definition of adjustment, including what is and is not included in this construct. Without this first step, the development and validation of relevant measures is misguided, given that it is not yet clear what is being measured. The field may then benefit from validation of theoretical models of adjustment. Consensus on key measures of adjustment is also needed to increase consistency in measurement across studies. These measures would require validation, including in underrepresented groups such as fathers, autistic parents and caregivers of autistic adults, and in a range of cultures. There is also a need to examine whether existing supports, such as caregiver-mediated interventions, are efficacious in improving adjustment. If existing interventions do not evidence sufficient benefit for caregiver adjustment, the small group of intervention studies identified in the current review reveal potential avenues for the development of more targeted support. Learnings from these identified next steps would allow optimal support for caregiver adjustment to be integrated within personalised care pathways following autism diagnosis (Lord et al., 2022), moving towards the broader goal of improving the well-being of autistic people and their families.

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