Online Mindful Parenting Intervention for Parents of Autistic Adolescents:

A Mixed-Methods Study of Impacts for Parents

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Abstract

Parents of autistic adolescents have been reported to experience higher levels of parenting stress and poor mental health outcomes compared to parents of neurotypical adolescents. Consequently, parent and adolescent wellbeing can be adversely impacted. Due to the negative impacts of these factors on parents and adolescents, finding effective and feasible interventions is required. Previous studies implementing mindful parenting interventions have been associated with reductions in parenting stress in parents of autistic and neurotypical children. However, there is limited evidence examining the impact of mindful parenting interventions for parents of autistic adolescents specifically. Additionally, there is preliminary evidence supporting the feasibility and effectiveness of online delivered and parent-facilitated mindful parenting interventions for increasing parent engagement and accessibility of parenting programmes. The current thesis reports on a mixed-methods study, using a single-case design and semi-structured qualitative interviews. The aim of the study was to examine the feasibility and acceptability of an online, parent-facilitated mindful parenting intervention for parents of autistic adolescents and the effect on parent and adolescent outcomes. Seven parents took part in an adapted version of the Mindful Parenting programme (MP) developed by Bögels & Restifo (2013), taking place over six weeks. Parents had access to three online modules via a website, accompanied by four group sessions over Zoom delivered by a parent facilitator. Parent outcomes assessed were distress, wellbeing, parenting stress, mindful parenting, and parenting behaviour. Parents also reported changes in adolescent challenging behaviour. Feasibility and acceptability were explored by assessing participant attendance, recruitment and retention rates, and an evaluation survey. One parent exited the study prior to the intervention beginning. Variable outcomes were observed in parents' outcome measures across the intervention. The most improvement was demonstrated in parents' wellbeing, parenting stress, and quality of life. From baseline to six-week follow-up, six parents demonstrated improvements in total wellbeing (ORS), five parents demonstrated improvement in parenting stress (PSI-SF distress subscale), and all parents demonstrated improvements in quality of life (WHO-5). Variable results were observed in parents' distress (DASS-21). From pre-intervention to six-week follow-up, approximately half the parents demonstrated clinically significant improvement in depression and anxiety symptoms, and one parent demonstrated clinically significant improvement in stress symptoms. Variable results were also observed in parenting measures. From pre-intervention to six-week follow-up, five parents demonstrated reliable improvement in mindful parenting (IM-P), and four parents demonstrated improvement in positive parenting (PBS-A). Similarly, variable changes in adolescent challenging behaviour (CBCL) were observed across study phases. Qualitative interviews and an evaluation survey indicated the online, parent-facilitated MP intervention was acceptable for parents in this study, with variable results regarding feasibility particularly due to low group session attendance. The findings of this study add to previous research by indicating the preliminary effectiveness of MP interventions for improving parenting stress, quality of life, and wellbeing in parents of autistic young people. Furthermore, this study provides preliminary evidence suggesting that online, parent-facilitated MP interventions can be an effective, accessible alternative to in-person, clinician-delivered MP interventions.

Chapter 1: Introduction

Language Use

Throughout this thesis, the language used to refer to autism and autistic people has been informed by the preferences of the community. Botha et al. (2021) explored the impacts of language in autism research and the current consensus on person-first (e.g. Autistic person) versus identity-first (e.g. person with autism) language. Research conducted both by and in collaboration with the autistic community indicates that identity-first language (e.g., autistic person) is preferred over person-first language (person with autism; Botha et al., 2021). Therefore, identity-first language will be used in this thesis.

What is Autism?

Medical Paradigm

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Autism Spectrum Disorder is characterised by differences in social communication, and by restricted and repetitive patterns of behaviour that emerge early in an individual's development (American Psychiatric Association [APA], 2013). The medical model is a lens through which the human condition is understood as the presence of health or disease (Waltz, 2008). The DSM-5 conceptualisation of autism is heavily rooted in the medical or neurobiological model of autism. While it references scientific reason, one of the limitations of the medical model is that it fails to take into account the broader picture of autism (Pellicano & den Houting, 2021). Early research reasoned that autism emerges from within an individual or is inherited (Kanner, 1943), therefore ignoring the impacts of environmental factors such as family, school, or even the wider community (Pellicano & den Houting, 2021).

Viewing autism as an atypical presentation of health aligns with the medical model perspective in which difference is synonymous with deficit, disease, and impairment (Waltz, 2008). Under this view, any shift away from 'normal' is seen as a negative change and thus is labelled 'abnormal', thereby creating a sense of otherness (Leysen et al., 2021). In making this link, the medical model implies that the differences associated with being autistic are a deviation from the 'norm'. As a consequence of this view, many conventional approaches to autism have been with the aim of normalising behaviour to non-autistic norms (Waltz, 2008).

The term 'autism' was originally used in the early 20th century to describe observations of people with schizophrenia which were akin to social withdrawal (Leysen et al., 2021). Physician and psychiatrist, Leo Kanner, subsequently wrote about autism in the mid-20th century, describing it as a neurobiological disorder categorised by social 'aloneness', lack of affective contact with others, and a desire for sameness (Harris, 2018; Kanner, 1943). Rather than viewing autism as a difference, Kanner described autism largely in terms of deficit and the failure of the individual to reach certain expected milestones and acquire particular skills (Kanner, 1943).

In the decades following the early research on autism, the medical model has been a dominant influence on autism research and practice. The idea that autism is a genetic disorder with genetic or biological origins within the individual has contributed to a significant body of research. Much of this has been dedicated to identifying the causes of autism, and ways to effectively treat and even prevent this perceived abnormality (Dawson, 2008; Thompson, 2013; Waltz, 2008). This deficit-based conceptualisation has contributed to autism research being dominated by investigations of 'abnormal' brain development (Leysen et al., 2021) and even the causal links between vaccinations and autism (Doja & Roberts, 2006). An analysis of recent autism research has identified that the majority of this has a biological focus, with 38% of publications since 2010 related to examining its biological nature (Interagency Autism Coordinating Committee [IACC], 2012). In contrast, only 10% of research publications explored the development of appropriate and effective services for the autistic community (IACC, 2012). Funding in the United States is also largely dedicated to areas of autism research examining its neurology and genetics, while significantly less funding is provided for researching services for autistic people and their families (Singh et al., 2009).

The nature and availability of services for the autistic community have been shaped by the medical model of autism. Until the 1970s, services for autistic people were largely limited to institutions in which they were separated from the general population and their families (Thompson, 2013). These facilities were often underfunded, crowded, and used unethical treatments on autistic young people and adults (De Young, 2015). The idea that the 'problem' lay within the child often led to assumptions of low intelligence and an inability to learn at all (Kanner, 1963). During this time, autistic children were often excluded from school (D'Astous et al., 2016; Lester & Lester, 2021) further promoting the idea that these young people were unequal to neurotypical children.

While changes in legislature led to the closure of institutions in the 1970s in the US and globally, many challenges remained for autistic people and their families (Mansell, 2006). Perceptions of autism perpetuated by the medical model meant that many autistic people transitioning into community living were, at times, poorly received by the communities they returned to (Dooley, 2011; Hamlin & Oakes, 2008). Dooley (2011) describes the animosity of the public towards the individuals moving into the community following the closing of an institution in Canada in 1966, detailing the anxiety and moral panic that was pervasive at the time. A survey of the affected community demonstrated the overwhelming perception that individuals moving from the institution into the community posed a great threat, thus illustrating an ingrained stigma (Dooley, 2011). Workers within the institution even reported that the community would physically avoid them: “It was like they thought you were contagious or something” (Dooley, 2011, p. 340).

The incorrect stereotypes and ‘otherness’ communicated by the medical model of autism have continued to influence autism services and research into the present day (Kapp, 2019; Pellicano & den Houting, 2022). By assuming deficit, the medical model has driven biologically based ideas such as the concept that autistic people lack theory of mind (attribution of emotion to self and others) and an absence of desire to engage with others (Kapp, 2019). The use of such models in research and practice further dehumanises autistic people, failing to acknowledge the perspective and experiences of autistic individuals themselves, discounting their agency (Kapp, 2019; Pellicano & den Houting, 2022). This is evident in the reference to the increasing rate of autism diagnoses by some as an “epidemic” (Leonard et al., 2010; Liu et al., 2010). This association implies that autism is disease-like, much like the thinking behind the medical model of autism, demonstrating that this concept is still pervasive today.

Consistent with the medical model, the DSM-5 describes a deficit-focused conceptualisation of autism (Anderson-Chavarria, 2022). Of the DSM-5 criteria for autism, many pertain to the lack of or absence of behaviour perceived as developmentally normative (APA, 2013), as opposed to describing the presence of differences. Furthermore, the strengths and abilities so often possessed by autistic individuals are given little to no weight in the DSM-5 (APA, 2013). Subsequently, when diagnoses of autism are made, they are done so using a framework that is deficit-focused, continuing the emphasis of the medical model in practice with the autistic community. Indeed, diagnoses of autism are determined by the DSM-5 criteria which aim to identify the presence of dysfunction and impairment (APA, 2013). Consequently, a power imbalance is created between clients and practitioners (Kapp, 2019). The diagnostic experience itself can be alienating and impact a person's autistic identity (Punshon et al., 2009).

The deficit-focused conceptualisation of autism in research and practice has left little room for the acknowledgement and appreciation of the strengths associated with autism. Changing the perspective through which autistic traits are viewed can change these behaviours from disadvantages to benefits (Russel et al., 2019). In order to be truly representative, discussions and definitions of autism should include the associated strengths of autism (Kenny et al., 2016; Pellicano & den Houting, 2021).

There is an incongruence between the medical model and the lived reality of autistic individuals. The educational, diagnostic, and intervention services for this population remain based on this conceptualisation, thus impacting the suitability of services for autistic young people and their families. Furthermore, this model has contributed to incorrect and deficit-based perceptions of autism in the medical and research communities, and the general public. The increased recognition of the autism self-advocacy movement helped to expose the inadequacies of the medical model for autism services and research (Leadbitter et al., 2021).

Neurodiversity Paradigm

In recent years, the neurodiversity paradigm has gained traction as a community-grounded view of autism, which is subsequently influencing research and practice. A new model of thinking was recommended by the autism self-advocacy movement, asserting that autism is simply a different variation of human existence and that equal rights must therefore be afforded to autistic people (Jaarsma & Welin, 2012; Leadbitter et al., 2021). Proponents of this paradigm argue that autism is viewed not as an individual deficit, but as individual diversity (Grinker, 2020; Pellicano & den Houting, 2022). In this understanding of autism, neurotypicality is not assumed to be the ideal or correct identity (Cascio, 2012; Pellicano & den Houting, 2022). A neurodiversity approach argues that autistic people do not have to be 'normalised', instead accepting autism as a valid way of being (Pellicano & den Houting, 2022). Drawing on a social model of disability, autism is thus viewed as a failure of one's environment to meet social, emotional, and physical needs of the individual (den Houting, 2019). Autism became understood not as a problem within the individual, but as a construct developed by the barriers and prejudice preventing autistic and disabled individuals from fully participating in society (Anastasiou & Kauffman, 2013). As a result, society itself is viewed as disabling, meaning that many in the autistic community do not view autism as a disability (Leadbitter et al., 2021).

Participatory research design is one way in which the neurodiversity approach promotes the interest of the autistic community (Cargo & Mercer, 2008; Fletcher-Watson et al., 2018; Raymaker & Nicolaidis, 2013). This involves working alongside the community directly affected by the research, a method that is beginning to be recognised as providing valuable new perspectives and depth to research (Cargo & Mercer, 2008). Furthermore, this approach ensures that subsequent research is respectful, informed, and valuable to the community it will serve (Raymaker & Nicolaidis, 2013). Within the neurodiversity approach, interventions for autistic people aim to support individuals with their challenges (Cascio, 2012; Leadbitter et al., 2021), as opposed to medically informed interventions that aim to reduce the presence of 'autistic behaviour' (Warren et al., 2011). Increases in participatory research have revealed that the autistic community desire more accessible, flexible mental health interventions, communication skills interventions, and social care services (Autistica, 2015). The need for services that support autistic people's wellbeing, skill-building, and independence is becoming better understood (Leadbitter et al., 2021).

Māori Perspectives of Autism

Understanding a Māori cultural perspective of autism is important in the bicultural context of Aotearoa New Zealand (Tupou et al., 2021). In accordance with the Treaty of Waitangi principles of partnership and protection, it is essential for autism research and services to be informed by Māori health models, values, and worldviews. As conceptualisations of autism differ between cultures, the research and services appropriate and accessible for the pākehā population may not be appropriate for Māori (Tupou et al., 2021). The Māori worldview differs greatly from the Western worldview, placing greater emphasis on holistic practices that acknowledge the interconnectedness of health and wellbeing (Bevan-Brown, 2013). This perspective is not always acknowledged and respected in healthcare (Graham & Masters-Awatere, 2020). The impacts of colonisation and continuing discrimination have contributed to poor health outcomes for Māori (Reid et al., 2014). Numerous barriers are faced by young autistic Māori including the lack of culturally responsive services (Graham & Masters-Awatere, 2020), funding and support for these services, later diagnosis, and discriminatory attitudes from healthcare professionals (Tupou et al., 2021).

While the DSM-5 and many Western approaches to autism are deficit-based, Māori perspectives demonstrate the advantages of a holistic approach to supporting autism (Hickey & Wilson, 2017; Tupou et al., 2021). A review of research pertaining to Māori perceptions of autism uncovered that, in general, Māori view autism and disability as a part of life to be accepted and celebrated despite the challenges that may be encountered (Tupou et al., 2021). Takiwātanga, one te reo kupu for autism from a Māori perspective, refers to allowing for one's own time and space (Te Pou o te Whakaaro Nui, 2019).

Similarly, the Whānau Hauā model supports these values of inclusion and acceptance. Informed by the Māori perspective, Whānau Hauā describes the interconnectedness between a disabled person and their whānau (Hickey & Wilson, 2017). This approach demonstrates how whānau of individuals with disabilities are continuously striving to support the individual with a disability in an environment that does not always cater to them (Hickey & Wilson, 2017). In this approach, disability is not a defining feature of an individual but is something to be managed alongside daily living (Hickey & Wilson, 2017).

The three models of autism discussed have widely varying approaches and implications for real-world practice. The deficit focus of the medical model of autism has had a distinct impact on the direction of autism research and services, indicating an emphasis on the reduction of abnormality. The neurodiversity model of autism has introduced an inclusive and community-informed approach to autism research, support services, and public perception. As opposed to the medical model, the alternative approaches of the neurodiversity model and Whānau Hauā validate the diverse and unique experiences of the autistic community. These models encourage equal and equitable outcomes for autistic individuals and will be used as a theoretical foundation in this thesis.

Characteristics of Autism

Unique Skills and Characteristics

One of the commonly identified strengths of autistic individuals is the possession of unique abilities (Davey, 2020; Remington & Fairnie, 2017; Soulières et al., 2011). Autistic people have demonstrated superior performance on visual-spatial (Soulières et al., 2011) and hearing discrimination tasks (Remington & Fairnie, 2017), in comparison to non-autistic individuals. Many autistic individuals develop high levels of skill and proficiency in specific areas of interest (Russel et al., 2019; Winter-Messiers et al., 2007). When an autistic individual's special interests are incorporated into daily life, social interactions, or academic work, better emotional coping, focus, and communication are experienced by these individuals (Winter-Messiers et al., 2007). Grant and Kara (2021), two autistic authors, highlight some of the strengths and insights contributed by autistic individuals in a work and research environment. Autistic individuals often have passion and hyperfocus that can contribute to a highly productive workflow (Grant & Kara, 2021). In a qualitative study, Russel et al. (2019) conducted interviews with autistic adults to explore their perceptions of the benefits of autism. The findings illustrated that the participants experienced increased attention to detail, hyper-focus, and creativity which served them well in employment (Russel et al., 2019). Special interests can also help autistic young people to engage with learning more effectively when a task incorporates their preferred interest (Davey, 2020). Parents of autistic young people reported positive personality strengths such as kindness and affection, motivation to achieve goals, assisting others, and skills in particular areas (e.g memory, music) (Wilkinson et al., 2022).

Social and Communication Differences

Autistic individuals often demonstrate differences in social interaction and communication with others compared to non-autistic people (APA, 2013; DePape & Lindsay, 2016; Lee et al., 2020; Tager-Flusberg, 1999). These social communication differences can contribute to difficulties in social interactions in non-autistic spaces, including recognising the emotions and thoughts of others and subsequently interpreting the underlying rules and nuances of social interactions (Lee et al., 2020). This difference has previously been conceptualised in terms of poor Theory of Mind, or the ability to see the world from another's point of view (Andreou & Skrimpa, 2020; Tager-Flusberg, 1999). Difficulties interpreting the thoughts and ideas of others can lead to miscommunications and are thought to impact autistic individuals' ability to engage in social situations (Andreou & Skrimpa, 2020). These difficulties in communication between autistic and non-autistic individuals are often blamed on autistic individuals, as opposed to acknowledging two different ways of communicating (Dinishak & Akhtar, 2013). An equally valid theory is that of double-empathy, suggesting that the differences in communication styles between autistic and non-autistic people contribute to misunderstandings by each party (Mitchell et al., 2021). Subsequently, this is viewed not as a problem within the autistic person, but as difficulties understanding each other shared by both autistic and non-autistic people (Mitchell et al., 2021).

Difficulties interpreting social cues from others are reported as a challenge by some autistic individuals, contributing to difficulties in making and sustaining friendships from childhood to adulthood (DePape & Lindsay, 2016; Sperry & Mesibov, 2005). Young autistic children report feeling isolated as a result of the challenges they experience in social situations (DePape & Lindsay, 2016). Autistic adults interviewed by Finch et al. (2022) described not understanding the nuances of social rules and cues, "I must say it differently, or wrong, or at the wrong time" [p. 13]. In order to fit into the non-autistic social norms, autistic individuals may engage in compensatory strategies to mask or camouflage their social communication style; masking has been shown to be associated with poor mental health outcomes (Livingston et al., 2019).

Sensory Processing

Autistic individuals often experience differences in processing sensory stimuli compared to neurotypical individuals (Marco et al., 2011). Previous research has identified that traits of hyperresponsivity (high sensitivity) and hyporesponsivity (under responding) to sensory stimuli are often experienced by autistic individuals from infancy into adulthood (Estes et al., 2015). As a result, some sensory input can be experienced as overwhelming and distressing by autistic people (Ashburner et al., 2013). These difficulties can make daily tasks challenging and uncomfortable, such as eating particular foods, brushing hair, or getting dressed (Kern et al., 2006).

The varying sensory environment of school life can also make it difficult for autistic young people to focus in class, preventing participation and learning (Jones et al., 2020). The literature demonstrates that these difficulties continue into adulthood (Leekam et al., 2007), contributing to fearful and anxious responses (Robertson & Simmons, 2015). Autistic adults report that their sensory difficulties can cause distress and impact workplace performance (Robertson & Simmons, 2015). Due to the discomfort and distress caused by overwhelming sensory experiences, autistic individuals may engage in avoidance of certain stimuli or have emotional reactions (Kern et al., 2006). This may also present as difficult behaviour in autistic individuals, particularly among those who have difficulty communicating their distress or are non-verbal (Leekam et al., 2007).

Differences in sensory processing can also provide sources of enjoyment and positive experiences for autistic individuals (Ashburner et al., 2013; MacLennan et al., 2022; Robertson & Simmons, 2015). When in a controlled setting, certain sensory experiences can provide comfort (Robertson & Simmons, 2015), and help autistic individuals in challenging situations or environments that may otherwise be overwhelming (Maclennan et al., 2022).

Restricted and Repetitive Behaviours

Restricted and repetitive behaviours (RRBs) are defined in the DSM-5 as (a) stereotypic, repeated movements or language, or (b) preference for sameness and routine (APA, 2013; Leekam et al., 2011). Stereotypic movements can present as self-stimulating movements (also known as stimming) and verbal repetition (echolalia), while preference for sameness may present as restricted interests and difficulty managing change (APA, 2013; Kapp et al., 2019b).

RRBs can have both negative and positive impacts for an autistic individual (Collis et al., 2022; Jaffey & Ashwin, 2022; Leekam et al., 2011; McCormack et al., 2022). A review of the literature by Leekam et al. (2011) presents evidence that RRBs are linked to sensory processing needs. Stimming or ritual preference may provide either the sensory input the individual is seeking, or provide relief from undesirable sensory input (Leekam et al., 2011). Interviews with autistic adults demonstrate that the self-regulatory nature of RRBs can create focus, increase task performance, and reduce stress (Collis et al., 2022; Kapp et al., 2019b).

Conversely, RRBs have been shown to be associated with negative experiences for autistic people (Collis et al., 2022; Jaffey & Ashwin, 2022; Joyce et al., 2017; Leekam et al., 2011). Restricted interests and desire for routine have been reported to impact time management and contribute to sleep difficulties after becoming preoccupied with a task (Collis et al., 2022;

Leekam et al., 2011). In some cases, RRBs can cause well-being and safety concerns for autistic individuals or others (Collis et al., 2022; Jaffey & Ashwin, 2022; Kapp et al., 2019b). RRBs may take the form of unintentional, self-injurious behaviours or feel a lack of control over their RRBS, which can be unpleasant for those who experience them (Collis et al., 2022; Kapp et al., 2019b).

The social and clinical perceptions of RRBs can also be harmful (Boyd et al., 2012; Collis et al., 2021; Kapp et al., 2019b). A number of studies have explored interventions that reduce RRBs (Boyd et al., 2012). This indicates a medically dominated perspective, implying that RRBs are abnormal and maladaptive. This perspective feeds into the public perception of RRBs as a point of otherness. As a possible result of this narrative, there is a lack of literature regarding the potential positive aspects of RRBs for autistic individuals. This deficit-based understanding can be seen in societal perceptions of autism. Autistic adults in Collis et al. (2021) reported negative reactions from others including bullying or physical attempts to stop their RRBs. Similarly, autistic adults in Kapp et al. (2019b) reported feeling the impacts of stigma, experiencing shame and increased suppression of RRBs in public places.

Co-occurrences

Autistic individuals often experience co-occurring conditions that can present additional challenges throughout their lifetime (Lai et al., 2019; Levy et al., 2010), with approximately 70% of autistic individuals also experiencing one co-occurring condition, and 41% with two or more co-occurring conditions (Simonoff et al., 2008).

Neurodevelopmental disorders such as Attention-Deficit Hyperactivity Disorder (ADHD), Intellectual Developmental Disorder (IDD), and Specific Learning Disorder (SLD) are frequently experienced by autistic individuals (Levy et al., 2010; Matson & Goldin, 2013; Mayes & Calhoun, 2006; Simonoff et al., 2008). Current research suggests that 21.3-30% of autistic people have a co-occurring diagnosis of ADHD (Levy et al., 2010), 40-70% of autistic people have a co-occurring diagnosis of IDD (Levy et al., 2010; Matson & Goldin, 2013), and 60-70% have a co-occurring diagnosis of SLD (Ibrahim, 2020; Mayes & Calhoun, 2006).

A large proportion of autistic people also experience anxiety and depression; 40% and 0.9-29% co-occurrence respectively (Rosen et al., 2018; Simonoff et al., 2008). Social anxiety in particular was found to have a high co-occurrence in autistic young people aged 10 – 14 years, with rates of 29.2% (Simonoff et al., 2008). Sleep difficulties are also frequently experienced by autistic young people at a greater rate than neurotypical young people (Richdale & Schreck, 2009). Evidence suggests that 50-80% of young people with an autism diagnosis have reported sleep-related difficulties, impacting the young person's daily functioning (Richdale & Schreck, 2009).

There is increasing evidence demonstrating that autistic people with co-occurring conditions are at risk for adverse outcomes (Buescher et al., 2014; Chiang & Gau, 2016; Dovgan & Mazurek, 2019; Leitner, 2014; Oakley et al., 2021). Co-occurring conditions in autistic children are associated with poorer social adjustment with peers, family, and at school (Bellini, 2004; Chiang & Gau, 2016). Anxiety and depression co-occurring with autism are also associated with poor physical health (Oakley et al., 2021). The presence of co-occurring conditions has been shown to decrease an autistic young person's quality of life and general participation in community, school, social and home environments (Dovgan & Mazurek, 2019).

Autistic individuals with co-occurring conditions do not show expected improvement when following intervention for the co-occurring condition, experiencing poorer trajectories

(Antshel et al., 2011; Dovgan & Mazurek, 2019; Reaven, 2009). As a result, providing effective care for autistic individuals with co-occurring difficulties can be a complex task. Furthermore, co-occurring conditions have also been shown to contribute to greater financial costs for families of autistic people (Peacock et al., 2012).

The literature demonstrates that the co-occurring difficulties associated with autism add additional barriers and challenges for autistic individuals. The high rates of co-occurrence suggest that it is not uncommon for autistic individuals to experience a range of difficulties which subsequently impact their daily functioning.

Exclusion and Discrimination

Autistic individuals experience discrimination and exclusion at community and systemic levels as a result of the misconceptions associated with the deficit-based understanding of autism (Brede et al., 2017; Waltz, 2008). Stigma against autistic people impacts progress towards inclusion by maintaining untrue stereotypes (Aubé et al., 2020). Autistic young people are often labelled by others as ‘different’, and their behaviours are labelled as strange and confusing (Kinnear et al., 2016). Subsequently, autistic young people are vulnerable to the unfavourable perceptions of others in the community. These experiences of discrimination and exclusion of autistic people vary from directly observable, to less discernible forms. A qualitative study by Jones et al. (2022) identified that autistic people experience open judgement, staring, and even verbal and physical aggression from members of the public. Jones et al. (2022) identified that most of the non-autistic participants believed autistic people experienced discrimination in the community. Despite this, their answers to further questions also indicated discriminatory responses against autistic people (Jones et al., 2022). This demonstrates that while non-autistic individuals may recognise the discrimination experienced by the autistic community, they are not aware of the impact of their own discriminatory responses.

The school environment remains a place where autistic young people experience discrimination (Brede et al., 2017; Maïano et al., 2016; McGregor & Campbell, 2001). Bullying is a prevalent issue for autistic young people at school, reporting higher rates of bullying victimisation than neurotypical peers particularly when co-occurring conditions were present (Schroeder et al., 2014). Interviews by Goodall (2018) with autistic young people aged 11 – 17 years demonstrate the distressing experiences of bullying, "It was like I had germs and they weren't to go near me" (pp. 8).

Schools may fail to provide appropriate support to autistic young people in order to meet their needs, contributing to permanent exclusion when the young person's behaviour is negatively impacted (Brede et al., 2017). Parents and autistic young people reported by Brede et al. (2017) that staff misunderstanding of the characteristics of autism led to harmful behaviour management techniques, punishment, and increased anxiety in the young person (Brede et al., 2017). Teaching staff report also feeling ill-equipped to support autistic young people at school (McGregor & Campbell, 2001). As a result, autistic young people are at increased risk of being excluded from school compared to neurotypical young people (Brede et al., 2017).

Autistic people are also vulnerable to discrimination and prejudice in adulthood. Autistic adults report negative experiences with healthcare providers (Nicolaidis et al., 2015), more so than the neurotypical population (Nicolaidis et al., 2013). Lack of knowledge, assumptions, and inflexibility of practitioners have been cited as sources of difficulty for autistic adults when seeking healthcare (Nicolaidis et al., 2015). In the workplace, autistic adults experience further barriers as a result of stereotypes and subsequent discrimination (Djela, 2021; Lorenz et al., 2021). Autistic adults are provided with limited support in the workplace and experience high rates of unemployment despite a desire to work (Djela, 2021). Employers with no experience working with neurodivergent employees show hesitance and unwillingness to employ them (Lorenz et al., 2021). Autistic adults report workplace bullying and isolation as commonplace, from management as well as colleagues (Djela, 2021).

It is evident from the literature that discrimination and exclusion are experienced by autistic individuals throughout their lifetime. The lingering effects of the medical model conceptualisation of autism become clear, illustrating the impact of this approach as ‘othering’. During the vulnerability of adolescence, these attitudes can have far-reaching impacts.

Autism and Adolescence

Adolescence can be a time of increased risk of mental health difficulties, increased peer influences, and potential for risk-taking behaviour (Andrews et al., 2021). The transition period of adolescence brings with it change and uncertainty, particularly for those who identify as neurodivergent (Browning et al., 2009). Autistic young people experience new and complex difficulties as they move into adolescence (Cresswell et al., 2019; DePape & Lindsay, 2016; Humphrey & Symes, 2010; McGovern & Sigman, 2005).

Moving into a secondary school environment can produce new challenges for autistic adolescents. Due to the sensory processing differences often associated with autism, the high intensity sensory environment of high school can be difficult to traverse (Howe & Stagg, 2016; Makin et al., 2017). Increases in class size, expectations for self-management, and frequent routine changes can all impact an autistic adolescent's capacity to function effectively in a secondary school environment (Saggers, 2015). Similarly, loud classrooms have been shown to greatly reduce concentration and increase physical discomfort in autistic adolescents, reducing effective learning (Howe & Stagg, 2016). Autistic adolescents report difficulties managing the frequently changing schedule typical of high schools and busier hallways, “I felt closed in and like I couldn’t breathe as there were so many people” (Goodall, 2018, pp. 7).

Adolescence is considered a time of considerable development. Brain changes taking place during this developmental period are associated with changes in self-perception and identity, and greater sensitivity to exclusion and desire for inclusion (Blakemore, 2008). Social relationships become more hierarchical and status driven at this time, with more complex social rules (Blakemore, 2008). As social interactions become more complex, autistic young people are more likely to experience rejection by peers as a result of their difficulty understanding the changing social sphere (Cresswell et al., 2019). Autistic young people can find it difficult to form friendships and connections, leaving them vulnerable to peer rejection and subsequent isolation (Ochs et al., 2001). Bullying is often experienced by autistic adolescents, varying in degree of severity and type (Cresswell et al., 2019; Humphrey & Lewis, 2008). Other characteristics of autism may also be poorly received by peers, contributing to social rejection, mocking, and even physical bullying (Humphry & Lewis, 2008). Such exposure in autistic adolescents has been found to be associated with adverse mental health outcomes and increased suicidality (Hoover & Kaufman, 2018). Additionally, the way in which peers interact with autistic adolescents can be characterised as profoundly negative (Fisher & Taylor, 2016; Humphrey & Lewis, 2008). Autistic adolescents report being avoided by peers, with few people interacting with them in a positive manner (Humphrey & Lewis, 2008).

Autistic adolescents are vulnerable to mental health difficulties. Anxiety and mood disorders are common challenges for autistic adolescents (DeFilippis, 2018; van Steensel et al., 2011). A review of the literature by van Steensel et al., (2011) identified that approximately 40% of autistic young people experience an anxiety disorder compared to 15% of the neurotypical population. Similarly, autistic adolescents report increased experiences of anxiety and depression (Hebron & Humphrey, 2014). As changes in brain development occur, autistic young people report an increase in social anxiety and poor self-evaluation as they move into adolescence compared to childhood (Kuusikko et al., 2008). Autistic adolescents are also more likely to experience depression than autistic children and neurotypical adolescents (DeFilippis, 2018). A study by Close et al. (2012) found that 79% of autistic adolescent participants reported experiencing two or more co-occurring conditions in addition to their autism diagnosis, a greater percentage of co-occurring conditions than was experienced by the autistic children in the sample.

Autistic adolescents moving into adulthood have also reported barriers to accessing healthcare, including a lack of support transitioning to adult healthcare providers, a lack of understanding and accommodation by providers (Cheak-Zamora et al., 2015), and previous negative experiences with physicians (Vogan et al., 2017). In a study by Anderson et al. (2018), parents and autistic adolescents described the multiple barriers to receiving other services supporting adolescents' transition into adulthood. Parents described the battle involved in applying for educational, employment, and mental health services, citing the difficulty being accepted by providers and the refusal of other providers to take on autistic clients; "We really cannot do the autism" (Anderson et al., 2018, p. 303). This lack of support is concerning, particularly as autistic adolescents are at greater risk of adverse mental and general health outcomes (Close et al., 2012; DeFilippis, 2018), and experience low levels of employment compared to non-autistic adolescents (Seltzer et al., 2004). These findings indicate the importance of support for this at-risk population.

Parenting and Autism

Parenting an Autistic Young Person

Parents of autistic people have described varied and diverse experiences in the literature. Qualitative research exploring the experiences of these parents reveals the differences and joys in parenting and daily life for these families. Woodgate et al. (2008) conducted qualitative interviews with 21 parents of autistic young people, finding that the parents frequently felt they were “living in a world of our own” [pp. 1078]. Parents reported that raising an autistic young person not only involved adjusting their parenting but managing outsiders’ judgement and behaviour (Woodgate et al., 2008).

While it is often the challenging aspects of parenting an autistic young person that become the focus, qualitative research has also highlighted the joys. Across the qualitative research exploring parenting autistic young people, joy and appreciation emerge as a common theme (Corcoran et al., 2015; Kuhaneck et al., 2012; Woodgate et al., 2008). Mothers of autistic children interviewed in Kahuneck et al. (2012) described the value of appreciating the joyful moments they experienced with their children. Parents noted the importance of practising appreciation of their child’s achievements no matter the scale (Corcoran et al., 2015). A qualitative study with fathers of autistic young people identified a focus on their child’s strengths and vast abilities, the rewarding moments in parenting, and pride in achievements (Potter, 2016). These parent accounts demonstrate the positives of parenting an autistic young person, bringing attention to an aspect of this parenting experience not often highlighted in the research.

Seeking a diagnosis for a child can be a long and challenging process for parents. Parents of autistic children have been shown to have mixed experiences with practitioners on the journey to diagnosis (DePape & Lindsay, 2015; Ryan & Sailsbury, 2012). Obtaining a diagnosis can be a stressful process in which many parents feel unheard, becoming advocates for their child as a result (DePape & Lindsay, 2015; Siklos & Kerns, 2007). Following diagnosis, parents of autistic children report feelings of validation, relief, and grief (DePape & Lindsay, 2015). The inconsistency between previous hopes of a child's life and the challenges accompanying diagnosis means that many parents feel the loss of what could have been (Altiere & von Kluge, 2009; Siklos & Kerns, 2007; Woodgate et al., 2008).

Parents of autistic young people must navigate a new world following diagnosis. Changes are made to accommodate the needs of the child that have since been identified, accompanied with changes for parents (DePape & Lindsay, 2015). More time given to the child's needs tends to result in less time for parents (Woodgate et al., 2008). As a result, parents find it difficult to balance work, other children, partner relationships and self-care (Altiere & von Kluge, 2009; DePape & Lindsay, 2015). Support for parents of autistic children can be found in intervention services as well as social support from family and friends. Finding and funding appropriate intervention can be a difficult task, and even then the supports available are limited (Smith-Young et al., 2022). As a result, parents of autistic young people report becoming advocates and experts for their child (Boshoff et al., 2016; Smith-Young et al., 2022; Woodgate et al., 2008). For parents, seeking the best possible outcomes for their child and other autistic children is a constant and time-consuming task (Boshoff et al., 2016).

Parenting Challenges

Parenting an autistic young person can be challenging for parents to navigate. Not only can some of the characteristics of autism be stressful for parents to manage (Ludlow et al., 2011; Mount & Dillon, 2014; Woodgate et al., 2008), learning to navigate the service system and societal perceptions can be challenging (Altiere & von Kluge, 2009; Bonis, 2016; DePape & Lindsay, 2015; Ludlow et al., 2011).

The characteristics of autism require parents to manage complex parenting tasks that parents of neurotypical children do not (Ludlow et al., 2011; Mount & Dillon, 2014; O'Nions et al., 2018). Across the literature, parents have reported difficulties in responding to behaviours that they find challenging such as meltdowns, emotional dysregulation, and RRBs (Bonis, 2016; Estes et al., 2012; Ludlow et al., 2011; Myers et al., 2009). Parents of autistic young people often adapt their lives around their child, making extra modifications, creating routines, and developing increased vigilance in order to provide for their child's needs (O'Nions et al., 2018; Woodgate et al., 2008). When challenging behaviour involves self-injury or aggression towards others, there is the additional responsibility of risk management for parents (Bonis, 2016; Myers et al., 2009; Ooi et al., 2016). Parents of autistic young people experience increased stress (Myers et al.,2009; Ooi et al., 2016), demonstrating more fatigue than parents of neurotypical young people (Giallo et al., 2013).

Navigating the many systems required to support an autistic young person can be difficult for parents (DePape & Lindsay, 2015; Myers et al, 2009; Ooi et al., 2016; Phelps et a., 2009; Safe et al., 2012; Woodgate et al., 2008). A review of the advocacy experiences of parents of autistic adolescents demonstrated that a great deal of parents' personal efforts and finances are required to find appropriate services for their child (Boshoff et al., 2016). Finding appropriate, affordable services can be difficult as parents are often left to independently identify the best services available for their child (Ooi et al., 2016; Phelps et al., 2009). The wait times and financial costs of accessing support services can be high, creating additional strain on parents' financial and emotional resources (Myers et al., 2009; Smith-Young et al., 2020). This constant battle to advocate for their child can contribute to increased stress (Boshoff et al., 2016) and lead to parents sacrificing their own needs and wellbeing (Safe et al., 2012).

Parents of autistic young people must also contend with several barriers when accessing appropriate education for their child (Dillenburger et al., 2010; Ludlow et al., 2011; Myers et al., 2009; Phelps et al., 2009). In the literature parents who report negative experiences with schools cite staff inexperienced in working with neurodivergent young people, the inability of school staff to meet the child's needs, and misconceptions about autism (Ludlow et al., 2011; Safe et al., 2012). Conflict may arise between parents and educational providers when parents feel they have less input and collaboration with staff and reduced communication (Tucker & Schwartz, 2013). Teachers often report feeling ill-equipped to support autistic young people at school (Lindsay et al., 2013), indicating a need for greater resources in order to promote inclusion in schools.

As a result of the inadequacies of some educational and support services, parents of autistic young people must also step into the role of advocate for their child (Broady et al., 2017; Smith-Young et al., 2022; Woodgate et al., 2008). Parents interviewed by Woodgate et al. (2008) reported feeling as though they were battling against the services that intended to support them. This was a result of a lack of resources and understanding of autism by professionals, resulting in parents feeling isolated and unsupported within the system (Woodgate et al., 2008). Parents of autistic young people report that they often felt excluded from their own families due to this lack of understanding (Broady et al., 2017; Woodgate et al., 2008). Dismissive and belittling comments from grandparents and extended family members made parents feel as though their experience of parenting an autistic young person was not validated or accepted (Broady et al., 2017). Parents reported rejection of applications to multiple schools and rejection of their own job applications as a result of others' perceptions of their children (Broady et al., 2017). As a result of these responses from family, schools, and community services, parents of autistic young people must become advocates and educators for their children (Voulgarakis et al., 2021; Woodgate et al., 2008). While some parents have reported finding strength in informing others about autism (Voulgarakis et al., 2021; Woodgate et al., 2008), some parents describe being an advocate as a difficult task expected by others (Broady et al., 2017), placing an additional burden on parents.

Parents are negatively impacted by stigma against themselves and their child (Gray et al., 2002; Kinnear et al., 2016; Ooi et al., 2016). Parents in qualitative studies consistently report feelings of shame and embarrassment following negative reactions from the public to their child's behaviour (Altiere & von Kluge, 2009; Ludlow et al., 2011; Myers et al., 2009). Society's lack of understanding of stimming behaviours or meltdowns, and absence of sympathy for parents of autistic young people have been shown to elicit feelings of exclusion and shame in both the child and parent (Kinnear et al., 2016; Ooi et al., 2016). Parents report being accused of 'bad parenting' by outsiders, contributing to feelings of embarrassment and anger (Ooi et al., 2016). Interviews with parents of autistic young people by Broady et al. (2017) uncovered experiences in which parents had been directly shamed by members of the public in response to their child's behaviour, "People would say things, "Control your daughter!"... [my wife] would end up in tears coming home" (p. 228). Such comments deterred parents from going out in public with their children to avoid the distress caused by these encounters, further contributing to their experience of isolation and exclusion (Broady et al., 2017; Kinnear et al., 2016; Myers et al., 2009).

Parents of autistic young people report feeling isolated by parents of other young people, impacting their own social wellbeing identity (Broady et al., 2017; Kinnear et al., 2016). As parenting an autistic young person requires additional emotional resources, parents' social lives are often negatively impacted (Nealy et al., 2012). Parents interviewed by Nealy et al. (2012) reported that the dissonance between their lives and the lives of other parents is too great. They noted that maintaining friendships became difficult as a result of the additional needs of their child, feeling guilt when wanting their child to be neurotypical (Nealy et al., 2012).

The unique characteristics and needs of each autistic young person often impact the kind of life they will live in adulthood. Parents of autistic young people often report in the literature that their child's future is a frequent source of worry (Broady et al., 2017; Woodgate et al., 2008). As their child moves into young adulthood, parents often develop concerns about their real-world functioning and the responses of the outside world (Broady et al., 2017). Depending on the needs of the child, parents report concerns regarding their safety, ability to engage in society without their families (Bonis, 2016), and grieving for the milestones that may never be reached (Bravo-Benítez et al., 2019).

Parental Wellbeing

There is a wealth of literature exploring the stress experienced by parents of autistic young people (Bonis, 2016; Hayes & Watson 2012; McStay et al., 2014b; Ooi et al., 2016; Tehee et al., 2009). Child, parent, and external environmental factors are associated with changes in parents' stress (Bonis, 2016). It is important to note that the term "parenting stress" refers to the stress directly associated with the task of parenting, while general stress refers to stress as a result of other factors.

Parents of children with additional needs are more likely to experience increased stress compared to parents of neurotypical children (McStay et al., 2014a; Rivard et al., 2014) and young people with other disabilities such as Down syndrome or developmental delays (Craig et al., 2016; Estes et al., 2009). A review of risk and protective factors contributing to parental stress in parents of autistic children identified key parental concerns related to accessing sufficient care and resources for their child, managing demanding behaviours, and feelings of isolation and otherness (Bonis, 2016). The high stress levels experienced by parents of autistic young people have been found to be positively correlated with poor management of difficult child behaviour (Bonis et al., 2016; Hayes & Watson, 2012), increased financial strain (Bonis et al., 2016), and higher prevalence of marital difficulties (Bonis et al., 2016). Mothers interviewed in Nealy et al. (2012) reported that the stress of parenting their autistic child had negative impacts on their relationship with their partner. It is clear that managing parent stress for this population is critical for maintaining both parent and child well-being.

Previous research has indicated that parenting stress in caregivers of autistic young people has also been linked to the experience of child behaviours that challenge the parent (Argumedes et al., 2018; Bonis, 2016; Phetrasuwan & Miles, 2009). The literature indicates there is a bidirectional relationship between parenting stress and child behaviour, in which each impacts directly upon the other (Neece et al., 2012; Rodriguez et al., 2019). As a result, increased stress related to parenting is likely to be associated with an increase in challenging child behaviour (Neece et al., 2012). In addition, there is evidence to suggest that the severity of the young person's challenging behaviour is associated with increased parenting stress (Bonis, 2016; Lyons et al., 2010).

The challenges faced by parents of autistic young people have been shown to contribute to their own poor mental health and wellbeing (Bonis, 2016; Bromley et al., 2004; Falk et al., 2009; Phelps et al., 2009). The stress and challenges experienced by parents of autistic children can contribute to increased depressive symptoms, feelings of hopelessness, and anxiety (Bonis, 2016, Phelps et al., 2009). When assessing the distress of parents of autistic children, higher levels of depression have been identified in mothers as opposed to fathers (Durukan et al., 2018; Ozturk et al., 2014). This may be indicative of the typical maternal parenting role in which mothers take on more of the caregiving role than fathers (Ozturk et al., 2014).

Previous research also suggests that parents of autistic young people report poorer quality of life (QOL) in relation to parents of typically developing children, particularly impacting the physical domain of QOL (Vasilopoulou & Nisbet, 2016). As a result, parents report adverse impacts on their sleep, fatigue, and ability to complete daily work and activities (Vasilopoulou & Nisbet, 2016). The wide-reaching impact of poor QOL has shown that this is a key variable to be targeted in intervention with parents of autistic young people (Cappe et al., 2011).

There are conflicting findings in the literature regarding the associations between parenting stress and mental health outcomes (Ooi et al., 2016). The links between these two constructs are difficult to evaluate due to the many other factors that may influence parent wellbeing (Dunn et al., 2001). Social support, the severity of their child's challenging behaviour, and perceived control all appear to moderate parenting stress and mental health outcomes (Falk et al., 2014; Sipowicz et al., 2022). External locus of control and low social support are correlated with increased depressive symptoms in mothers of autistic young people (Dunn et al., 2001; Falk et al., 2014). This indicates that when parents feel as if events are out of their control they are more likely to experience depression (Dunn et al., 2001; Falk et al., 2014). Furthermore, this negatively impacts the efficacy of social support the parent may receive from others (Dunn et al., 2001). Social support significantly influences parents of autistic children's wellbeing and stress (Dunn et al., 2001; Pottie & Ingram, 2008; Sipowicz et al., 2022). Positive connections and assistance from others are associated with increases in positive mood (Pottie & Ingram, 2008), reductions in negative mental health outcomes (Dunn et al., 2001), and lower levels of parenting stress (Ekas et al., 2010). Without adequate social support, parents of autistic adolescents are vulnerable to higher levels of stress, anxiety, and depression (Boyd, 2002; Ooi et al., 2016). The added burden placed on parents of autistic young people and lack of support present a considerable concern for parent wellbeing, demonstrating the need for further support options.

Stress in parents can not only affect their own mental and emotional wellbeing, but parenting behaviour and parent-child interactions (Deater-Deckard, 1998). A highly stressed parent has a lower threshold for difficult child behaviour or disruptions, impacting the way in which they parent that child (Fonseca et al., 2020). A negative cyclical pattern can emerge, in which parents' stress adversely affects parenting behaviour, which can impact child behaviour, and so on. Previous research by Fonseca et al. (2020) has demonstrated that stressed parents demonstrated reduced psychological flexibility which subsequently increased the likelihood of maladaptive authoritarian (high control, low warmth) or permissive (high warmth, low control) parenting styles (Fonseca et al., 2020; Smetana, 2017). High levels of parenting stress in particular have been shown to relate to increased dysfunctional parenting (Abidin, 1992) and harsher parenting practices (Streit & Davis, 2022). As a result, exposure to high levels of parenting stress negatively impacts the parent-child relationship (Crnic et al., 2005), and is associated with increased behaviour difficulties in childhood (Crnic et al., 2005) and adolescence (Streit & Davis, 2022).

High levels of parenting stress in parents of autistic young people can contribute to poor parenting practices and subsequent adverse outcomes for the young person (Baker et al., 2003; Clauser et al., 2021; Meadan et al., 2010; Osborne & Reed, 2010). As discussed, increased parenting stress detracts from a parent's ability to respond effectively to their child, particularly in moments of high stress (Fonseca et al., 2021). Consequently, parents may be unable to provide sufficient support for their autistic young person (Meadan et al., 2010). As a result, autistic young people with highly stressed caregivers are at increased risk for maladaptive behaviour and mental health difficulties (Clauser et al., 2021). Subsequently, by reducing parenting stress in parents of autistic young people, their children are likely to benefit.

Parenting Autistic Adolescents

Parenting an autistic adolescent comes with different challenges. The changes in school, social lives, and increased independence make adolescence a difficult time to navigate for autistic young people (Blakemore, 2008; Cresswell et al., 2019; Seltzer et al., 2003). Subsequently, autistic adolescents have different support needs during this developmental period (Seltzer et al., 2003). Despite this, the research demonstrates that autistic adolescents receive fewer support resources than autistic children (Friedman et al., 2013) and that parents pay more for support services during adolescence than in childhood (Cidav et al., 2013; Tehee et al., 2009). There are conflicting findings in the literature regarding the association between the age of an autistic young person and parenting stress (McStay et al., 2014b; Smith et al., 2008; Tehee et al., 2009). Evidence in the literature has demonstrated that parents of autistic children and adolescents both experience greater stress compared to normative data, neither more so than the other (McStay et al., 2014b; Smith et al., 2008). However, Smith et al. (2008) identified that parents of autistic adolescents were more likely to use emotion-focused coping strategies, associated with a lack of perceived control and poor wellbeing. There is evidence to suggest that parents of autistic adolescents demonstrate fewer positive parenting practices than parents of younger autistic children (Maljaars et al., 2014). Although parents of autistic adolescents demonstrate improving wellbeing compared to when their children were younger, these parents' levels of depression and anxiety remain significantly higher than the normative population (Lounds et al., 2007). As a result, the decrease in support for autistic adolescents and their families during adolescence is concerning. While a large proportion of support services and research are targeted towards young autistic children and their parents, fewer services and research address autism during adolescence (Friedman et al., 2013). As a result, there is an imbalance between the needs of parents of autistic adolescents and the support they receive. This discrepancy demonstrates the need for additional support for this population.

Parenting an autistic child is a complex, varied, and unique experience. The difficulties faced are innumerable, yet the joys are undeniably evident in descriptions of parents' experiences. The literature highlights that many of the difficulties faced by parents of autistic young people stem from systemic barriers and failures that prevent appropriate support and service provision for parents of autistic adolescents. There is a marked difference between the support these families should be receiving, and the reality of the support provided.

Mindfulness-Based Interventions

The negative effects of parenting stress and poor wellbeing for both parents and autistic adolescents highlight the need for effective supports. One of the ways in which stress can be reduced and positive wellbeing promoted is through the practice of mindfulness (Brandmeyer et al., 2019; Burgdorf et al., 2019; Chaplin et al., 2021).

Mindfulness can be a trait, a state, or a practice (Dorjee, 2010). Mindfulness practice refers to the process of developing one's ability to attain a temporary moment or state of mindfulness, while trait mindfulness refers to a consistent characteristic that one develops (Dorjee, 2010; Shapiro et al., 2006). The origins of mindfulness practice lie in Buddhist philosophy, which emphasises the oneness of the body and the mind (Kabat-Zinn, 2015; Shapiro et al., 2006). In this tradition, mindfulness itself is not a goal to be reached, but a constant practice of a skill; one's intentional awareness of the present moment with open-mindedness and non-judgement (Shapiro, 2009). Practising mindfulness allows for a change in perspective, in which participants are able to step back and observe their own experience rather than being immersed in it (Shapiro et al., 2006). In doing so, practising mindfulness allows one to gain distance from difficult emotional states such as anxiety, increasing the ability to self-regulate in difficult moments (Shapiro et al., 2006).

In recent years, mindfulness practices have been incorporated into psychotherapies initially developed to reduce stress and improve well-being (Gu et al., 2015). The two key Mindfulness-Based Interventions (MBIs) are Mindfulness-Based Stress Reduction (MBSR) and Mindfulness-Based Cognitive Therapy (MBCT) (Zhang et al., 2021). MBSR was originally developed by Jon Kabat-Zinn as a method of reducing stress and increasing self-regulation in people with chronic pain (Kabat-Zinn, 1982). The programme introduced mindfulness practice through breathing exercises, yoga, and body scanning, with accompanying homework tasks to practice and an additional focus on stress reduction by incorporating psychoeducation about stress physiology (Kabat-Zinn, 1982). MBSR today is an eight-week group programme teaching the integration of mindfulness into daily living (Carmody et al., 2009), and has been applied to multiple conditions (anxiety, chronic pain) and settings (healthcare, education, workplaces) (Zhang et al., 2021).

MBCT was initially developed for implementation for those experiencing recurrent depression (Segal et al., 2002). The mindfulness teachings within MBCT are based on MBSR, and the programme integrates elements of cognitive behavioural therapy (CBT) (Piet & Hougaard, 2011; Segal et al., 2002). Now used in intervention with other psychological conditions, this eight-week programme involves techniques such as examination of one's thoughts and feelings, the connections between the two, and learning to recognise automatic thoughts (Segal et al., 2002).

MBIs have demonstrated effective stress reduction in a variety of populations. MBCT has exhibited efficacy with participants with anxiety (Evans et al., 2008; Hofmann et al., 2010; Hofmann & Gómez, 2017), depression (Hofmann et al., 2010; Hofmann & Gómez, 2017; Kingston et al., 2007; Sipe & Eisendrath, 2012;), bipolar disorder (Williams et al., 2008), and anxiety in elderly individuals (Helmes & Ward, 2017). Similarly, MBSR has been shown to reduce stress in people with cancer (Ledesma & Kumano, 2009), and those with depression and anxiety (Hofmann et al., 2010; Hofmann & Gómez, 2017).

Mindful Parenting

In recent years, mindfulness research and practice have also specifically targeted parents and parenting stress. General MBIs, such as MBSR, have been offered to parents (e.g. MBCT and MBSR). In addition, parenting-specific MBIs have been developed, and have been coined 'mindful parenting' (Duncan et al., 2009).

Mindful parenting can be conceptualised as the use of a mindful approach to parenting

(Duncan et al., 2009). Five dimensions of mindful parenting have been proposed; listening with attention, nonjudgmental acceptance, emotional awareness, self-regulation, and compassion in relation to oneself and one's child (Duncan et al., 2009). When parents are able to adopt a mindful approach, their interactions with their children become more positive (Duncan et al., 2009). Increases in adaptive coping strategies, reduced parenting stress, and positive child outcomes all contribute to the disruption of the negative cyclical reactions that may have been previously present (Duncan et al., 2009). In parents of autistic young people, increased mindful parenting is associated with lower levels of stress and depressive symptoms, while lower levels of mindful parenting are associated with lower levels of parental self-compassion, increased challenging child behaviour, and symptoms of depression and anxiety (Beer et al., 2013).

The Mindful Parenting (MP) programme is an established MBI using principles of mindful parenting (Bögels & Restifo, 2013). This programme was developed to reduce parenting stress and increase self-awareness in parents in order to improve subsequent parenting practices (Bögels & Restifo, 2013). MP is centred around mindfulness practice for parents in the context of their child, focusing on a non-judgemental approach (Bögels & Restifo, 2013). In doing so, MP aims to build parents' attention, acceptance, and recognition of inner thought processes and reactivity in order to promote parent and child well-being (Bögels & Restifo, 2013). MP is based on the format of MBSR, consisting of an eight-week group-based programme, with weekly meetings facilitated by trained psychotherapy practitioners and home practice to integrate mindfulness into daily life (Bögels & Restifo, 2013). Participants are guided through imagination exercises, imagining hypothetical parenting situations and practising awareness and mindful techniques in these moments (Bögels & Restifo, 2013). MP is also specifically tailored towards the task of parenting and the parent-child relationship (Bögels & Restifo, 2013). As opposed to simply teaching parents mindfulness techniques, MP encourages parents to use the non-judgemental attitudes and focus of attention that embody mindfulness practice into the way they observe and interact with their child, their partner, and who they are as a parent (Bögels & Restifo, 2013). MP aims to foster increased awareness and acknowledgement of one's stress and automatic thought patterns related to parenting and difficult situations, promoting measured response rather than reaction (Bögels & Restifo, 2013). MP has a focus on managing any conflict in the parent-child relationship that may arise (Bögels & Restifo, 2013). The eight-week programme provides the teaching of mindfulness techniques and a subsequent focus on mindfulness in the context of parenting (Bögels & Restifo, 2013). One of the key exercises used in MP to promote this is using beginner's mind. Using this technique, parents learn to observe their child mindfully in situations of different intensities (Bögels & Restifo, 2013). The other mindfulness techniques taught are breathing meditation, walking meditation, breathing space, body scan, yoga, and mindful eating (Bögels & Restifo, 2013).

Mindful parenting interventions have been found to be effective with a range of parent and child populations. In a systematic review, Shorey & Ng (2021) evaluated the effectiveness of mindful parenting interventions for parents of young people with and without a clinical diagnosis based on 11 studies that implemented mindful parenting interventions. The findings of this review indicate that parents taking part in mindful parenting interventions develop increased mindful parenting in comparison to control groups, although no significant changes in parenting stress were reported (Shorey & Ng, 2021). Additionally, parents of children with and without clinical diagnoses reported improvements in challenging child behaviour (Shorey & Ng, 2021). These findings provide support for the use of mindful parenting interventions with parent populations, although less support for the reduction of parenting stress. This may be due to the combined analysis of parents of children with a clinical diagnosis and typically developing children.

A study by Van der Ord et al. (2012) examined the effects of an 8-week mindful parenting programme specifically adapted for children (aged 8-12) with ADHD and their caregivers. Following the intervention, parents reported significant decreases in child ADHD symptoms, increased mindful awareness, and significant reductions in parenting stress (Van der Ord et al., 2012). Similar results were reported by Behbahani et al. (2018), in which parents of children with ADHD (aged 7-12) engaged in a mindful parenting intervention. Parents reported significant reductions in parenting stress and child ADHD symptoms post-intervention (Behbahani et al., 2018).

Conclusion

This chapter has explored the models of autism that have shaped the current conceptualisation of autism and the unique skills and challenges experienced by autistic individuals. The increased recognition of the neurodiversity paradigm over the medical model of autism is beginning to contribute to community-informed, inclusive practices and services that are more suitable for autistic young people and their families. The experiences of autistic adolescents have been highlighted in this chapter as unique and nuanced, requiring specifically designed supports that address the specific needs of this population. Furthermore, the parents of autistic young people have been shown to experience different challenges to parents of autistic young children, reporting high parenting stress, distress, and fewer available supports. Previous research has identified that mindfulness-based parenting programmes, such as MP, are an effective intervention for reducing parenting stress and poor mental health outcomes (Duncan et al., 2009; Shorey & Ng, 2021). As these are some of the key challenges experienced by parents of autistic adolescents, mindful parenting programmes for parents of autistic young people are explored in the following chapter.

Chapter 2: Literature Review

There is increasing evidence in the literature supporting the effectiveness of MBIs for parents of autistic young people. Mindful parenting programmes are a form of MBI that addresses the stress associated with the task of parenting (Bögels & Restifo, 2013; Zhang et al., 2021). While general MBIs have been offered to parents, mindful parenting interventions are tailored to the task of parenting, and specifically target parenting stress. This key difference means that mindful parenting interventions may be more appropriate and efficacious for parents of autistic adolescents whose difficulties are often associated with stress attributed to parenting. In order to explore this difference in greater depth, both MBIs for parents and mindful parenting interventions are reviewed in the following section.

This literature review had two aims. The first was to evaluate the effects of the form of delivery of MBIs on participant acceptability, feasibility, and effectiveness. In doing so, a greater understanding of the impacts of methods of intervention delivery was developed. The second aim was to explore the relationship between MBI and mindful parenting interventions, and outcomes for parents and their autistic adolescents. The impact of MBIs and mindful parenting interventions on parental wellbeing, dispositional mindfulness, mindful parenting, mental health, stress, parenting behaviour, and challenging child behaviour are reviewed separately. This format was used in order to assess the strengths and limitations of both intervention types, before directly comparing the effectiveness of these interventions at the end of this review. Evaluating the effect and limitations of MBIs and mindful parenting interventions for parents of autistic young people will contribute to an understanding of suitable supports.

Selection of Studies

This review explored the impacts of MBIs and mindful parenting interventions on parents and their autistic children and adolescents. While the current study relates to parents of autistic adolescents as opposed to autistic children, there is limited research that applied to this population. For this reason, interventions with populations including parents of autistic children were included in this review. MBIs were considered those interventions that implemented MBSR, MBCT, or MBPBS, while studies were considered to be mindful parenting interventions when including a programme designed to teach mindful parenting (e.g MP). The studies that included parents of children older than 18 years were included when the mean age of young people in these studies was under 18 years. A variety of study methodologies were included; qualitative (1), single case design (2), randomised (1), randomised controlled trial (1), quasi-experimental (4), within-subjects design (1), between-subjects design (1). The inclusion criteria for this review were broad due to the limited number of studies addressing mindful parenting interventions for parents of autistic young people.

The following review of the literature is organised into three areas; delivery of MBIs, interventions that implement mindfulness interventions (general MBIs) with parents of autistic young people, and interventions that implement mindful parenting programmes with parents of autistic young people.

Table 1

Summary of Mindful Parenting and MBI Studies

	Country	Participants	Child age	Intervention type	Delivery	Data Collection	Research Design	Outcome Measures	Main Findings
Bögels et al. (2014)	Netherlands	n = 86 (77 mothers, 9 fathers) Parents referred to secondary mental health care services for parent and/or child psychopathology	2 - 21 years (*M* = 10.7)	Mindful Parenting (Bögels & Restifo, 2013)	8 weekly group sessions, one f/up group session at 8-week f/up	Waitlist, pre-intervention, post- intervention and 8-weeks f/up.	Quasi-experimental design	CBCL, YASR, D-PSI - Sense of Competence subscale, RBI, CS, MSCQ	- Sign. improvement in all RBI subscales from pre-intervention to 8-week f/up. - Sign. reductions in parenting stress from pre to post-intervention, maintained at 8-week f/up. - Sign. decrease in child internalising and externalising behaviour at post-intervention and 8-week f/up.
Emerson et al. (2019)	Netherlands	n = 89 (77.2% mothers) Parents of child and youth secondary mental health care services	1.5 - 18 years (*M* = 10.17) (23% diagnosis of autism, 29% ADHD diagnosis)	Mindful Parenting (Bögels & Restifo, 2013)	8 weekly group sessions, one f/up group session at 8-week f/up	Pre-intervention, post-intervention, and 8-weeks and 1-year f/up.	Repeated measures design	CBCL, ASR, FFMQ, PSI, PS, PAAQ, IM-P	- Sign. increase in dispositional mindfulness at 8-week f/up, not maintained at 1 year f/up. - Sign. increase in mindful parenting at 8-week f/up, not maintained at 1-year f/up. - Sign. reduction in parents' overreactivity (PS), maintained at 1-year f/up. - Sign. reductions in parenting stress from pre to post-intervention, maintained at 8-week and 1-year f/up. - Sign. reductions ASR subscales from preintervention to 8-week f/up. Only remained sign. for externalising problems at 1 year f/up. - Sign. reduction in child internalising, externalising, and attention problems from pre-intervention to 8-week f/up, reduction only maintained in attention problems at 1 year f/up.

de Bruin et al. (2015)	Netherlands	n = 18 Parents of autistic adolescents (18 mothers, 11 fathers) recruited from mental health care services. n = 23 Autistic adolescents	11 - 23 years (*M* = 15.8)	MYmind programme for adolescents Mindful parenting programme for parents (Bögels & Restifo, 2013)	9 weekly group sessions	1 week pre-intervention, immediately post-intervention, and 9-week f/up	Repeated measures design	AQ, MAAS-A, PSWQ, RRS, WHO-5, SRS, FFMQ, IM-P, PS, PSI-C	- Sign. increase in dispositional mindfulness at post-intervention and maintained at 9-week f/up. - Sign. increase in mindful parenting at post- intervention and 9-week f/up. - Borderline sign. decrease in parents' laxness (PS) from pre-intervention to 9-week f/up. - Sign. improvements in QOL post-intervention, not maintained at 9-week f/up.
Ridderinkhof et al. (2018)	Netherlands	n = 74 parents of autistic young people (43 mothers, 31 fathers) n = 45 young people Recruitment method no reported	8 - 19 years	MYmind - Adolescents and parents meet in separate groups (de Bruin et al., 2015), parent programme based on MP (Bögels & Restifo, 2013)	9 weekly group sessions, one f/up session at 9-week f/up	Pre-intervention, immediately post-intervention, and 2 months and 1-year f/up.	Repeated measures design	SRS, CBCL, YSR, CAMM, SRS-Adult form, ASR, PSI-C, IM-P	- Sign. improvement in mindful parenting at post- intervention, 2-month and 1-year f/up. - Sign. reduction in parents' overreactivity (PS), maintained at 1-year f/up. - Sign. reductions ASR subscales at 2-month f/up, reductions in internalising and externalising problems maintained at 1-year f/up, but not attention problems.
Ridderinkhof et al. (2019)	Netherlands	n = 31 parents of young people n = 14 autistic young people Parents and young people recruited from previous study completors from	9 - 17 years	MYmind - Adolescents and parents meet in separate groups (de Bruin et al., 2015), parent programme based on MP	9 weekly group sessions, one f/up session at 9-week f/up	Pre- intervention, immediately post-intervention, and 2 months and 1-year f/up.	Qualitative design	Interviewed parents and children about programme experiences	- Positive parent perceptions of programme.

		Ridderinkhof et al. (2018)		(Bögels & Restifo, 2013)					
Salem-Guirgis et al. (2019)	Canada	n = 23 Parents and their autistic adolescents (20 mothers, 3 fathers) recruited from local autism services	12-23 years (M = 15.65)	MYmind - Adolescents and parents meet in separate groups (de Bruin et al., 2015), parent programme based on MP (Bögels & Restifo, 2013)	9 weekly group sessions, one f/up session at 9-week f/up	10 weeks pre-intervention, one week pre-intervention, one week post-intervention, and 10-week f/up.	Within-subject repeated measures design	BASC-2, BASC-2-PRS, BASC-2-SRP, ERC, RRS, ERQ-CA, CAMM SRS-2 DASS-21 FFMQ-SF IEM-P	- Sign. improvement in dispositional mindfulness from pre-intervention to post- intervention, maintained at 10-week f/up. - No improvement in mindful parenting at post- intervention, sign. improvement at 10-week f/up. - No sign. decrease in DASS-21 stress subscale scores at post-intervention or f/up. - No sign. reductions in DASS-21 anxiety or depression subscales between the 10-week baseline period, post-intervention, or f/up.
Singh et al. (2006)	United States	n = 3 Mothers of autistic children (recruitment method unclear)	4-6 years	Mindfulness parenting programme (unclear how this was developed)	12 individual sessions with practitioner, followed by 52 weeks of individual practice	Daily during baseline, intervention, and for a year post-intervention	Single case design - Multiple-baseline across parent–child dyads (5, 12, and 15 weeks)	Child aggression, non-compliance, and self-injury SUPS, SUIS, SUUM	- Target behaviours in all three parent-child dyads decreased significantly from baseline to 1-year f/up.
Rayan & Ahmad. (2016)	Jordan	n = 104 Parents of autistic young people recruited from autism support centres (73 mothers, 31 fathers)	1.5 - 17 years	Adapted MBCT	5 weekly group sessions, one telephone f/up session	First week of intervention (pre-test) and the 5th week of intervention (post-test)	Randomised Control Trial - randomly assigned to control or MBCT	WHOQOL-BREF, CERQ - PSR subscale, MAAS	- MBCT group significant increase in MAAS scores from pre to post-intervention, no significant improvements were observed in control group MAAS scores from pre to post-intervention. - Sign. improvements from pre to post-intervention in the psychological health and social relationships subscales, not physical health subscale.

Ferraioli & Harris. (2013)	United States	n = 15 Parents of autistic young people recruited from a developmental disabilities service and autism service (10 mothers, 5 fathers)	3 - 18 years	Adapted MBCT	8 weekly group sessions	Prior to intervention, immediately after intervention, and at 3-month f/up	Between subjects design - matched into pairs based on baseline PSI-SF scores, one of each pair randomly assigned to MBCT programme or SBPT programme.	PSI-SF, GHQ, MAAS	- Significant increase in MBCT group MAAS scores from pre-test to post-test, no between-group differences were identified at post-test. - MBI group sign. reduced PSI-SF total scores at post-intervention, no longer significant at 3 month f/up. - No sign. change in PSI-SF total scores in SBPT group post-intervention.
Lunsky et al. (2021)	Canada	n = 39 Parents of autistic adolescents and adults recruited from local autism services (35 mothers, 3 fathers)	16 - 39 years (*M* = 20.92)	Adapted MBCT - Virtually delivered	6 weekly group sessions delivered virtually via Zoom Conducted with a facilitator and two parent-facilitators with prior peer-support experience	Baseline, one week post-intervention, and at 12-weeks f/up	Repeated measures design	DASS-14, FFMQ, BMPS, SCS-SF, R-CAS, PGS	- Significant increase in dispositional mindfulness from baseline to post-intervention, maintained at three month-follow-up. - Improvements in mindful parenting maintained at 3-month f/up. - Sign. reduction in stress and depression symptoms from baseline to post-intervention, maintained at f/up.
Dykens et al. (2014)	United States	n = 243 Mothers of young people with autism or developmental disorder	2 - 54 years (*M* = 10.85)	MBSR	6 weekly group sessions Each group conducted	Baseline, mid-treatment, end of treatment, and 1, 3, and 6 months f/up.	Randomised Trial - Parents randomly assigned to MBSR	PSI-SF, BDI, BAI, ISI, RSPW-SF, LSS	- Sign. reductions in parental distress subscale scores from baseline to 6-month f/up, no sign. difference between MBSR and PAD groups. - MBSR group showed greater reduction in BDI scores than PAD

		recruited via advertisements online and at disability organisations.			with two parent-facilitators who were parents of children with disabilities.		condition or PAD condition.		group post-intervention. PAD group demonstrated greater improvements in depressive symptoms than MBSR group at 6-month f/up. - MBSR group showed greater reductions in BAI scores than PAD group from baseline to post-intervention, no significant between-group differences at f/up
Ruiz-Robledillo et al. (2015)	Spain	n = 13 Parents of autistic and typically developing adolescents (12 mothers and one father) recruited from an autism support group (Unspecified recruitment of parents of typically developing young people)	Adolescents ages unspecified (*M* = 15)	Adapted MBSR	8 fortnightly group sessions, one f/up session two weeks later	Pre-intervention, mid-intervention, and immediately post-intervention	Quasi-experimental repeated measures design	STAI-S, POMS, STAXI-2, ESS-R, GHQ-28, BDI, Cortisol levels, AQ, ZBI	- No sign. reductions in depressive symptoms from pre-intervention to post-intervention. - STAI-S scores reduced significantly from pre-intervention to post-intervention.
Singh et al. (2014)	United States	n = 3 Mothers of autistic adolescents (recruitment method unclear)	15 - 19 years	MBPBS	8 full-day sessions once a week for 8 weeks. Parents took part in pre-training mindfulness session prior to baseline.	Child behaviour recorded daily throughout baseline, intervention, and 48 weeks post-intervention.	Single case design - multiple baseline across participants design	Aggressive, disruptive, and non-compliant child behaviour PSS-10	- Significant decrease in PSS-10 scores from baseline to 48 weeks post-intervention. - Sign. decrease in adolescent aggressive and disruptive behaviour, sign. increase in compliance from baseline to 48-week f/up.

Singh et al. (2019)	United States	n = 92 47 mothers of autistic adolescents and 45 mothers of adolescents with ID, recruited from advertisements in the community, autism services, and medical services.	13 - 17 years (*M* = 15.15)	MBPBS	3 day group training, parents assigned to ID or ASD parent group.	Adolescent behaviour recorded daily during 10-week control phase, intervention, and 30 weeks post-intervention. Parenting stress recorded 10 weeks before and 30 weeks after intervention.	Experimental design, equivalent two group design - Control phase, intervention phase, practice phase.	PSS-10 Aggressive, disruptive, and non-compliant child behaviour	- Sign. reductions in PSS-10 scores from baseline to 30 weeks post-intervention. - Sign. decrease in adolescent aggressive and disruptive behaviour, sign. increase in compliance from baseline to 30-week post-intervention.

CBCL = Childhood Behaviour Checklist, YASR = Young Adult Self Report, D-PSI = Dutch version Parenting Stress Index, RBI = Rearing Behaviour Inventory, CS = Coparenting Scale, MSCQ = Marital Satisfaction and Communication Questionnaire, SUPS = Subjective Units of Parenting Satisfaction, SUIS = Subjective Units of Interaction Satisfaction, SUUM = Subjective Units of Use of Mindfulness, BASC-2 = Behavior Assessment System for Children Second Edition, RRS = Ruminative Response Scale, BASC-2 PRS = Behavior Assessment System for Children Second Edition Parenting Rating Scale, BASC-2 SRP = Behavior Assessment System for Children Second Edition Self Report of Personality, ERC = Emotion Regulation Checklist, ERQ-CA = Emotion Regulation Questionnaire-Child, CAMM = Child and Adolescent Mindfulness Measure, SRS-2 = Social Responsiveness Scale Second Edition, DASS-21 = Depression, Anxiety, and Stress Scale, FFMQ-SF = Five Facets of Mindfulness Questionnaire-Short Form, IEM-P = Interpersonal Mindfulness in Parenting Scale, AQ = Autism Questionnaire, MAAS-A = Mindful Attention and Awareness Scale–Adolescent version, PSWQ = Penn State Worry Questionnaire, WHO-5 = World Health Organization–Five Well-Being Index, SRS = Social Responsiveness Scale, IM-P = Interpersonal Mindfulness in Parenting Scale, PAD = Positive Adult Development, PS = Parenting Scale, PSI-C = Parenting Stress Index–Competence Scale, ASR = Adult Self Report, PSI = Parenting Stress Index, PAAQ = Parental Acceptance and Action Questionnaire, WHOQOL-BREF = World Health Organization QOL Assessment-Brief, SBPT = Skills-Based Parenting programme, CERQ = Cognitive Emotion Regulation Questionnaire, MAAS = Mindful Attention Awareness Scale, PSI-SF = Parenting Stress Index - Short Form, GHQ = General Health Questionnaire, BMPS = Bangor Mindfulness Parenting Scale, SCS-SF = Self-Compassion Scale—Short Form, R-CAS = Revised Caregiving Appraisal Scale, PGS = Positive Gain Scale, BDI = Beck Depression Inventory, BAI = Beck Anxiety Inventory, ISI = Insomnia Severity Index, RSPW-SF = Ryff Scales of Psychological Well-Being, LSS = Life Satisfaction Scale, PSS-10 = Perceived Stress Scale (PSS-10), MBPBS = Mindfulness-Based Positive Behaviour Support, STAI-S = State-Trait Anxiety Inventory - Spanish, POMS Profile of Mood States, STAXI-2 = State-Trait Anger Expression Inventory-2, ESS-R = Spanish Somatic Symptoms Scale, GHQ-28 = General Health Questionnaire, ZBI = Zarit Burden Inventory, YSR = Youth Self Report, CAMM = Children's Acceptance and Mindfulness Measure.
Sign. = significant, f/up = follow-up

Delivery of Mindfulness-Based Interventions

Digital/Online Delivery

Several studies have investigated the feasibility, effect, and participant experiences of MBIs delivered to parents of children with additional needs in an online or digital format (Flynn et al., 2020; Luberto et al., 2021; Lunsky et al., 2021; Potharst et al., 2019). Due to the lack of previous research in this area with parents of autistic young people, studies with parents of children with an intellectual disability were also included.

Lunsky et al. (2021) and Luberto et al. (2021) both examined the impacts of an online MBI on parents of young people with a diagnosis of autism. Lunsky et al. (2021) conducted an online group MBCT programme over six weeks for parents of autistic adolescents and adults aged 16 – 39 years. The 1.5 hour online sessions were delivered via Zoom, allowing parents to engage with other parents and the programme facilitator directly, with a technology facilitator available if any difficulties arose (Lunsky et al., 2021). Resources were provided via email and meditations were video recorded and emailed to participants in cases of absence (Lunsky et al., 2021). Of the 39 parents who completed baseline measures, 54% completed the post-intervention measures, and 46% completed the follow-up measures three months later (Lunsky et al., 2021), indicating low retention. Parents reported high levels of satisfaction with the Zoom sessions, but noted some difficulty with online links and other technical difficulties (Lunsky et al., 2021). Notably, parents reported feeling connected with their fellow parents (Lunsky et al., 2021), indicating that the virtual delivery of the intervention still allowed for peer connection and support.

Luberto et al. (2021) also employed a mind-body intervention that was delivered to parents of autistic children or learning difficulties via video conferencing. Although not expressly mindfulness-based, the similarities in teaching deep breathing, visualisation, and other practical skills in this intervention are relevant to the review question. Similar to Lunsky et al. (2021), parents attended six weekly group sessions online via Zoom, when they interacted with a group facilitator and other parents virtually (Luberto et al., 2021). Qualitative feedback provided via a questionnaire post-intervention showed that the majority of parents felt the online delivery increased accessibility to the intervention, while a few reported the disruptive nature of technical difficulties in the online delivery (Luberto et al., 2021).

In a randomised controlled trial, Flynn et al. (2020) investigated the feasibility of a 10-session MBI for parents of children and adults (1 – 55 years) with an ID. The BeMindful programme teaches general mindfulness to parents via recorded video sessions, with additional resources and homework accompanying each session (Flynn et al., 2020). Of the 60 participants who completed baseline outcome measures, 50 (83%) completed the intervention, demonstrating high retention (Flynn et al., 2020). Following the intervention, participants completed a semi-structured interview via telephone, in which parents reported on the ease of using the BeMindful intervention as they could complete sessions when convenient for them (Flynn et al., 2020). Some parents noted that without face-to-face interaction they felt less accountable and felt it was more difficult to persevere (Flynn et al., 2020). This finding suggests that group interaction may be helpful in creating an environment of support and inclusion.

Co-facilitation

Parent co-facilitation; also referred to as peer mentorship, or peer support, pertains to the inclusion of trained or experienced parents acting as co-facilitators, usually in a group parent training setting. The purpose of including a parent co-facilitator is to provide participants with a peer who has shared similar experiences in order to support other parent participants (Thomson et al., 2015). Three studies included parent co-facilitation within an MBI for parents of autistic young people or those with a developmental disability. Dykens et al. (2014) and Lunsky et al. (2021) both carried out group MBIs in which parent advisors or mentors who were parents of autistic children were engaged in co-facilitation of group meetings. The two parent mentors in Dykens et al. (2014) were given four months of training in MBSR or the active control (PAD) prior to the intervention and co-led sessions with a clinical facilitator. In Lunsky et al. (2021), two parent advisors co-led group MBI sessions along with two clinical facilitators. The parent advisors did not receive any training prior to the intervention (Lunsky et al., 2021). In this study, parent advisors provided support to parents and participated in group exercises alongside the participants in an advisory role (Lunsky et al., 2021). Parent participants in Lunsky et al. (2021) demonstrated significant increases in mindfulness (measured with the FFMQ) and significant reductions in stress and depression symptoms (DASS-14).

Parent mentors in Dykens et al. (2014) were parents of children with a disability and were given four months training in the intervention content and mentorship. Mentors worked alongside a social worker and the clinical facilitator, taking a co-leadership role in each session of the intervention (Dykens et al., 2014). At post-intervention, parent participants in both the MBSR and control groups demonstrated reductions in stress, although no significant between-group difference was found. Neither study evaluated the impacts of the parent facilitator role on the parent experience of the intervention in any way.

In the BeMindful study, Flynn et al. (2020) reported that one arm of the study included a peer-mentoring element in the form of weekly phone calls with a parent of a child with ID (Flynn et al., 2020). Peer mentors spoke with participants regarding any difficulties experienced, guiding parents through challenges with technology or content (Flynn et al., 2020). No between-group differences were observed, with both groups demonstrating increased wellbeing post-intervention (Warwick-Edinburgh Mental Well-being Scale) (Flynn et al., 2020). Despite this, qualitative findings through semi-structured interviews highlighted that parents in the peer mentor group valued the phone calls and the support they provided (Flynn et al., 2020).

While research reporting on the efficacy of parent co-facilitation is limited, previous research suggests that the addition of peer mentors in some capacity is beneficial for parents (Flynn et al., 2020; Luberto et al., 2021; Lunsky et al., 2021; Thomas et al., 2015). Parent co-facilitation has been included in different interventions for parents of autistic young people. A qualitative study conducted by Thomas et al. (2015) sheds light on the experiences of peer facilitators themselves, showing that while their time in the role increased their own confidence and contributed to family cohesion, the role was also highly demanding. This finding is informative as it emphasises the importance of support for parent co-facilitators. Fung et al. (2018) used a similar protocol, placing a parent facilitator with each parenting group within an ACT group intervention for parents of autistic children. There was, however, no qualitative or quantitative evaluation of the impacts of the parent facilitators.

Effects of Mindfulness for Parents Interventions

Seven studies were identified that had implemented general mindfulness-based interventions for parents of autistic young people. Each study implemented a programme based on either MBSR, MBCT or MBPBS to teach parents general mindfulness practice. MBPBS blends mindfulness for parents with Positive Behavioural Support (PBS), a behavioural intervention to support the development of positive behaviour in children (Singh et al., 2014;

Singh et al., 2019). Outcomes relevant to the current study were assessed across the literature, including parents' mindfulness, mindful parenting, parenting stress, general stress, mental health, quality of life, and parent-reported adolescent behaviour.

Mindfulness and Mindful Parenting

Three studies examined the effects of MBIs on mindfulness and mindful parenting in parents of autistic young people (Ferraioli & Harris., 2013; Lunsky et al., 2021; Rayan & Ahmad, 2016). Dispositional, or trait, mindfulness refers to the development of a stable trait of mindfulness (Dorjee, 2010). As an extension of dispositional mindfulness, mindful parenting refers to the use of a mindful approach to parenting specifically (Duncan et al., 2009).

In two studies, outcomes were measured using the Mindful Attention Awareness Scale (MAAS) (Rayan & Ahmad, 2016, Ferraioli & Harris, 2013), while one used the Five Facets of Mindfulness Questionnaire-Short Form (FFMQ) (Lunsky et al., 2021). Within two studies, effects of the MBI were evaluated using a randomised control trial design. Ferraioli & Harris, (2013) assigned parents of autistic children (3-18 years) to either an active control condition (Skills-Based Parent Training) or an adapted MBCT intervention group consisting of eight sessions (Ferraioli & Harris, 2013). In the second study, parents of autistic children (1.5 – 17 years) were assigned to a non-equivalent control group or adapted MBCT intervention group delivered over five sessions (Rayan & Ahmad, 2016). In Rayan & Ahmad (2016), parents in the MBCT group demonstrated a significant improvement in dispositional mindfulness with a large effect size (Cohen's d =0.87) as measured on the MAAS (Rayan & Ahmad, 2016). No significant improvements were observed in the control group participants' MAAS scores from pre-intervention to post-intervention (Rayan & Ahmad, 2016). This indicates the intervention had a significant treatment effect on parents' dispositional mindfulness and demonstrated greater efficacy than the control group. In contrast, in Ferraioli & Harris (2013), parents in the MBCT group showed a significant increase in MAAS scores from pre-test to post-test, although no between-group differences were identified at post-test (Ferraioli & Harris, 2013). The lack of difference in dispositional mindfulness between parents in the two intervention conditions indicates that the MBCT intervention was not more effective at improving dispositional mindfulness than the control SBPT (Ferraioli & Harris, 2013). A repeated measures design study by Lunsky et al. (2021) delivered a six-session adapted MBCT intervention online via Zoom for parents of autistic young people (16 – 39 years, *M* = 20.92), with parent-facilitators of children with disabilities providing additional peer support alongside the lead facilitator. Participants in Lunsky et al. (2021) demonstrated a significant increase in dispositional mindfulness from baseline to post-intervention, which was maintained at follow-up three months later. The influence of an MBI on mindful parenting was also examined by Lunsky et al. (2021) using the Bangor Mindfulness Parenting Scale (BMPS). Participants demonstrated an improvement in mean BMPS score from baseline to post-intervention, and baseline to follow-up, but this was not a statistically significant improvement (Lunsky et al., 2021).

The findings from these studies indicate that the MBCT intervention produced a greater increase in dispositional mindfulness compared to a non-equivalent control (Rayan & Ahmad, 2016) and in comparison to baseline levels (Lunsky et al., 2021). In addition, the parenting intervention that did not target mindfulness specifically produced similar associated effects on dispositional mindfulness as the MBCT intervention (Ferraioli & Harris, 2013). This finding does not indicate MBIs increase mindful parenting in parents of autistic young people.

Impacts of MBIs on Parenting Stress and General Stress

Within this review, four studies reported the associated impact of MBIs on stress in parents of autistic young people (Ferraioli & Harris, 2013; Dykens et al., 2014; Singh et al., 2014; Singh et al., 2019).

Ferraioli & Harris (2013) and Dykens et al. (2014) both assessed the impact of MBIs on parenting stress in parents of autistic adolescents using the PSI-SF. The PSI-SF is designed to measure parent stress associated with the task of parenting using three subscales; Parental Distress, Dysfunctional Parent-Child Interactions, and Difficult Child (Abidin, 2012). While each study is implemented with parents of autistic young people of different age groups (3 – 18 years (Ferraioli & Harris, 2013) and 2 – 54 years (Dykens et al., 2021)), both compare MBIs against an active control condition. Ferraioli & Harris (2013) reported total PSI-SF scores, while Dykens et al. (2021) only reported subscale scores, making it difficult to compare across studies.

Parents in the MBI groups in both studies demonstrated a decrease in parenting stress as measured by the PSI-SF (Dykens et al., 2014; Ferraoili & Harris, 2013). In Ferraioli & Harris (2013), participants in the MBI group showed significantly reduced PSI-SF total scores at post-intervention, while no significant change in PSI-SF total scores was reported by parents in the behavioural skills group post-intervention (Ferraioli & Harris, 2013). However, this reduction in stress in the MBI group was no longer significant when measured again three months post-intervention (Ferraioli & Harris, 2013). In contrast, Dykens et al. (2021) observed that while both groups demonstrated significant reductions in parental distress subscale scores from baseline to six-month follow-up, there was no significant difference between the MBSR and Positive Adult Development (PAD) groups (Dykens et al. 2014). This indicates that MBSR was similarly effective at reducing parenting stress than the PAD active control condition, offering a potential alternative intervention.

The Perceived Stress Scale (PSS-10) was used by Singh et al. (2014) and Singh et al. (2019) to assess parents of autistic adolescents' perceptions of their own psychological stress. Singh et al. (2019) and Singh et al. (2014) carried out MBPBS interventions with mothers of children with ASD or ID (Singh et al., 2019) and mothers of autistic adolescents (Singh et al., 2014). Parents in Singh et al. (2014) demonstrated a significant decrease in PSS-10 scores from baseline to 48 weeks post-intervention. Parents of autistic adolescents in Singh et al. (2019) also demonstrated reductions in PSS-10 scores from baseline to 30 weeks post-intervention. These findings suggest that MBIs also reduce parents' general stress as well as parenting stress as demonstrated above. However, the intervention MBPBS includes different elements to other MBIs, with the addition of positive behaviour support (PBS) strategies. The added behaviour focus may produce different effects on parents' general stress outcomes.

The results of these studies indicate limited efficacy of MBIs for reducing parenting stress in parents of autistic young children (Dykens et al., 2014) and autistic adults (Lunsky et al., 2021). Overall, preliminary evidence suggests that MBIs for parents of autistic young people do not contribute to significant long-term stress reduction in this population compared to other parenting interventions or control conditions.

Impacts on Parent Mental Health

Four studies were identified that investigated the effects of MBIs on the mental health of parents of autistic young people (Dykens et al., 2014; Ferraioli & Harris, 2013; Lunsky et al., 2021; Ruiz-Robledillo et al., 2015).

Two studies used the Beck Depression Inventory (BDI) to assess the effects of MBIs on depressive symptoms in parents of autistic young people and adults (2 – 54 years) (Dykens et al., 2014) and parents of autistic adolescents (*M* = 15 years) (Ruiz-Robledillo et al., 2015). Dykens et al. (2014) used a between-groups design to compare MBSR and another parent training programme, while Ruiz-Robledillo et al. (2015) implemented a quasi-experimental design comparing the impacts of MBSR for parents of autistic adolescents and parents of neurotypical adolescents from pre-intervention to post-intervention. While parents of neurotypical adolescents and parents of autistic adolescents both demonstrated reductions in depressive symptoms, this was not a significant improvement (Ruiz-Robledillo et al., 2015). In Dykens et al. (2014), those in the MBSR condition showed greater reductions in BDI scores compared to mothers in the alternative treatment group from baseline to post-intervention. However, at six-month follow-up, parents in the alternative treatment group demonstrated greater improvements in depressive symptoms compared to parents in the MBSR group (Dykens et al., 2014). This provides evidence indicating that MBIs did not improve parents' depressive symptoms. Alternatively, Lunsky et al. (2021) used the depression and stress subscales of the DASS-21. Significant reductions in parents' depression and stress symptoms from baseline to post-intervention were identified and maintained at 12-week follow-up. The findings of this study conflict with that of Dykens et al. (2014) and Ruiz-Robledillo et al. (2015), possibly indicating the use of MBCT is more effective at improving parent mental health than MBSR.

Similar results have been found for the effect of MBIs on anxiety symptomatology in parents of autistic adolescents (Dykens et al., 2014; Ruiz-Robledillo et al., 2015). While both studies were MBSR-based, two different measures were used to assess anxiety; the Beck Anxiety Inventory (BAI) (Dykens et al., 2014) and the State-Trait Anxiety Inventory (STAI-S) (Ruiz-Robledillo et al., 2015). Mothers in the MBSR condition in Dykens et al. (2014) showed greater reductions in BAI scores compared to mothers in the PAD group from baseline to post-intervention. Despite this, no significant between-group differences were identified at follow-up (Dykens et al., 2014). Conversely, in Ruiz-Robledillo et al. (2015), STAI-S scores of parents of autistic adolescents reduced significantly from pre-intervention to post-intervention, indicating a reduction in anxiety symptoms. While these results suggest the MBI reduced anxiety symptoms in parents of autistic adolescents (M = 15 years), the small sample size and lack of a control group prevent further analysis. As such, neither study provides strong evidence of the impact of MBIs on anxiety symptoms in parents of autistic young people and adults due to these limitations.

The above studies provide preliminary evidence of the positive effects associated with MBIs on the mental health of parents of autistic children and adolescents. However, the lack of consistent findings in each study and the limitations of study designs demonstrates the need for further research in this area.

Parental Quality of Life

Rayan & Ahmad (2016) was the only study that examined the effect associated with a brief MBI on the quality of life of parents of autistic children (1.5 – 17 years). Using the World Health Organization QOL Assessment-Brief (WHOQOL-BREF), parents in both the MBSR and control groups reported significant improvements from pre-intervention to post-intervention in the total quality of life score, although the change in scores in the MBSR group indicated a larger effect size (0.76) than the control group (0.34) (Rayan & Ahmad, 2016). This study provides preliminary evidence for the effectiveness of MBIs in improving quality of life in parents of autistic adolescents.

Impacts on Parent-Reported Child Behaviour

Two studies were identified that examined the impact of MBIs on parent-reported challenging behaviour of their autistic children (Singh et al., 2014; Singh et al., 2019). Parents of autistic adolescents aged 15 – 19 years (Singh et al., 2014) and parents of autistic adolescents and adolescents with an ID aged 13 – 17 years (Singh et al., 2019) engaged in MBPBS interventions. The first study implemented a three-day MBPBS programme (Singh et al., 2014), while the other delivered an MBPBS programme over eight weekly sessions (Singh et al., 2019). In each study, caregivers were asked to record the frequency of their child's aggressive and disruptive behaviour, as well as compliance with requests. Parents of autistic children reported a significant decrease in both aggressive and disruptive behaviour and a significant increase in compliance from the four-week baseline period to 48-week follow-up (Singh et al., 2014). Significant decreases in aggressive and disruptive behaviour and a significant increase in compliance with parental requests were also found by Singh et al. (2019) from the ten-week baseline period to the end of the 30-week practice phase. These findings indicate that MBPBS interventions are an effective intervention for reducing challenging behaviour in autistic adolescents with maintained effects.

While two MBIs have been identified as evaluating the impact on child and adolescent behaviour, both used mindfulness in conjunction with PBS. While these studies both demonstrated a positive impact on challenging behaviour, both implemented interventions with an additional behaviour-based element. Therefore, conclusions cannot be drawn on the efficacy of the mindfulness component of the intervention alone on challenging behaviour in autistic young people.

Effects of Mindful Parenting Interventions

Impacts on Mindfulness, Parenting Style, and Mindful Parenting

Previous research on mindful parenting interventions with parents of autistic young people has assessed the changes in participants' dispositional mindfulness and mindful parenting. These studies demonstrate that following engagement in such interventions, parents report an increase in mindful parenting with their child, positive parent-child interactions, adaptive parenting styles, and reduced negative parenting behaviours (Bögels et al., 2014; de Bruin et al., 2015; Emerson et al., 2019; Ridderinkhof et al., 2018; Salem-Guirgis et al., 2019).

The three studies examining the effect of mindful parenting interventions on dispositional mindfulness in parents of autistic adolescents observed similar results (de Bruin et al., 2015; Emerson et al., 2019; Salem-Guirgis et al., 2019). Each implemented an MP intervention for parents based on the programme by Bögels & Restifo (2013), although a simultaneous adolescent intervention was implemented by de Bruin et al. (2015) and Salem-Guirgis et al. (2019). Additionally, participants in Emerson et al. (2019) were parents of children with autism and other diagnoses including ADHD and anxiety disorders. The FFMQ was used in two studies, while Salem-Guirgis et al. (2019) used the short form of this questionnaire (FFMQ-SF). As these measures are highly correlated with one another and share very similar factor loadings (Bohlmeijer et al., 2011), they can be compared to one another.

Parents in all three studies demonstrated increases in FFMQ and FFMQ-SF total scores from pre-intervention to one-week post-intervention (Salem-Guirgis et al., 2019), eight-week follow-up (Emerson et al., 2019), and nine-week follow-up (de Bruin et al., 2015) with medium and large effect sizes reported respectively by Emerson et al. (2019) and de Bruin et al. (2015). Long-term data collected at 10-week follow-up by Salem-Guirgis et al. (2019) indicated that this improvement in parents' dispositional mindfulness had been maintained. In comparison, data collected at 1-year follow-up by Emerson et al. (2019) indicated that the improvement in parents' dispositional mindfulness had not been maintained. As participants in Emerson et al. (2019) were parents of autistic young people and those with other diagnoses, we cannot be as confident in these results when making connections to parents of autistic young people. Participants in Salem-Guirgis et al. (2019) and de Bruin et al. (2015) were parents of autistic young people only, making these results more relevant to the present study. These results indicate that mindful parenting interventions are associated with greater and far more stable increases in dispositional mindfulness than MBI interventions in parents of autistic children and adolescents.

Mindful parenting has been linked to positive mental health and stress reduction in parents of autistic young people (Beer et al., 2013; Duncan et al., 2009). Four studies explored the effects of mindful parenting interventions on mindful parenting in this population, identifying improvements in mindful parenting (de Bruin et al., 2015; Emerson et al., 2019; Ridderinkhof et al., 2018; Salem-Guirgis et al., 2019). The 29-item Interpersonal Mindfulness in Parenting Scale (IM-P) and 10-item Interpersonal Mindfulness in Parenting scale (IEM-P) were used to measure mindful parenting.

Parents' IM-P scores increased significantly from pre-intervention to post-intervention in three studies (de Bruin et al., 2015; Emerson et al., 2019; Ridderinkhof et al., 2018), but not in the remaining study (Salem-Guirgis et al., 2019). Parents' interpersonal mindfulness in parenting scores increased at eight-week follow-up (Emerson et al., 2019; Ridderinkhof et al., 2018), nine-week follow-up (de Bruin et al., 2015), and 10-week follow-up (Salem-Guirgis et al., 2019).

Studies that collected data for longer periods demonstrated different results; parents' IM-P scores reduced at one-year follow-up in Emerson et al. (2019) and Ridderinkhof et al. (2018) and only remained significant in comparison to pre-intervention in Ridderinkhof et al. (2018). The results from Ridderinkhof et al. (2018) are given more weight in this review as the parents in this study were those of autistic young people only, as opposed to parents of children with different diagnoses. These findings suggest that mindful parenting interventions may significantly improve mindful parenting in parents of autistic children and adolescents (1.5 – 23 years), although there is insufficient evidence to indicate if this is a long-term improvement.

Changes in parenting in parents of autistic young people as a result of mindful parenting interventions were assessed in three studies (de Bruin et al., 2015; Emerson et al., 2019; Ridderinkhof et al., 2018). Parents in Emerson et al. (2018) and Ridderinkhof et al. (2018) were administered the overreactivity subscale of the Parenting Scale (PS). Parents in both studies identified significant reductions in the overreactivity subscale of the Parenting Scale (PS), a dysfunctional parenting style that is associated with poor child outcomes (Arnold et al., 1993). Significant improvements in overreactivity subscale scores were maintained at one-year follow-up in both studies (Emerson et al., 2019; Ridderinkhof et al., 2018). The PS was also used by de Bruin et al. (2015), finding a borderline significant decrease in parents' laxness subscale scores from pre-intervention to nine-week follow-up, but found no significant improvements in overreactivity as in the previous two studies (de Bruin et al., 2015). Despite these promising results, it is important to note that these studies did not use a comparison group or control group, therefore no conclusions are able to be drawn about the effect of mindful parenting interventions compared to alternative parenting interventions.

In another study, Bögels et al. (2014) used the Rearing Behaviour Inventory (RBI) to assess changes in overprotectiveness, encouragement of child autonomy, rejection, and acceptance in parents of autistic children and adolescents recruited from mental health care services (2 – 21 years). This study used a quasi-experimental design to assess the impacts of an MP programme consisting of eight weekly group sessions and one follow-up group session eight weeks later. Parents either began intervention immediately or were waitlisted (27%), during which parents completed waitlist measures. Parents demonstrated significant improvement in all RBI subscales from the waitlist phase and pre-intervention to eight-week follow-up, indicating an increase in parents' improvements in adaptive parenting behaviours (acceptance) and reductions in harmful parenting behaviours (overprotection and rejection) (Bögels et al., 2014).

The research provides evidence for the positive impacts of mindful parenting interventions on dispositional mindfulness, mindful parenting, parenting style, and parenting behaviours in parents of autistic children and adolescents. Of note is that the mindful parenting interventions implemented by Salem-Guirgis (2019), de Bruin et al. (2015), and Ridderinkhof et al. (2018) were used in conjunction with a mindfulness intervention for adolescents. It is feasible that improvements in adolescent wellbeing as a result of this intervention may have had subsequent positive impacts on the parent participants' parenting behaviours, dispositional mindfulness, and mindful parenting. When the mix of diagnoses in young people in Emerson et al. (2019) is also considered, there is a glaring lack of data related to mindful parenting interventions with parents of autistic adolescents alone.

Impacts on Parenting Stress and General Stress

Three studies were identified that investigated the impacts of mindful parenting interventions on general stress and parenting stress in parents of autistic young people (Bögels et al., 2014; Emerson et al., 2019; Salem-Guirgis et al., 2019). Both Emerson et al. (2019) and Bögels et al. (2014) assessed parenting stress using the Dutch version of the Parenting Stress Index (PSI). Parents in both studies demonstrated significant reductions in parenting stress, maintained at an eight-week (Bögels et al., 2014) and one-year follow-up (Emerson et al., 2019). No significant difference in general stress in parents of autistic young people (12 – 23 years) was identified by Salem-Guirgis et al. (2019) using the DASS-21 stress subscale scores from pre-intervention to post-intervention and ten-week follow-up.

The literature indicates that mindful parenting interventions decrease parenting stress in parents of autistic children and adolescents (aged 8 – 23 years) (Bögels et al., 2014; Emerson et al., 2019), but not general stress (Salem-Guirgis et al., 2019). This preliminary evidence indicates promising effects of mindful parenting interventions on parenting stress in parents of autistic young people, although more evidence is required to support this link. High levels of parenting stress and general stress have been shown to link to several adverse outcomes for parents of autistic young people and their children, including associations with challenging child behaviour and poor parental mental health (Baker et al., 2003; Clauser et al., 2021). Increasing our understanding of the impact of mindful parenting interventions on parenting stress in this population will have subsequent positive effects in multiple domains of parent and adolescent wellbeing.

Impacts on Parent Mental Health

Three of the identified studies investigated the impact of mindful parenting interventions on different aspects of mental health in parents of autistic young people (Emerson et al., 2019; Ridderinkhof et al., 2018; Salem-Guirgis et al., 2019).

Ridderinkhof et al. (2018) and Emerson et al. (2019) examined parents' internalising, externalising, and attention difficulties using the Adult Self Report (ASR). Parents of autistic young people demonstrated significant reductions in all three subscales at two-month follow-up, indicating improvements in internalising, externalising, and attention difficulties (Ridderinkhof et al., 2018). Reductions in internalising and externalising problems remained significant at one-year follow-up but reductions in attention problems were no longer significant at this point (Ridderinkhof et al., 2018). Parents of autistic young people and those with developmental disabilities in Emerson et al. (2019) demonstrated significant reductions in all three subscales from preintervention to eight-week follow-up. However, this change only remained significant for externalising problems at one-year follow-up (Emerson et al., 2019).

Conversely, Salem-Guirgis et al. (2019) assessed parent psychopathology using the Depression, Anxiety, and Stress Scale (DASS-21), finding no significant reductions in anxiety or depression subscales between the ten-week baseline period and post-intervention. This does not support the findings of the previous two studies (Emerson et al., 2019; Ridderinkhof et al., 2018). This may be a result of the different mental health measures or the slightly older age of the parents' children (12-23) (Salem-Guirgis et al., 2019). Interestingly, Ridderinkhof et al. (2018) and Salem-Guirgis et al. (2019) both used a simultaneous intervention for adolescents. Ridderinkhof et al. (2018) reported slightly more improvement in child mental health outcomes while Salem-Guirgis et al. (2019) reported no improvements. This may have subsequently impacted parents' mental health.

It is difficult to extrapolate from the results of these studies as one used a sample population of parents of autistic young people and those with other developmental difficulties (Emerson et al., 2019) and two implemented adolescent interventions at the same time as the mindful parenting interventions (Ridderinkhof et al., 2018; Salem-Guirgis et al., 2019). These factors prevent conclusions from being drawn about the impact of mindful parenting interventions alone on parents of autistic adolescents due to the confounding nature of the population samples and intervention types.

Given the high rates of mental health difficulties in parents of autistic adolescents, it is important that further research is undertaken to enhance our understanding of the impacts of mindful parenting interventions on this population's mental health outcomes. Therefore, further research is required to determine the efficacy of mindful parenting interventions on parent mental health in parents of autistic adolescents.

Parental Quality of Life

De Bruin et al. (2015) investigated the impacts of a nine-session MYmind intervention for parents of autistic young people aged 11-23 years using a repeated measures design. This study reported the effects on parents' self-reported quality of life (QOL) using the World Health Organisation-Five Well-being Index (WHO-5) (de Bruin et al., 2015). The MYmind intervention was associated with statistically significant improvements in QOL reported by parents immediately following the intervention, compared to the one-week baseline period. However, this improvement in quality of life was not maintained at nine-week follow-up (de Bruin et al., 2015). As the MYmind intervention programme involves intervention for parents and adolescents, it is feasible that the impacts of the adolescent intervention may have had positive outcomes on parents' QOL, but not long term.

No further studies in this review investigated the impact of mindful parenting interventions on parent quality of life. The lack of previous studies on quality of life is a particular limitation of the current literature. Measures that relate to more positive conceptualisations of parenting and parent wellbeing are vital to improving our understanding of the potential broad benefits of mindful parenting interventions. Positively framed outcome measures are of particular relevance to mindful parenting interventions, given that these interventions are based on a positive psychology model and understanding of distress and wellbeing. Further research regarding the impact of mindful parenting interventions on the QOL of parents of autistic young people is required.

Impacts on Parent-Reported Child Behaviour

In addition to measuring the impact of mindful parenting interventions on parent-related outcomes (e.g. stress, quality of life), many of the studies reviewed here also considered the benefits of mindful parenting on child-related outcomes. In particular, the most commonly measured child-related outcome was parents' perceptions of their child's behaviour.

Singh et al. (2006) assessed changes in child behaviour by asking parents to record the frequency of their child's aggression, compliance, and self-injurious behaviour (4 – 6 years). Parents digitally recorded their child's behaviour for five to ten hours per week during multiple baseline periods (5, 12, and 15 weeks respectively), the 12-week mindful parenting training, and the year following (Singh et al., 2006). The use of a single case design allowed for an in-depth assessment of the effects of the mindful parenting intervention on challenging child behaviour (Singh et al., 2006). Target behaviours in all three parent-child dyads decreased significantly from baseline to post-intervention and one-year follow-up (Singh et al., 2006), indicating a significant decrease in challenging child behaviour in each parent-child dyad. Parents subsequently reported greater satisfaction with their parenting behaviour (Singh et al., 2006).

This demonstrates that parents' engagement in mindful parenting interventions is associated with long-term reductions in self-injurious and aggressive behaviour in young autistic children (Singh et al., 2006).

Similarly, de Bruin et al. (2015) asked parents to complete the Social Responsiveness Scale (SRS) and Autism Questionnaire (AQ) to measure their child's behaviour. While AQ scores remained the same, SRS scores increased significantly from baseline to the nine-week follow-up period. This indicates no change in children's core autistic characteristics, but an increase in social responsiveness and a decrease in RRBs (Singh et al., 2006). It should be noted that the current study does not target social behaviour or RRBs in autistic children as this is largely a medical view of autism, implying that these behaviours are abnormal, as opposed to different. The studies examining behaviours such as self-injury, aggression, and internalising or externalising difficulties, however, are examined as these can cause harm and distress to the child and family (Bonis, 2016; Myers et al., 2009; Ooi et al., 2016).

Parents in Emerson et al. (2019) and Bögels et al. (2014) completed the Child Behaviour Checklist (CBCL), a measure used to assess parent-reported internalising and externalising behaviour in their child. Parents in Bögels et al. (2014) reported a significant decrease in child internalising behaviour (medium effect size) and externalising behaviour (small effect size), a change which remained significant at eight-week follow-up. This was similarly represented in Emerson et al. (2019), in which CBCL scores demonstrated a significant reduction in child internalising, externalising, and attention problems from pre-intervention to eight-week follow-up, although this change was only maintained in attention problems at one-year follow-up (Emerson et al., 2019). Furthermore, Emerson et al. (2019) examined the predictors of change in child behaviour (1.5 – 18 years). Interestingly, they found that mindful parenting predicted improvements in child attention as measured by the CBCL, but not internalising or externalising difficulties (Emerson et al., 2019). Reduced child internalising difficulties were predicted by reduced parent experiential avoidance, while reduced child externalising difficulties were predicted by reduced over-reactivity in parents as measured by the parenting scale (Emerson et al., 2019). Reduced parenting stress was not found to be associated with improvements in child behaviour (Emerson et al., 2019). As mindful parenting practices teach skills associated with low reactivity in parenting situations, mindful parenting likely contributed to decreased reactivity and subsequent improvements in child externalising difficulties (Emerson et al., 2019).

The findings of the above studies provide evidence that mindful parenting interventions reduce child and adolescent externalising difficulties (Bögels et al., 2014; Emerson et al., 2019; Singh et al., 2006, but are less likely to improve internalising difficulties (Bögels et al., 2014; Emerson et al., 2019). The limited research available indicates that mindful parenting may have subsequent positive impacts on the behaviour of autistic young people, although further research is required.

The reviewed studies implemented interventions with parents of young people of various ages; one study with parents of autistic children, seven studies with parents of autistic children and adolescents, and six studies with parents of autistic adolescents. Only two studies examined mindful parenting interventions for autistic adolescents only. The results of previous studies with autistic children and adolescents suggest the efficacy of mindful parenting interventions for parents of autistic adolescents, but further evidence is required to support this. As this population receives less support despite great support needs, determining the effectiveness of this intervention for these parents will contribute to the support of these parents and their adolescents.

Feasibility

Assessing the feasibility and acceptability of an intervention is imperative to understanding if it is appropriate for future use with a given population. The support needs of parents of autistic adolescents (Lounds et al., 2007) and reduced support services for this population (Friedman et al., 2013) means that identifying feasible and effective interventions is needed. This section reviews studies of both MBIs and mindful parenting that have reported the feasibility and acceptability of these interventions for parents of autistic young people. As this literature is in its infancy, studies that examine the feasibility of MBIs with parents of children with similar needs such as developmental disorders have also been included in this review.

MBIs

Four studies were identified that assessed the feasibility of MBI with parents of autistic children and other diagnoses (Ferraioli & Harris, 2013; Lunsky et al., 2021; Roberts & Neece., 2015; Singh et al., 2014). These studies identified parents' positive experiences of MBI programmes. Singh et al. (2014) conducted informal interviews 9 months after an MBPBS intervention with three parents of autistic adolescents (15 – 19 years). It emerged that parents initially found some of the meditation exercises difficult and demanding, but once more confident in these techniques they were easier to incorporate into continued daily practice at home post-intervention (Singh et al., 2014). Participants also identified that they felt less stressed and had more warmth in interactions with their child over the 48-week practice period, allowing them to respond with appropriate composure when their child engaged in aggressive or disruptive behaviour (Singh et al., 2014). Importantly, the participants also reported increased feelings of joy following the intervention (Singh et al., 2014). This study illustrates the positive impacts of MBPBS on parents' lives, although the inclusion of the PBS component may have influenced this.

Roberts & Neece (2015) examined the impacts of an MBSR intervention for parents of children (2.5 – 5 years) with developmental delays. Following the eight-week intervention, parents were asked to complete a questionnaire created by the researchers that included questions about their experiences of the programme (Roberts & Neece, 2015). Parents noted decreased stress and calmer responses in difficult situations, and the positive impacts of the mindfulness skills learnt throughout the intervention (Roberts & Neece, 2015). As the MBSR intervention was in person, some parents reported difficulty in catching up on missed content (Roberts & Neece, 2015). A higher attrition rate of 15.7% was reported, with the key reasons noted by parents for exiting the programme child sickness and the distance required to travel to the group sessions (Roberts & Neece, 2015).

Lunsky et al., (2021), evaluated their experiences of a virtually-delivered six-week MBCT intervention. As reported by Singh et al. (2014), parents commented on the value of mindfulness practice in daily life, while also noting the connections made with other parents and the acceptance and support felt as a result (Lunsky et al., 2021). Parents reported that the online delivery of the intervention increased flexibility and accessibility to the intervention sessions, although some technological difficulties could be disruptive at times, and suggestions were made for the inclusion of automatic reminders for attendance of sessions and homework (Lunsky et al., 2021). 54% of parents who consented to take part in the study attended four of six sessions (Lunsky et al., 2021). Non-completers cited child difficulties and difficult timing as reasons for exiting the programme (Lunsky et al., 2021).

A similar analysis of feasibility and acceptability for an MBCT-based intervention completed by parents of autistic children and adolescents (3 – 18 years) was undertaken by Ferraioli & Harris (2013). A high attrition rate of 29% was reported, with similar rates of attendance between the MBCT and active control groups (Ferraioli & Harris, 2013). Parents rated aspects of each intervention on a 1-5 Likert scale, and answered brief questions about their perceptions of the intervention, although this was not reported separately for each group (Ferraioli & Harris, 2013). The majority of parents (67%) reported being highly satisfied with their assigned intervention group, with 33% reporting moderate satisfaction (Ferraioli & Harris, 2013). Similarly to Lunsky et al. (2021) parents reported appreciating the connection and support the group setting provided, but noted that larger groups would be preferred (Ferraioli & Harris, 2013).

Mindful Parenting Interventions

Three studies were identified that have investigated the feasibility and acceptability of mindful parenting interventions with parents of autistic young people (de Bruin et al., 2015; Ridderinkhof et al., 2019; Salem-Guirgis et al., 2019). As there is only a small amount of literature addressing the acceptability of mindful parenting interventions with parents of autistic young people, studies that implemented mindful parenting interventions with parents of children with other diagnoses were also included (Siebelink et al., 2021).

Parents of autistic young people report positive experiences of mindful parenting interventions. Ridderinkhof et al. (2019) conducted qualitative interviews investigating caregivers' and children's experiences of a nine-week group MYmind intervention conducted separately for parents and their children (aged 9 – 17 years) (Ridderinkhof et al., 2018). Parents were taught mindful parenting, including exercises such as seeing your child with a beginner's mind, meditation directed towards visualisation of specific difficulties parents experienced with their child, and took part in a combined parent and child session nine weeks post-intervention (Ridderinkhof et al., 2018). Parents' experiences of the intervention were assessed via individual interviews 1-12 weeks after the final intervention session and reported by Ridderinkhof et al. (2019). The findings of these interviews demonstrated the positive changes felt by caregivers in their parenting experiences (Ridderinkhof et al., 2019). Parents felt understood by other parents in similar positions, feeling validation and understanding from the other parents in the group (Ridderinkhof et al., 2019). Parents noted skills they had developed during the programme, including increased frequency of adaptive strategies during stressful parenting situations (Ridderinkhof et al., 2019). As a result of incorporating mindfulness techniques into daily interactions with their child and partner, parents described increased connection with their children and increased awareness of their child's needs (Ridderinkhof et al. (2019).

Parent satisfaction and validity of mindful parenting interventions were assessed in two studies (de Bruin et al., 2015; Salem-Guirgis et al., 2019). Three of the 18 parents exited the programme before the third session in de Bruin et al. (2015), and four parents left the programme in Salem-Guirgis et al. (2019), demonstrating drop-out rates of 15% and 14% respectively. In de Bruin et al. (2015) attendance rates of sessions were 86% and 88% for mothers and fathers respectively, while Salem-Guirgis et al. (2019) reported an attendance rate of 91.3%. Parents' ratings of mindfulness exercises taught in the programme indicated that the breathing meditation and walking meditation were the most useful (de Bruin et al., 2015). Parents in de Bruin et al. (2015) completed an additional evaluation survey, indicating largely positive experiences of the MYmind intervention. Parents noted that the experience of group sessions with other parents provided greater social support, but noted that the mindfulness practice itself was difficult to continue once the programme had ended (de Bruin et al., 2015). These studies suggest that MYmind interventions are largely feasible and acceptable for parents of autistic young people (de Bruin et al., 2015; Ridderinkhof et al., 2018; Ridderinkhof et al., 2019; Salem-Guirgis et al., 2019).

Other qualitative studies have evaluated participant experiences of mindful parenting interventions for parents of young people with ADHD. Siebelink et al. (2021) invited parents of young people with ADHD (aged 9 – 16 years) to take part in MindChamp, an 8-week mindful parenting intervention in which parents and their children took part in separate mindfulness groups. Semi-structured interviews were conducted two months post-intervention to assess parents' experiences of the intervention and perceived facilitators and barriers surrounding participation (Siebelink et al., 2021). While parents reported feeling that the intervention improved their ability to mindfully parent their child and resulted in warmer parent-child relationships, the large time investment was reported to become overwhelming for some parents (Siebelink et al., 2021). The authors suggest future research into online mindful parent training may alleviate some of this time pressure and increase flexibility (Siebelink et al., 2021). While the findings of this study relate to parents of children with ADHD as opposed to ASD, the similarities in impact on parents' lives allow us to infer relevance to the current study (Leitch et al., 2019; Miranda et al., 2015).

Summary

This review of the literature has presented and discussed the current research regarding MBIs and mindful parenting interventions, particularly for parents of autistic young people. The evidence suggests that mindful parenting interventions for parents of autistic young people are associated with greater reductions in parenting stress, symptoms associated with anxiety and depression, and greater increases in dispositional mindfulness, mindful parenting, and parental quality of life than MBI interventions. While this research is still in its infancy, these results indicate that mindful parenting programmes are appropriate and acceptable interventions for parents of autistic young people. Limited previous research also suggests that the online delivery of mindful parenting programmes is acceptable and effective for parents of autistic young people and those with other diagnoses.

The literature supports further investigation of an online MP intervention for parents of autistic adolescents. As the large majority of previous studies examined the impact of these interventions with parents of younger autistic children, there is little evidence regarding the impact for parents of autistic adolescents specifically. Furthermore, very few studies have assessed the feasibility and effects of online mindful parenting and MBI interventions, or those delivered by a parent facilitator for parents of autistic young people. The evidence suggests that the benefits of both these delivery components overcome barriers presented by face-to-face, clinician-delivered interventions.

Rationale for the Current Study

Autistic adolescents face new and different social and mental health challenges compared to autistic children (Cresswell et al., 2019; DeFilippis, 2018; Kuusikko et al., 2008). As discussed in Chapter 1, the increasingly complex nature of social interactions in adolescence can be overwhelming and challenging (Andrews et al., 2021), with a high frequency of autistic adolescents reporting frequent bullying by peers (Cresswell et al., 2019; Humphrey & Lewis, 2008). The secondary school environment can also be far more intense and difficult to manage than early school life, introducing new sensory challenges (Goodall, 2018), academic and independence expectations, and routine changes (Saggers, 2015). In addition, the period of adolescence is accompanied by increased mental health difficulties, with increases in poor self-evaluation (Kuusikko et al., 2008), social anxiety (Kuusikko et al., 2008), and depression compared to autistic children and neurotypical adolescents (DeFilippis, 2018).

Likewise, parents of autistic adolescents contend with new and different obstacles compared to parents of autistic children, yet have access to fewer resources and services (Friedman et al., 2013; Tehee et al., 2009). These parents must guide their adolescents through a period of immense transformation while receiving little support. It is therefore unsurprising that parents of autistic adolescents continue to experience significantly more symptoms of anxiety and depression than the normative population. These challenges faced by parents of autistic young people are associated with increased risk of high general and parenting stress levels (Bonis, 2016; McStay et al., 2014b; Rivard et al., 2014), adverse parental mental health outcomes (Bonis, 2016; Phelps et al., 2009), and parental poor quality of life (Cappe et al., 2011; Vasilopoulou & Nisbet, 2016). Mindful parenting programmes have been shown to have benefits for parents of autistic youth, including reductions in parenting stress (Bögels et al., 2014; Emerson et al., 2019) and distress (e.g. anxiety, depression, stress) (Salem-Guirgis et al., 2019), and increased mindful parenting (Bögels et al., 2014; de Bruin et al., 2015; Emerson et al., 2019; Ridderinkhof et al., 2018). There is, however, a lack of evidence for these programmes with parents of autistic adolescents, with the focus in previous research centring on parents of young children (Shorey & Ng, 2021). The current paucity of research addressing the needs of parents of autistic adolescents is a gap that this study aims to address.

Previous research has indicated that online mindful parenting interventions and MBIs are an accessible, effective, and feasible alternative to in-person intervention delivery (Flynn et al., 2020; Luberto et al., 2021; Lunsky et al., 2021). This method ensures that parents from across Aotearoa would be able to take part, a factor that is particularly valuable when no appropriate parenting programmes are available in their area. Furthermore, the literature has demonstrated that the inclusion of a peer in a facilitator role in parenting programmes increases parents' trust and positive experiences of parenting programmes (Lunsky et al., 2021; Thomas et al., 2015). As social isolation and discriminatory attitudes are experienced by many parents of autistic young people (Broady et al., 2017; Smith-Young et al., 2022; Woodgate et al., 2008), the inclusion of a trained parent-facilitator may increase parents' social wellbeing and affirm their own experiences through the support of a peer. By evaluating the feasibility of an online, parent-facilitated MP programme, it can be determined if such a method of delivery is a viable and acceptable intervention option for parents of autistic adolescents.

The current study used a mixed methods approach to assess the effects of a parent facilitated, digitally delivered Mindful Parenting programme for parents of autistic adolescents on parent stress and quality of life, and children's daytime behaviour. programme outcomes were evaluated using a single-case research design. Outcomes were assessed across baseline, intervention, and follow-up phases using measures of parent stress, quality of life, mental health, and child behaviour. Semi-structured interviews were also undertaken to assess participant experiences of the intervention process.

Research Aims

The aim of the current study was to explore the feasibility and preliminary effects of an online MP programme delivered by a trained parent facilitator for parents of autistic adolescents aged 12 – 18 years. In doing so, this study aimed to advance the current knowledge base regarding the effectiveness of mindful parenting interventions for parents of autistic adolescents, by addressing key gaps in our understanding. Much of the previous research has been conducted with parents of autistic children, with very limited research with caregivers of autistic adolescents. As parents of autistic adolescents face very different challenges from parents of autistic children, assessing the suitability of this intervention for this unique group is required to ensure informed, evidence-based practice. There is also limited previous research exploring the feasibility of online, parent-facilitated parenting interventions with parents of autistic children or adolescents. Such methods of delivery have been found to increase parent engagement, trust, and access to appropriate intervention. Gathering evidence surrounding the online delivery of a parent-facilitated MP programme for this population could provide parents of autistic young people with a more accessible and flexible intervention option without reduced effectiveness. Hypotheses and research questions regarding quantitative and qualitative outcomes are outlined below:

Quantitative Research Hypotheses

Hypothesis 1.

Participation in the mindful parenting programme will be associated with improvements in parent-reported stress (parenting stress), distress (anxiety, depression symptoms), and quality of life immediately post-intervention and at six-week follow-up. This study will explore the effect of a mindful parenting programme on perceived mindful parenting and parenting behaviour at baseline, post-intervention and six-week follow-up.

Hypothesis 2.

Parents taking part in the mindful parenting programme will report fewer adolescent behaviour problems as measured by the Child Behaviour Checklist (CBCL) immediately following the online MP intervention and at six-week follow-up. It is expected that a larger decrease would be evident in adolescent externalising problems than internalising problems.

Hypothesis 3.

Parents' responses to the programme evaluation survey will indicate the online Mindful Parenting programme as acceptable, socially valid, and feasible.

Qualitative Research Questions

Question 1.

How do parents who choose to participate in the follow-up interview perceive the intervention (parent co-facilitation, group training, and mindfulness practice)?

Question 2.

How do parents' perceptions of their parenting change following the programme?

Chapter 3. Methods

Design

A mixed-methods single case multiple baseline across participants design was utilised to gain a comprehensive understanding of the effects and feasibility of an online Mindful Parenting group program facilitated by a parent of an autistic young person. This design was used to examine the impact of the MP programme on parenting stress, distress, wellbeing, quality of life, parenting behaviour, and parents' perceptions of adolescents' challenging behaviour. Single case data were collected across three phases; baseline, intervention, and six-week follow-up. The use of a single case design has been shown to be effective at providing in-depth analysis of interventions and validity for real-world applications (Kazdin, 2019).

In addition, quantitative data relating to the acceptability of the MP programme was gathered. The qualitative component of this research consisted of semi-structured follow-up interviews assessing parents' experiences of the MP programme. The use of both quantitative and qualitative methods in this study enables the researcher to carry out both confirmatory and exploratory research into the given field (Ivankova & Wingo, 2018). This approach is appropriate for the current study as it allows the exploration of an adapted version of an intervention which has previously demonstrated effectiveness for this population. In the current study, this method will allow the evaluation of the MP programme from a measurable data-driven perspective. Qualitative data examining the parent perspectives can provide rich information about the experience of the programme to indicate the acceptability of this online MP programme. Using a combined approach ensures that changes can be directly observed through quantitative data, while also including the participant perspective. The mixed-method approach ensures that the limits of one method are supplemented by the inclusion of the other (Caruth & Amberton University, 2013).

Participants and Recruitment

Parents in the current study were recruited via a snowball method. Key organisations were contacted and asked to share the study advertisement with their community groups - including Autism New Zealand, the Pukemanu Centre (University of Canterbury), and Altogether Autism. The research team also distributed information about the study via their existing professional networks. The study advertisement (see Appendix A) was displayed online (e.g., via Facebook posts) and in physical form (poster on noticeboards) at these organisations. The advertisement provided general information about the study and directed potential participants to contact the lead researcher for further information. Approval to advertise the study was received from the appropriate liaisons at each organisation. Recruitment occurred over a five-week period (10/6/2022 - 15/7/2022).

Interested participants emailed the Masters research student and were sent a copy of the project information sheet (see Appendix B) along with a link to an online survey containing the consent form and screening questionnaire (see Appendix C). The information sheet outlined the purpose of the study, explaining in detail what participation in the study would involve and details regarding the storage of information and confidentiality. This also provided information regarding the koha participants would receive to acknowledge their involvement. If participants wanted to take part, they were invited to follow the online survey link to complete the consent form and screening questionnaire. The consent form required participants to check boxes signifying their understanding of the information presented in a particular statement, e.g, "I understand that it is voluntary (my choice) to take part in this study". Participants were also asked if they agreed to take part in the study and then to provide their contact details. The screening questionnaire was designed to collect information regarding both the parent and the young person's demographics, such as age, education, and the young person's autism diagnosis. Potential participants were asked to confirm that they were the parent/caregiver of an autistic adolescent aged 12 – 18 years and that they were not currently enrolled in another parenting programme. Parents were also asked to complete the Autism Spectrum Quotient – 10 (AQ-10) (Allison et al., 2012); scores were used to confirm that their adolescent child had characteristics of autism. Total AQ scores of six or above were considered positive screens (i.e recommended for further diagnostic assessment by AQ-10) (Allison et al., 2012).

Participants were included in the current study if they were the parent/caregiver of an autistic adolescent aged 12 – 18 years. Parents were required to not be enrolled in any other parent training programme during the study and their adolescent continued their care as usual. No further exclusion was made in order to ensure the ecological validity of real-world clinical practice. Parents who met inclusion criteria were contacted by a trained parent co-facilitator of the MP programme (post-graduate Psychology student and parent of autistic children) via phone to confirm they were suitable for the programme. During the screening interview, the parent co-facilitator outlined what was involved in the programme, and confirmed that eligible parents were able to commit to this expectation. Parents were asked to confirm that they were not currently experiencing acute life stressors that may impact their engagement with the programme, or might indicate that the mindful parenting programme was not a good fit for them at this time. Participants deemed suitable were then emailed information regarding the details of the programme dates and times and were sent an online demographic survey via email link by the Masters researcher.

Recruitment and consent procedures took place over a period of five weeks, prior to the mindful parenting programme commencing. This allowed sufficient time for potential participants to consider the project information and make an informed decision regarding their participation. Two more participants than required showed interest in the study. They were asked if they would like to be contacted for future study participation opportunities and were provided with a list of resources and services to contact for support. Participating parents were offered koha in the form of a $25 Prezzy card on three occasions that corresponded to data collection time points (pre-intervention, post-intervention and follow-up).

Parents who took part in the study are referred to in this thesis using pseudonyms. Eight parents initially consented to participating in the study, though one withdrew before the intervention began due to work commitments. The seven remaining participants were all mothers of autistic adolescents aged 12 – 18 years ($M = 14.3$) with a verified diagnosis of autism confirmed by a positive screen (score of ≥ 6) on the Autism Spectrum Quotient - 10 (AQ-10). None of the participants were enrolled in another parenting programme at the time of the study, therefore meeting the eligibility criteria. Most of the participants were aged 40 – 49 years (Julie, Sarah, Amy, Kim, Anna), with one aged 30 – 39 (Molly) and one aged 50 – 59 (Lisa). Four of the participants identified as New Zealand European (Sarah, Amy, Kim, Anna), two identified as NZ European/Māori (Julie and Molly), and one identified as Irish (Lisa). Parents reported a wide range of annual household income ($30,000-$40,000 – $200,000+) and mostly engaged in part-time employment. Several different formal and self-identified co-occurring adolescent diagnoses were reported by parents, of which anxiety was the most frequently reported co-occurring condition (4/7). One parent reported having a diagnosis of autism. Parent and child characteristics are reported in Table 2.

Parent participants were recruited from around New Zealand. Consent and screening surveys were answered by all participants online via Qualtrics. The baseline, pre-intervention, weekly, post-intervention, and follow-up measures were answered by all participants online via Qualtrics. The content of the MP programme was accessed by parents through a dedicated website, while the group sessions took place online via Zoom. Of the five follow-up interviews, four took place online via Zoom, and one took place in person at the Pukemanu Centre at the University of Canterbury.

Table 2

Description of Participants

	Age	Gender Identity	Ethnic Identity	Education	Employment	Relationship Status	Main Income Source	Annual Household Income (Thousands)	ASD Diagnosis	Number of Children	Relationship to Child	Child Age (Years)	Child Diagnoses (Formal)	Child Diagnoses (Self-Identified)
Julie	40-49	Female	NZ European /Maori	Diploma	PT Self employed /contract work	Never married	Govt income support	50-60	No	3	Mother	15	Autism, Anx, Dep	-
Sarah	40-49	Female	New Zealander	Diploma	PT Voluntary employment	Divorced	Govt income support	30-40	Yes	2	Mother	17	Autism	Anx, Dep, MCD
Lisa	50-59	Female	Irish	NCEA	PT Paid employment	Defacto	Wages, salary	150-200	No	3	Mother	18	Autism, LDD, MCD, SLD	-
Amy	40-49	Female	New Zealander	Master's degree	PT Paid employment	Married	Wages, salary	200+	No	2	Mother	12	Autism, Anx, Gifted	-
Kim	40-49	Female	NZ European	Bachelor's degree	PT Paid employment	Defacto	Wages, salary	70-100	No	3	Mother	13	Autism, S/LD, Anx, Dep, MCD, CD	SLD, LDD
Molly	30-39	Female	Maori European	NCEA	PT Paid employment	Married	Wages, salary	70-100	No	4	Mother	13	Autism, ADHD	-
Anna	40-49	Female	NZ European	NCEA	PT Self employed/ contract work	Married	Self employment or business	100-150	No	3	Mother	12	Autism	Anx, OCD, MCD

Note: ASD = Autism Spectrum Disorder, Anx = Anxiety, Dep = Depression, MCD = Motor/Coordination Difficulties, LDD = Learning/Developmental Disability, SLD = Specific Learning Disability, CD = Coeliac Disease, S/LD = Speech or Language Disorder, OCD = Obsessive Compulsive Disorder, PT = Part Time

Ethical Considerations

Ethics approval (2021/167) was obtained from Te Komiti Matatika Rangahau, Human Research Ethics Committee at the University of Canterbury. Several ethical risks were taken into consideration in order to ensure the safety and well-being of all participants and researchers involved. The online surveys required participants to answer questions that could be potentially distressing as they related to stress and mental health experiences. The follow-up interview may have led to the disclosure of personal experiences and sensitive information with an unfamiliar individual and possible psychological distress. It was important to take into account that this may have prevented full disclosure of experiences and issues to the researcher. Social risks were also accounted for in this study. The intervention took place in groups with other parents in which sensitive and personal information would be shared as part of the group process by the parent facilitator or group participants. It was possible that parents may know one another or share private information outside of the group. In order to mitigate this, the consent form contained a tick box asking parents not to share personal information or opinions spoken about in the parenting group with people outside of this group. In addition, it was assumed that the parent facilitator may be exposed to emotional stress in her role as this involved discussion of personal experience and examples. To counteract this risk, the parent facilitator received regular supervision from the Principal Investigator, Lisa Marie Emerson, to discuss and manage any arising issues. These issues were mitigated by the prior provision of information about the study, informed consent from participants, and a confidentiality agreement completed by all consenting participants. The confidentiality agreement asked parents to consent and show understanding of what the study entailed, the nature of data storage and publication of data, and the risks involved in partaking in the study.

The follow-up interview also posed potential ethical risk as sensitive personal information was discussed that could be distressing. To mitigate this risk, participants were reminded at the beginning of the interview that they may stop the interview at any time. If they became distressed there were plans in place to provide them with a referral to additional local support services for parents if needed, as referred to in the information sheet (e.g. Pukemanu services; local mental health services; Autism organisations). Any adverse events were noted as part of the feasibility outcomes of the study. As the interviewing researcher was a thesis student, they were also in regular communication with the research supervisor.

Measures

Parents completed secondary measures at three time points; pre-intervention, immediately post-intervention, and at six-week follow-up. Parents completed the following measures; the Parental Distress subscale of the Parenting Stress Index - Short Form (PSI-SF), the Interpersonal Mindfulness in Parenting Scale (IM-P), the Depression Anxiety Stress Scale (DASS-21), The World Health Organisation - Five Well-Being Index (WHO-5), Parenting Behaviour Scale – Autism (PBS-A), and the Child Behaviour Checklist (CBCL). Following each of the four Zoom group sessions, parents were also asked to complete the Group Rating Scale (GRS). This survey was sent to participants the day following each group zoom session via email link.

Outcome Rating Scale (ORS)

The ORS is a brief measure of global distress and wellbeing used to assess efficacy of therapies by clinicians (Miller et al., 2003). Increases in ORS scores are indicative of a successful intervention outcome (Miller et al., 2003). Four items are used to assess participants' overall, individual, interpersonal, and social wellbeing (Miller et al., 2003). Using a sliding scale, participants rated each area of their life from a low level to a high level. Lower scores were associated with higher levels of distress and lower wellbeing (Miller et al., 2003).

Parenting Stress Index - Short Form (PSI-SF)

The Parenting Stress Index - Short Form (PSI-SF) is a 36-item version of the Parenting Stress Index designed to measure self-reported parenting stress (Abidin, 2012). Participants rated each of the items on a Likert scale from 1 (strongly disagree) to 5 (strongly agree) (Abidin, 2012). This study used the Parental Distress subscale only in order to assess this element of parenting stress as this has shown validity with parents of autistic young people (Zaidman-Zait, et al., 2010). Participants completed 21 items related to distress associated with perceived parenting ability (Abidin, 2012). Higher scores indicated greater levels of parenting stress. Scores from 15-80 are considered typical, scores from 81-89 indicate high stress, and scores of ≥90 indicate clinically high levels of stress (Abidin, 2012). The Parenting Stress Index professional manual indicates that the Parental Distress subscale of the PSI-SF has a Cronbach's alpha of 0.87 and a standard deviation of 10 (Abidin, 2012).

Depression, Anxiety and Stress Scale - 21 (DASS-21)

The Depression, Anxiety, and Stress Scale - 21 (DASS-21) is a 21-item self-report measure that uses three subscales to assess depression, anxiety, and stress (Lovibond & Lovibond, 1995). Participants rated each item on a rating scale from 0-3 (Did not apply to me at all - Applied to me very much, or most of the time) in terms of application to them over the last week (e.g., I felt that I had nothing to look forward to) (Lovibond & Lovibond, 1995). The DASS-21 produces scores related to each subscale that are categorised from normal to extremely severe; Depression subscale (normal 0-4, mild 5-6, moderate 7-10, severe 11-13, extremely severe ≥14), anxiety subscale (normal 0-3, mild 4-5, moderate 6-7, severe 8-9, extremely severe ≥10), and stress subscale (normal 0-7, mild 8-9, moderate 10-12, severe 13-16, extremely severe ≥17) (Lovibond & Lovibond, 1995). Higher scores indicated greater levels of the relevant difficulty. The Cronbach's alpha values for the depression, anxiety, and stress subscales are 0.96, 0,92, and 0.95, with standard deviation values of 6.97, 4.91, and 7.91 respectively as reported by Lovibond & Lovibond (1995).

World Health Organisation Quality of Life (WHO-5)

The WHO-5 is a measure of quality of life and general psychological well-being (Bech, 2004). The five-item measure uses a

Likert scale from 0 (at no time) to 5 (all of the time), asking participants to rate how well each item applies to them in the context of the preceding two weeks (Bech, 2004). Scores were multiplied by four to produce a total quality of life score presented as a percentage (Bech, 2004). Clinically significant change in WHO-5 scores was indicated by a ≥10% difference in percentage scores (WHO Regional Office for Europe, 1984). Higher scores indicated higher quality of life.

Interpersonal Mindfulness in Parenting Scale (IM-P)

The IM-P Scale is a 31-item measure assessing mindful parenting. Responses fall under five subscales; (1) listening with full attention to the child, (2) non-judgmental acceptance of the self and the child, (3) emotional awareness of the self and the child, (4) self-regulation in the parenting relationship, (5) compassion for the self and the child (Duncan, 2007). Higher total IM-P scores indicated increased levels of mindful parenting practices (Duncan, 2007). The Cronbach's alpha (0.89) and standard deviation (11.13) reported by Duncan (2007) were used to calculate reliable change.

Parental Behaviour Scale-Autism (PBS-A)

The 52-item Parental Behaviour Scale - A (PBS-A) is used to assess the frequency of parenting behaviours in the context of parenting an autistic young person (Van Leeuwen & Noens, 2013). This measure asked participants to rate how often they engage in a particular behaviour using a five-option rating scale; (almost) never, rarely, sometimes, often, (almost) always (Van Leeuwen & Noens, 2013). The PBS-A is based on observable parenting behaviours associated with positive and unfavourable parenting (Van Leeuwen, & Noens, 2013). Six subscales are used to assess these behaviours; Positive parenting, material rewarding, rules, discipline, harsh punishment, stimulating development and adapting the environment (Van Leeuwen & Noens, 2013). Subscale scores are reported as mean scale scores. The Cronbach's alpha and standard deviation values reported by Van Leeuwen & Noens (2013) are detailed in Appendix G.

Child Behaviour Checklist (CBCL)

The Child Behaviour Checklist for Ages 6-18 (CBCL) is a well-validated and reliable measure of parent-reported problematic child behaviour (Achenbach & Rescorla, 2001). This 113-item measure assessed internalising, externalising, and total child difficulties, asking responders to score each item as 0 = not true, 1 = somewhat or sometimes true, or 2 = very true or often true (Achenbach & Rescorla, 2001). Scores were categorised in the normal range, borderline range, or clinical range (Achenbach & Rescorla, 2001). Higher scores indicated greater levels of problem behaviour. Cronbach's alpha and standard deviations reported by Achenbach & Rescorla (2001) are detailed in Appendix H. This data was normed from a referred population of young people aged 6-18 years (Achenbach & Rescorla, 2001).

Group Rating Scale

The group rating scale asked participants to rate their engagement and experience of each group session using four items; relationship, goals and topics, approach or method, and overall.

Participants are asked to rate their experience of each on a sliding scale with descriptive indicators on each extreme, e.g “There was something missing in the group today, I was not engaged — Overall, today’s group was right for me, I felt engaged”. Higher total scores indicated greater satisfaction with group sessions.

Programme Evaluation Form

An evaluation form adapted by Bögels & Restifo (2013) was used in this study to assess the acceptability of the MP programme. Originally used to assess participants’ evaluation of MBSR by the University of Massachusetts, this evaluation form has been used in a previous evaluation of mindful parenting programs for parents of autistic and non-autistic children (Bögels & Restifo, 2013; Potharst et al., 2017). The programme evaluation survey was made up of three sections. The first asked participants to answer seven questions related to changes experienced during the programme as yes, no, or prefer not to answer, e.g “Did you become more aware of your parenting as a result of participating in the programme?”. The second asked participants to rate parts of the mindful parenting programme from 1 (not at all useful) to 10 (extremely useful), e.g body scan. The final section asked participants to indicate levels of change experienced in different areas of life, e.g “Feeling self-confident as a parent”. Participants rated each item as either negative change, no change, some positive change, positive change, or prefer not to answer. Higher scores indicated positive evaluation of the MP intervention.

Procedure

Study Phases

The single case data were collected across three phases; baseline, intervention, and six-week follow-up as outlined below.

Baseline

During the baseline phase, participants completed the outcome rating scale (ORS) weekly for at least three weeks prior to beginning the intervention. Different baseline lengths were used in this study, with three parents assigned to complete baseline measures for four weeks, and four parents assigned a baseline period of three weeks. Multiple baseline lengths were assigned randomly to participants, allowing for a closer examination of changes over the baseline phase compared to the intervention phase. Baseline periods were not extended in any cases due to time constraints for beginning the intervention phase.

Intervention

The intervention used in the current study is an adapted online version of Mindful Parenting (MP), a programme designed by Bögels & Restifo (2014). This adaptation involved the online delivery of MP with a combination of self-study modules and group sessions facilitated by a trained parent. An outline of the programme is included in Appendix F. The intervention was delivered over six weeks via Zoom. Participants took part in self-directed online lessons via a dedicated website in the form of audio and video recordings, Youtube videos, and a PDF workbook for participants to refer to. Exercises in the PDF workbook accompanied each module and group session, supporting the focus of each week of the intervention. The PDF workbook included readings about parenting stress, mindful parenting, and reflective exercises. Four, 60-minute Zoom group sessions were conducted every second week, with all parents in one group. Group sessions were facilitated by a parent of an autistic child under the supervision of a clinical facilitator certified in MBIs and MP specifically. Participants were given homework in the form of mindfulness practices between sessions (up to one hour per day) such as body scan, informal mindfulness, and breathing space, supported by the audio/visual recordings and workbook that was provided.

At the start of week one, parents took part in an introductory group session to outline the basics of the programme and introduce the group to one another. At this time, parents were also given access to module one, detailing the basics of mindfulness and mindful parenting, with access to videos and audio recordings of mindfulness exercises. The second group session took place at the end of the second week of intervention, in which parents learnt about the breathing space exercise, body scan, and imagination exercises. During weeks three and four, parents had access to module two in which mindful awareness in parenting was introduced, and rupture and repair of parent-adolescent relationships was addressed. This was supported by the third group session in which parents practised mindful parenting in imagined stressful parenting situations. During weeks five and six, parents had access to the third module on the website, focusing on compassion for the self and the adolescent, and problem-solving.

Follow-up Interviews

Consenting participants took part in a follow-up interview six weeks post-intervention. These interviews were conducted by the research Masters student. Parents were given the option to complete the interview via Zoom or in person at the University of Canterbury campus. The study information sheet was reviewed, and verbal and written consent for the interview and recording was explained and completed by the participants. In-person interviews were audio-recorded and Zoom interviews were audio-video recorded. Participants on Zoom were informed that they could turn off their video if they did not wish for their image to be recorded and reminded that they could withdraw consent at any time. These recordings were used to transcribe the interviews for subsequent analysis. Participants were asked if they would like a copy of the completed transcription to review. Otter.ai was used to transcribe the audio-recorded interviews, which were then reviewed for accuracy.

The semi-structured interviews explored the caregivers' experiences of the MP programme and any changes they had experienced since engaging in the programme, e.g "What components of the MP programme did you find useful? Have you noticed any changes in your parenting?" The discussion points and associated questions are noted in Appendix E. At the end of the interview, participants were thanked for their time and provided with information about local support services should they have any further questions about their own or their child's needs/support. Two parents asked to review the transcript from their interview, while the rest declined the opportunity. No changes were requested by participants following their review.

Data Analysis

Single Case Data

Single case design analysis (SCDA) was used to assess changes in measures of wellbeing (ORS) and parenting stress (PSI-SF parental distress subscale). This included visual analysis of changes in outcome measure scores over phase A (baseline) and phase B (intervention) by assessing level, trend, and stability (Gast, 2009). A larger percentage (20%) was used to calculate level stability as this is recommended when participants have fewer opportunities to respond (i.e less than 5) (Gast & Spriggs, 2010). The calculation of effect size was evaluated by calculating the percentage of data exceeding or below the median (PEM/PBM) of the baseline period depending on the therapeutic direction (Ma, 2009). The percentage above/below the median equates to effect size (Ma, 2009). Intervention effectiveness is determined by effect size; ≥0.9 (highly effective), 0.7 – 0.9 (moderately effective), <0.7 (not effective) (Ma, 2009).

Repeated Measures Data

Reliable change index (RCI) and clinical significance (CS) were calculated for standardised measures. RCI is used to calculate if reliable change has occurred across phases for a participant within a particular measure (Jacobson & Truax, 1991). RCI was calculated for each of the repeated measures (PSI-SF, DASS-21, WHO-5, IM-P, PBS-A, CBCL). RCI indicated if the change in scores between pre-intervention, post-intervention, and follow-up time points was both reliable and statistically significant (Jacobson & Truax, 1991). Normative data including standard deviation and Cronbach's alpha were used to calculate the standard error of Difference Score (S_{Diff}). Reliable change was then calculated by dividing the difference between two time points by $S_{Diff.}$ RCI values of ±1.96 indicate the change is reliable between time points (Jacobson & Truax, 1991). As some measures produced scores in clinical, borderline, or normal ranges, clinically significant change was evaluated by observing when scores shifted between ranges. Maintenance of effects was measured through a comparison of post-intervention to follow-up assessment using a similar approach. Analysis was conducted in the R package. Outcomes were reported in accordance with the Single-Case Reporting Guideline in Behavioural Interventions statement (Tate et al., 2016).

Feasibility and Acceptability Data

The acceptability of the mindful parenting programme to parent participants was evaluated using an adapted version of the mindful parenting evaluation form (Bögels & Restifo, 2014). A minimum 80% positive endorsement of the intervention was required to demonstrate the acceptability of the programme. Feasibility was assessed through any adverse effects for participants or the facilitator, recruitment and retention, and group attendance using established cut-offs and frequencies.

Qualitative data from the semi-structured interviews were analysed using reflexive thematic analysis (Braun & Clarke, 2006). Braun & Clarke outline a six-step method designed to identify themes and patterns in a qualitative data set (2006). Using this approach to thematic analysis allowed for immersion in the data, particularly throughout the transcription process in order to become more familiar with the content. Secondly, data were coded by the Masters researcher based on common latent features, from which groups of meaningful data will be formed. Following this step, the coded data were organised into broader themes rather than specific codes. This process was aided by the use of mind maps to identify these themes. Themes and subthemes were reviewed for evidence support and relevance, then named in order to present a clear, cohesive account of the data gathered.

Chapter 4: Results

Quality of Data

For one participant (Anna) baseline data were collected for two data points only. Lisa and Anna completed 83% of the weekly outcome measures (both missing data for week 5), while Molly completed 67% of weekly outcome measures (missing data for weeks 1 and 6). The total percentage of missing single case data is 19.3%. All participants completed the pre-intervention, post-intervention, and follow-up surveys.

Single Case Data

ORS Overall Subscale Scores

Outcome Rating Scale (ORS) data for all seven participants, across baseline, intervention, and six-week follow-up phases are presented in Figure 1. Of the seven participants, five parents (Sarah, Lisa, Amy, Kim, and Anna) demonstrated improvements in ORS Overall scores from baseline to intervention indicated by increasing trends in data points. Of the seven parents, five demonstrated improvement in ORS Overall scores from baseline to six-week follow-up, with three shown to have an intervention effect (Sarah, Lisa, and Kim) and two with no intervention effect (Julie and Amy). One parent (Anna) demonstrated improvements in ORS Overall score from baseline to mid-intervention, although this improvement was not maintained at the end of intervention or six-week follow-up. One parent (Molly) demonstrated no change in the Overall ORS subscale, indicating no improvement in overall wellbeing as a result of the MP programme. Normative data was only available for the Total ORS scores and no normative data was available for each of the four subscales.

ORS Overall Scores - Julie

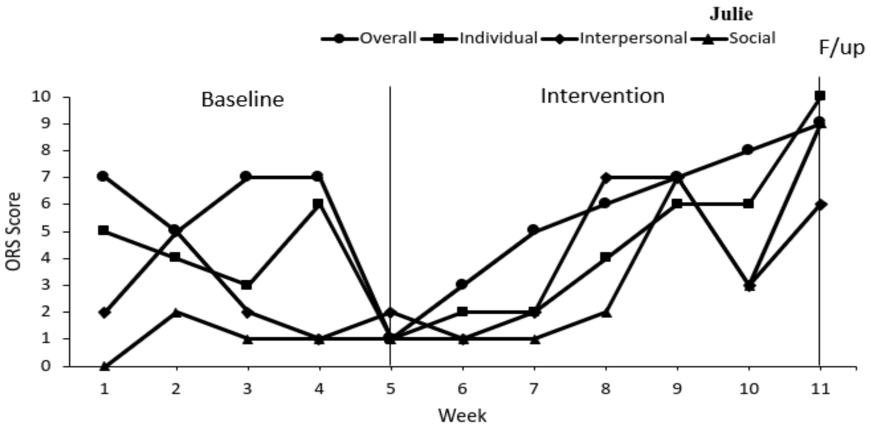
During baseline, Julie’s ORS overall scores ranged from 54 – 73 (*M* = 66.3) indicating stability in her general wellbeing at this time. There was a substantial decrease in the overall ORS score from the end of baseline (70) to the beginning of intervention (6), indicating deterioration in general well-being. However, her ORS overall score steadily increased and returned to baseline levels by the conclusion of the intervention (*M* = 48.7; range = 6 – 77). Julie’s overall ORS score continued to increase at six-week follow-up (91), suggesting improvement at the six-week follow-up period. However, the PEM score of 33% indicated no intervention effect.

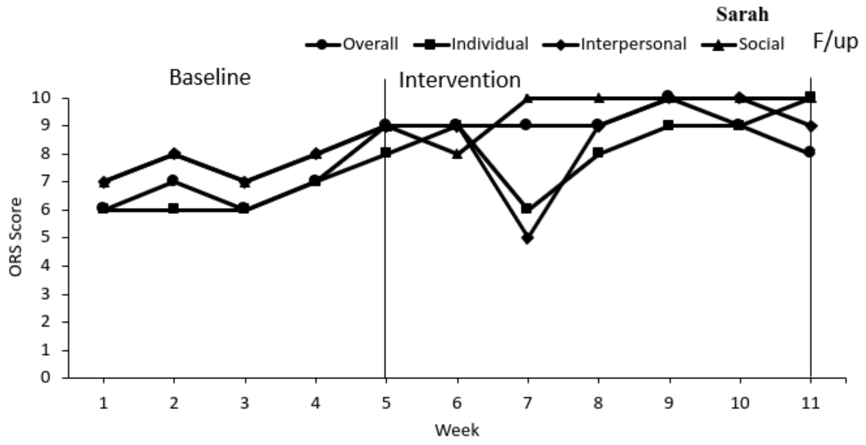
ORS Overall Scores - Sarah

During baseline, Sarah’s ORS overall scores ranged from 58 – 74 (*M* = 66.3) indicating stability in her general wellbeing at this time. There was an increase in the overall ORS score during the intervention phase, indicating improvement in general well-being (*M* = 90.8; range = 87 – 100). Sarah’s overall ORS score remained higher than baseline levels at six-week follow-up (84), suggesting maintained improvement. The PEM score of 100% suggests that the intervention was highly effective.

Figure 1

Outcome Rating Scale Subscale Scores across baseline, intervention and follow-up for each of the seven participants.


Julie
Overall
Individual
Interpersonal
Social
F/up
Baseline
Intervention
ORS Score
0
1
2
3
4
5
6
7
8
9
10
1
2
3
4
5
6
7
8
9
10
11
Week


Sarah
Overall
Individual
Interpersonal
Social
F/up
Baseline
Intervention
ORS Score
0
1
2
3
4
5
6
7
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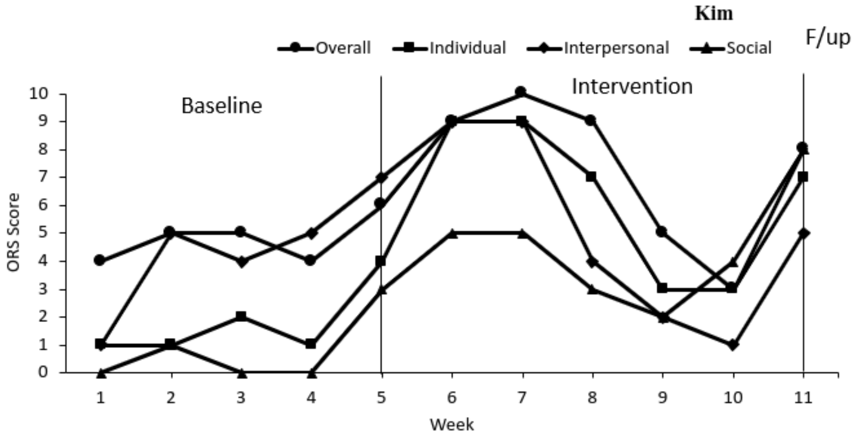
6
7
8
9
10
11
Week


Kim
Overall
Individual
Interpersonal
Social
F/up
Baseline
Intervention
ORS Score
0
1
2
3
4
5
6
7
8
9
10
1
2
3
4
5
6
7
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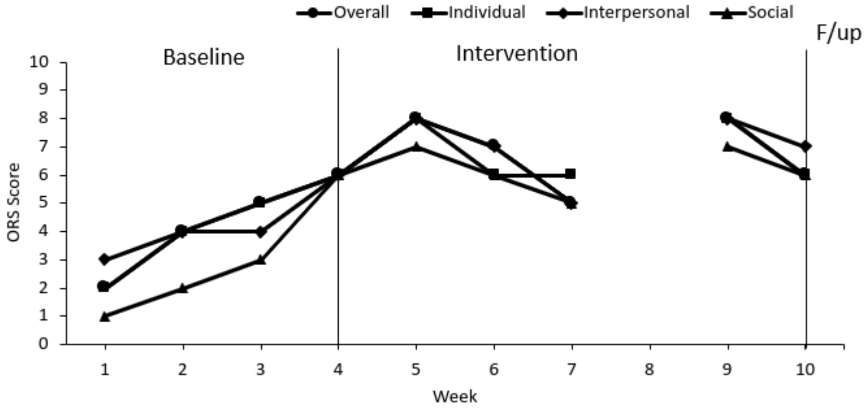
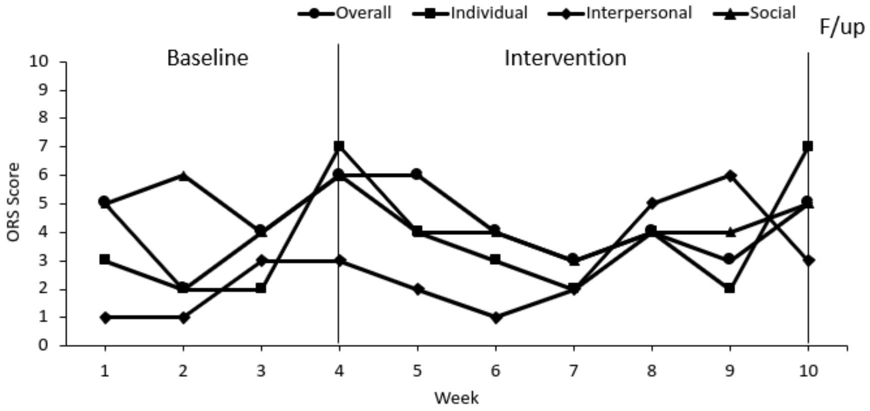
11
Week

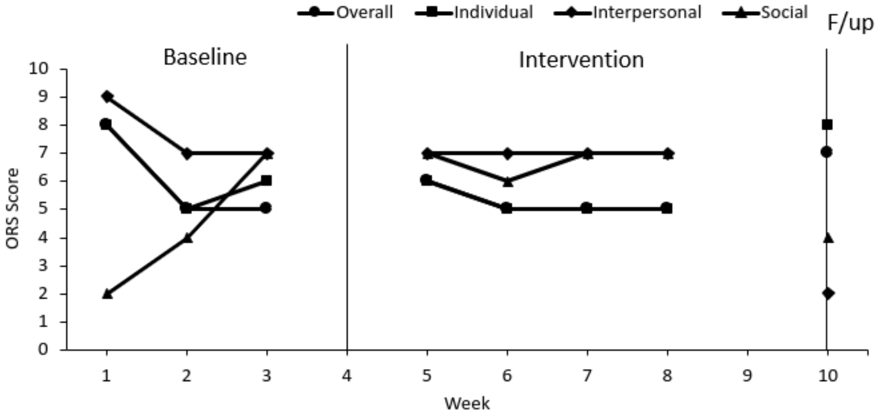
Lisa

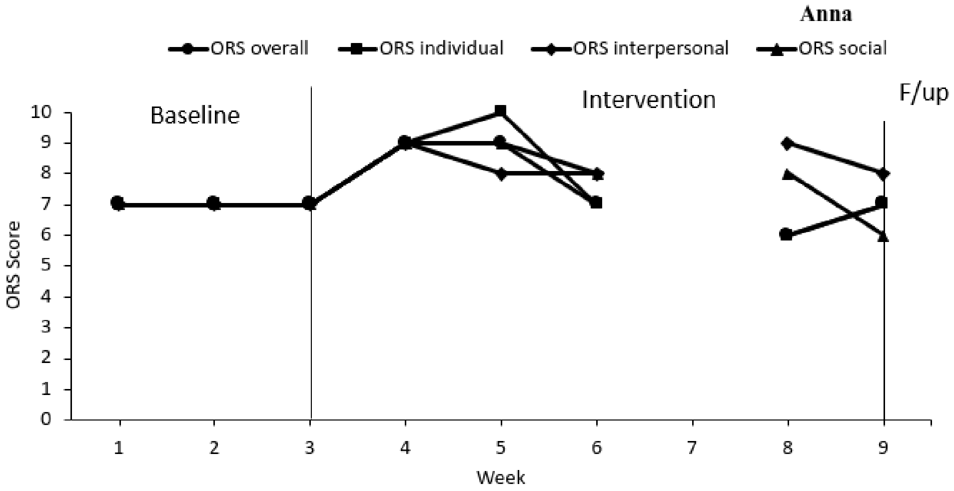


Amy



Molly





ORS Overall Scores - Lisa

During baseline, Lisa's ORS overall scores increased (*M* = 36.3; range = 19 – 50) indicating instability in her general wellbeing at this time. Due to time constraints, the baseline could not be extended to reach stability. There was an increase in the overall ORS score at intervention, indicating improvement in general well-being (*M* = 65.8; range = 54 – 77). Lisa's overall ORS score remained higher than baseline at six-week follow-up (61), suggesting maintained improvement. The PEM score of 100% indicated highly effective intervention.

ORS Overall Scores - Amy

During baseline, Amy's ORS overall scores increased (*M* = 35.7; range = 19 – 48), indicating some stability in her general wellbeing at this time. There was an increase in the overall ORS score at the beginning of intervention, which then returned to baseline levels at the end of intervention, indicating no change in general well-being (*M* = 42.8; range = 29 – 61). Amy's overall ORS score increased from baseline to six-week follow-up (50), suggesting some improvement in Amy's general well-being. While Amy's overall ORS score trended down from baseline to intervention, and six-week follow-up, the mean ORS was higher during the intervention and six-week follow-up than baseline. It is important to note that Amy's responses indicate highly variable scores in this subscale. The PEM score of 50% indicated no intervention effect.

ORS Overall Scores - Kim

During baseline, Kim's ORS overall scores ranged from 40 – 50 (*M* = 45.5) indicating stability in her general wellbeing at this time. There was a substantial increase in ORS overall score at the start of intervention, however, this decreased substantially at the end of intervention, returning to baseline levels. This decrease in wellbeing coincided with Kim experiencing mental health difficulties for which she received professional support. Overall, her mean score indicated some improvement in general well-being (*M* = 70; range = 28 – 95). Kim's overall ORS score increased to mid-intervention levels at six-week follow-up (83), suggesting an increase in general well-being at this time. The PEM score of 83% indicated moderately effective intervention.

ORS Overall Scores - Molly

During baseline, Molly's ORS overall scores ranged from 52 – 75 (*M* = 60) suggesting some instability in her general wellbeing at this time. A decreasing trend in her ORS overall scores is observed during baseline. There were no changes in overall ORS score during intervention, indicating no change in general well-being (*M* = 52.8; range = 49 – 60). Data are missing for two of the six weeks (weeks one and six) meaning it is difficult to determine a pattern in the data. Molly's overall ORS score remained similar to baseline and intervention levels at six-week follow-up (72), suggesting no change in Molly's general well-being. The PEM score of 25% indicated no intervention effect.

ORS Overall Scores - Anna

Anna was only able to complete two baseline data points, making it difficult to determine if her ORS overall scores are stable. There was no variation in her baseline ORS overall scores (M = 70). There was a small increase in overall ORS score during intervention, indicating improvement in general well-being (M = 76.8; range = 61 – 93). Anna's overall ORS score returned to baseline levels at six-week follow-up (72), suggesting no maintained improvement in Anna's general well-being. The PEM score of 80% indicated moderately effective intervention.

ORS Individual Subscale Scores

ORS individual subscale data for all seven participants is presented in Figure 1. ORS individual subscale scores were used to assess changes in parents' personal wellbeing. From baseline to the intervention phase, four parents (Sarah, Lisa, Amy, and Kim) demonstrated improvements in ORS individual subscale scores as indicated by trends in the data. Three parents demonstrated improvement in ORS Individual subscale scores from baseline to six-week follow-up with intervention effect assessed using PEM (Sarah, Lisa, and Kim), three demonstrated improvement in ORS Individual subscale scores from baseline to six-week follow-up with no intervention effect (Julie, Amy, and Molly), and one parent demonstrated some improvement in ORS Individual subscale score mid-intervention, but no maintained improvement at the end of intervention or six-week follow-up (Anna). PEM scores indicated mixed intervention effects.

ORS Individual Score – Julie

During baseline, Julie's ORS individual scores ranged from 27 – 58 (*M* = 44.5) indicating stability in her personal wellbeing at this time. There was a substantial decrease in the ORS individual score from the end of baseline (58) to the beginning of intervention (7), indicating deterioration in personal wellbeing. However, her ORS individual score steadily increased during intervention and returned to baseline levels by the conclusion of intervention (*M* = 34.2; range = 7 – 57). Julie's ORS individual score increased at six-week follow-up (95), suggesting an increase in personal well-being. The PEM score of 33% indicated no intervention effect.

ORS Individual Score – Sarah

During baseline, Sarah's ORS individual scores ranged from 57 – 65 (*M* = 61.8) indicating stability in her personal wellbeing at this time. There was an increase in ORS individual score during intervention, with a brief decrease at intervention week three. At the end of intervention, the ORS individual score increased compared to baseline, indicating an improvement in personal well-being (*M* = 82.5; range = 56 – 93). Sarah's ORS individual score increased at six-week follow-up (96), suggesting the increase in personal well-being during intervention was maintained. The PEM score of 83% indicated moderately effective intervention.

ORS Individual Score – Lisa

During baseline, Lisa's ORS individual scores ranged from 19 – 51 (*M* = 37), with an increasing and variable trend indicating instability in her personal wellbeing at this time. There was an increase in the ORS individual score at intervention, indicating improvement in general well-being (*M* = 65.4; range = 55 – 76). Lisa's ORS individual score remained higher than baseline at six-week follow-up (62), suggesting maintained improvement at the six-week follow-up period. The PEM score of 100% indicated highly effective intervention.

ORS Individual Score - Amy

During baseline, Amy's ORS individual scores increased (*M* = 24.7; range = 19 – 32) indicating stability in her personal wellbeing at this time. There was a substantial increase in her ORS individual score from the end of baseline (23) to the beginning of intervention (67), which then returns to baseline levels at the end of intervention. However, the average intervention score (*M* = 35; range = 15 – 61) indicated an overall increase in personal wellbeing from baseline to intervention, although this was highly variable. Amy's ORS individual score increased at six-week follow-up (71), suggesting improvement in Amy's personal well-being at this time. The PEM score of 67% indicated no intervention effect.

ORS Individual Scores - Kim

During baseline, Kim's ORS individual scores ranged from 6 – 19 (*M* = 11.5) indicating stability in her general wellbeing at this time. There was a substantial increase in ORS individual score at the start of intervention, which then decreased at the end of intervention but remained higher than baseline levels, indicating improvement in general well-being (*M* = 58.5; range = 30 – 88). As noted previously, the decrease in wellbeing coincided with Kim experiencing a mental health crisis for which she received professional support. Kim's ORS individual score increased from baseline levels to six-week follow-up (73), suggesting Kim's increase in personal well-being was maintained. The PEM score of 100% indicated highly effective intervention.

ORS Individual Scores - Molly

During baseline, Molly's ORS individual scores ranged from 54 – 77 (*M* = 62.7) indicating some stability in her personal wellbeing. There were no changes in her ORS individual score during intervention, indicating no change in personal well-being (*M* = 53.8; range = 50 – 61). It is important to note that there are two missing data points of the six intervention data points. Molly's ORS individual score increased slightly from baseline to six-week follow-up (75), suggesting some improvement in Molly's personal well-being. The PEM score of 25% indicated no intervention effect.

ORS Individual Scores - Anna

Anna was only able to complete two baseline data points, making it difficult to determine if her ORS individual scores are stable. Her baseline ORS individual scores suggest stability, ranging from 70 – 70 (*M* = 70). There was an increase in ORS individual score at the beginning of intervention, but then decreased to baseline levels, indicating brief improvement in personal well-being (*M* = 77.6; range = 62 – 97). Anna's ORS individual score returned to baseline levels at six-week follow-up (70), suggesting no maintained improvement in Anna's personal well-being. The PEM score of 80% indicated a moderate intervention effect.

ORS Interpersonal Subscale Scores

ORS interpersonal subscale data for all seven participants is presented in Figure 1. Six of the seven parents demonstrated improvement in interpersonal wellbeing. Of the seven parents, six (Julie, Sarah, Lisa, Amy, Kim, and Anna) demonstrated improvements in interpersonal wellbeing from baseline to intervention. Three parents demonstrated improvements in ORS Interpersonal subscale scores from baseline to six-week follow-up with intervention effect (Sarah, Lisa, and Amy). Three parents demonstrated improvement in ORS Interpersonal subscale scores from baseline to follow-up with no intervention effect (Julie, Kim, and Anna). One parent demonstrated deterioration in ORS Interpersonal subscale score from baseline to follow-up with no intervention effect (Molly). PEM scores indicated mixed intervention effects.

ORS Interpersonal Score – Julie

During baseline, Julie's ORS interpersonal scores ranged from 14 – 50 (*M* = 24.8) indicating stability in her interpersonal wellbeing at this time. There was a substantial increase in the ORS interpersonal score from the first half of intervention (*M* = 14.7) to the second half of intervention (*M* = 56), indicating improvement in interpersonal wellbeing. Julie's ORS interpersonal score remained higher than baseline levels at six-week follow-up (61), suggesting an increase in interpersonal wellbeing. The PEM score of 50% indicated no intervention effect.

ORS Interpersonal Score – Sarah

During baseline, Sarah's ORS interpersonal scores ranged from 66 – 78 (*M* = 73) indicating stability in her interpersonal wellbeing at this time. There was an increase in ORS individual score during intervention, a brief decrease at intervention week three, which then returned to an increased level compared to baseline, indicating an improvement in interpersonal well-being (*M* = 86.8; range = 53 – 100). Sarah's ORS interpersonal score increased at six-week follow-up (90), suggesting the increase in interpersonal wellbeing had been maintained. The PEM score of 83% indicated a moderately effective intervention.

ORS Interpersonal Score – Lisa

During baseline, Lisa's ORS interpersonal scores ranged from 30 – 44 (*M* = 38), indicating stability in her interpersonal wellbeing at this time. There was an increase in the ORS interpersonal score at intervention, indicating improvement in interpersonal well-being (*M* = 69; range = 51 – 83). Lisa's ORS interpersonal score remained higher than baseline at six-week follow-up (70), suggesting maintained improvement in interpersonal wellbeing. The PEM score of 100% indicated highly effective intervention.

ORS Interpersonal Score - Amy

During baseline, Amy's ORS interpersonal scores increased (*M* = 15.3; range = 6 – 30) demonstrating instability in her interpersonal wellbeing at this time due to an increasing trend. Amy's ORS individual scores remained similar to baseline levels at the beginning of intervention, which then increased at the end of intervention, indicating improvement in interpersonal well-being (*M* = 32.2; range = 14 – 62). Amy's ORS individual score remained higher than baseline at six-week follow-up (28), indicating maintained improvement in Amy's interpersonal wellbeing. The PEM score of 100% indicated highly effective intervention.

ORS Interpersonal Scores - Kim

During baseline, Kim's ORS interpersonal scores ranged from 10 – 52 (*M* = 38.8) indicating some stability in her interpersonal wellbeing at this time. There was an increase in ORS interpersonal score at the start of intervention, which then decreased at the end of intervention, indicating deterioration in interpersonal well-being. This decrease in wellbeing coincided with Kim experiencing mental health difficulties. However, the mean score remained higher than the mean baseline score, indicating improvement in interpersonal wellbeing (*M* = 58.5; range = 8 – 89). Kim's ORS interpersonal score remained higher than baseline at six-week follow-up (51), indicating the increase in interpersonal wellbeing was maintained at follow-up. The PEM score of 50% indicated no intervention effect.

ORS Interpersonal Scores - Molly

During baseline, Molly's ORS interpersonal scores ranged from 70 – 90 (*M* = 76.7) indicating some stability in her interpersonal wellbeing. There was a decrease in her ORS interpersonal score during intervention, indicating deterioration interpersonal well-being (*M* = 53.8; range = 70 – 72). It is important to note that there are two missing data points of the six intervention data points. Molly's ORS interpersonal score decreased again at six-week follow-up (17), suggesting deterioration in Molly's interpersonal wellbeing The PEM score of 50% indicated no intervention effect.

ORS Interpersonal Scores - Anna

Anna was only able to complete two baseline data points, making it difficult to determine if her ORS interpersonal scores are stable. Her baseline ORS interpersonal scores suggest stability, ranging from 70 – 73 (*M* = 71.5). There was an increase in ORS interpersonal score during intervention, indicating improvement in interpersonal well-being (*M* = 77.6; range = 70 – 92). Anna's ORS interpersonal score remained higher than baseline at six-week follow-up (82), suggesting maintained improvement in interpersonal wellbeing. The PEM score of 80% indicated a moderate intervention effect.

ORS Social Subscale Scores

ORS social subscale data for all seven participants is presented in Figure 1. Of the seven parents, five (Julie, Sarah, Lisa, Kim, Molly, and Anna) demonstrated improvement in social wellbeing from baseline to intervention. Three parents demonstrated improvements in social wellbeing from baseline to six-week follow-up with intervention effect (Sarah, Lisa, and Kim). One parent demonstrated improvement in ORS Social subscale scores from baseline to follow-up with no intervention effect (Julie). Two parents demonstrated some improvement in ORS Social subscale scores at mid-intervention but this was not maintained at the end of intervention or at six-week follow-up (Molly and Anna). One parent demonstrated no change in ORS Social subscale score throughout the intervention (Amy). PEM scores indicated mixed intervention effects.

ORS Social Score – Julie

During baseline, Julie's ORS social scores ranged from 1 – 19 (*M* = 9) indicating stability in her social wellbeing at this time. There was a substantial increase in the ORS social score from the first half of intervention (*M* = 7.7) to the second half of intervention (*M* = 39), indicating improvement in interpersonal wellbeing (range = 5 – 72). Julie's ORS social score increased again at six-week follow-up (87), suggesting an increase in social wellbeing. The PEM score of 67% indicated no intervention effect.

ORS Social Score – Sarah

During baseline, Sarah's ORS social scores ranged from 68 – 81 (*M* = 74.5) indicating stability in her interpersonal wellbeing at this time. There was an increase in ORS social score during intervention, indicating an improvement in social well-being (*M* = 86.8; range = 84 – 100). Sarah's ORS interpersonal score increased at six-week follow-up (94), suggesting the increase in interpersonal wellbeing was maintained. The PEM score of 100% indicated a highly effective intervention.

ORS Social Score – Lisa

During baseline, Lisa's ORS social scores ranged from 10 – 30 (*M* = 20), indicating instability in her interpersonal wellbeing at this time as there was an increasing trend. There was an increase in the ORS social score at intervention, indicating improvement in social well-being (*M* = 62; range = 53 – 70). Lisa's ORS social score remained higher than baseline at six-week follow-up (60), suggesting maintained improvement in social wellbeing. The PEM score of 100% indicated highly effective intervention.

ORS Social Score - Amy

During baseline, Amy's ORS social scores increased (*M* = 50.7; range = 41 – 60), demonstrating stability in her interpersonal wellbeing. Amy's ORS social scores decreased during intervention, indicating deterioration in social well-being (*M* = 39.8; range = 25 – 61).

Amy’s ORS social score returned to baseline levels at six-week follow-up (45), suggesting no improvement in Amy’s social wellbeing. The PEM score of 16% indicated no intervention effect.

ORS Social Scores - Kim

During baseline, Kim’s ORS social scores ranged from 1 – 7 (*M* = 3.5) indicating stability in her social wellbeing at this time. There was an increase in ORS social score during intervention, indicating improvement in social well-being (*M* = 36.5; range = 22 – 51). Kim’s ORS social score increased at six-week follow-up (80), indicating Kim’s social wellbeing improvement was maintained at follow-up. The PEM score of 100% indicated highly effective intervention.

ORS Social Scores - Molly

During baseline, Molly’s ORS social scores ranged from 20 – 70 (*M* = 43.3) with an increasing trend, indicating instability in her social wellbeing. Due to this instability it is difficult to ascertain if the intervention positively impacted her social wellbeing or if this was already improving. There was an increase in Molly’s ORS social scores during intervention, indicating some improvement in social well-being (*M* = 68.8; range = 62 – 73). Molly’s ORS social score decreased slightly at six-week follow-up (40), suggesting deterioration in Molly’s interpersonal wellbeing from baseline. The PEM score of 100% indicated highly effective intervention.

ORS Social Scores - Anna

Anna was only able to complete 2 baseline data points, making it difficult to determine if her ORS social scores are stable. Her baseline ORS social scores suggest stability, ranging from

71 – 73 (*M* = 72). There was an increase in ORS social score during intervention, indicating improvement in interpersonal well-being (*M* = 80; range = 70 – 89). Anna's ORS social score decreased at six-week follow-up (57), suggesting the improvement in interpersonal wellbeing was not maintained. The PEM score of 80% indicated moderately effective intervention.

ORS Total Scores

Total ORS scores were attained by adding all four subscales to form a total score (Refer to Figure 2). Results from the current study were compared to normative data. The clinical population mean ORS total score is 19.6, and the mean non-clinical population total score is 28 (Miller et al., 2003). Five parents demonstrated ORS total scores below the non-clinical population mean at baseline (Julie, Sarah, Lisa, Amy, and Kim), while one parent demonstrated baseline ORS total scores above the clinical population mean (Molly), and one parent demonstrated baseline ORS total scores equal to the non-clinical population mean (Anna). At the end of intervention, five parents demonstrated ORS total scores above the clinical population mean (Julie, Sarah, Lisa, Molly, and Anna), while two parents ORS total scores remained below the clinical population mean (Amy and Kim). At six-week follow-up, four parents demonstrated ORS total scores above the non-clinical population mean (Julie, Sarah, Kim, and Anna), and three parents demonstrated ORS total scores above the clinical population mean (Lisa, Amy, and Molly), indicating improvement in overall wellbeing compared to population norms.

Of the seven parents, four (Sarah, Lisa, Amy, and Kim) demonstrated improvement in Total ORS from baseline to intervention. Three parents demonstrated improvements in wellbeing from baseline to six-week follow-up with intervention effect (Sarah, Lisa, Kim, and Anna). Two parents demonstrated improvement in Total ORS scores from baseline to follow-up with no intervention effect (Julie and Amy). One parent demonstrated some improvement in Total ORS scores at mid-intervention but this was not maintained at the end of intervention or at six-week follow-up (Molly). PEM scores indicated mixed intervention effects on this outcome.

Julie - Total ORS Score

During baseline, Julie's ORS total score ranged from 13 – 16 (*M* = 14.5), indicating stability. All four of Julie's baseline total score data points were below the clinical cut-off, indicating low levels of wellbeing. During intervention, Julie's ORS total score ranged from 5 – 27 (*M* = 14.7), increasing towards the end of the intervention phase, demonstrating no change from baseline. Five data points were below the clinical cut-off, and one intervention data point was above the clinical cut-off. Julie's ORS total score (34) increased from baseline to six-week follow-up, indicating improvement in total wellbeing from baseline. This was above the clinical cut-off, indicating Julie's wellbeing was no longer clinically low at follow-up. The PEM score of 50% indicated no intervention effect.

Sarah - Total ORS Score

During baseline, Sarah's ORS total score ranged from 26 – 30 (*M* = 27.8), indicating stability. All four of Sarah's baseline total score data points were above the clinical cut-off, indicating expected levels of wellbeing. Sarah's ORS total score increased from baseline to intervention, ranging from 30 – 39 (*M* = 35.5), and all six data points were above the clinical cut-off. At six-week follow-up Sarah's ORS total score (37) remained higher than baseline levels and remained above the clinical cut-off, indicating maintained, clinically significant improvement in total wellbeing. The PEM score of 100% indicated highly effective intervention.

Lisa - ORS Total Score

During baseline, Lisa's ORS total score ranged from 8 – 17 (*M* = 13), indicating stability. All three of Lisa's baseline total score data points were below the clinical cut-off, indicating clinically significant low wellbeing. Lisa's ORS total scores increased from baseline to intervention, ranging from 21 – 31 (*M* = 26.6). Two intervention data points were below the clinical cut-off, and three data points were above the clinical cut-off. At six-week follow-up, Lisa's ORS total score (25) remained higher than baseline and was equal to the clinical cut-off. This indicates clinically significant and maintained improvement in Lisa's wellbeing. The PEM score of 100% indicated highly effective intervention.

Amy - ORS Total Score

During baseline, Amy's ORS total score ranged from 11 – 14 (*M* = 12.7), indicating stability. All three of Amy's baseline total score data points were below the clinical cut-off, indicating clinically low wellbeing levels. Amy's ORS total scores increased slightly from baseline to intervention, ranging from 10 – 22 (*M* = 15.3). A dip in Amy's total wellbeing score during this phase coincided with reported challenges with her adolescent's mental health. All intervention phase data points were below the clinical cut-off, indicating clinically low wellbeing levels. At six-week follow-up Amy's ORS total score (20) remained below the clinical cut-off, although remained higher than baseline levels, indicating maintained but not clinically significant improvement in wellbeing from baseline to follow-up. The PEM score of 67% indicated no intervention effect.

Kim - ORS Total Score

During baseline, Kim's ORS total score ranged from 6 – 12 (*M* = 13), indicating stability. All four of Kim's baseline total score data points were below the clinical cut-off, indicating clinically low wellbeing levels. Kim's ORS total score increased from baseline to intervention, ranging from 11 – 33 (*M* = 21.8). An abrupt decrease in week five of intervention coincided with Kim experiencing mental health difficulties. Four intervention phase data points were below the clinical cut-off, and two intervention phase data points above the clinical cut-off. At six-week follow-up Kim's ORS total score (28) increased from baseline and was above the clinical cut-off. This demonstrated maintained and clinically significant improvement in Kim's wellbeing. The PEM score of 100% indicated highly effective intervention.

Molly - ORS Total Score

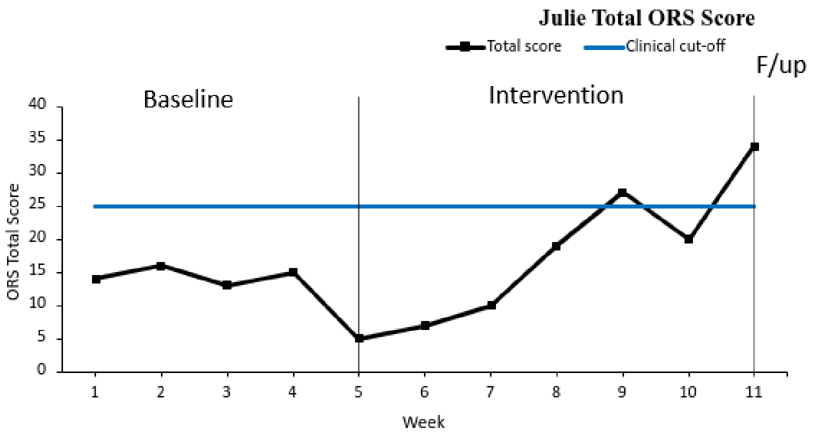
During baseline, Molly's ORS total score ranged from 21 – 27 (*M* = 24.3), indicating stability. One of Molly's baseline total score data points was below the clinical cut-off, and two data points were above the clinical cut-off. Molly's ORS total scores remained the same from baseline to intervention, ranging from 23 – 26 (*M* = 24), demonstrating no change in total wellbeing. Three intervention phase data points were below the clinical cut-off, and one intervention data point was above the clinical cut-off. At six-week follow-up Molly's ORS total score (21) remained below the clinical cut-off and below baseline levels, indicating no change in total wellbeing. The PEM score of 25% indicated no intervention effect.

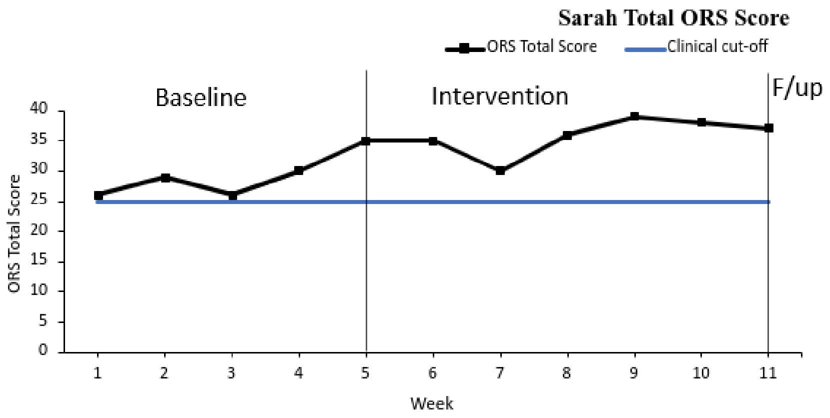
Anna - ORS Total Score

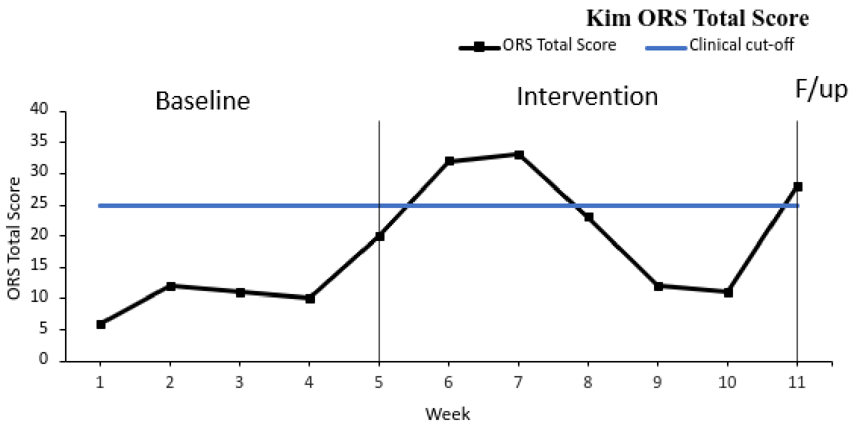
During baseline, Anna's ORS total score ranged from 28 – 28 (*M* = 28), indicating stability. All three of Anna's baseline total score data points were above the clinical cut-off, indicating expected levels of wellbeing. Anna's ORS total scores increased slightly from baseline to intervention, ranging from 28 – 36 (*M* = 31.8). All five intervention phase data points were above the clinical cut-off. At six-week follow-up Anna's ORS total score (28) remained above the clinical cut-off, although reduced back to baseline levels, indicating no maintained improvement in total wellbeing. The PEM score of 100% indicated highly effective intervention.

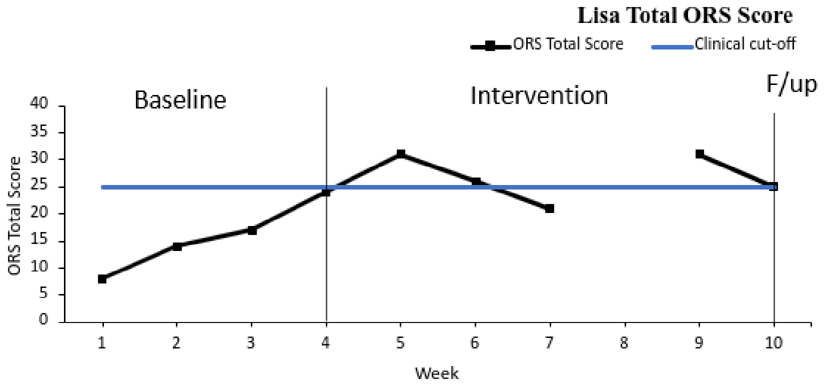
Figure 2

Outcome Rating Scale Total Score across baseline, intervention and follow-up for each of the seven participants.





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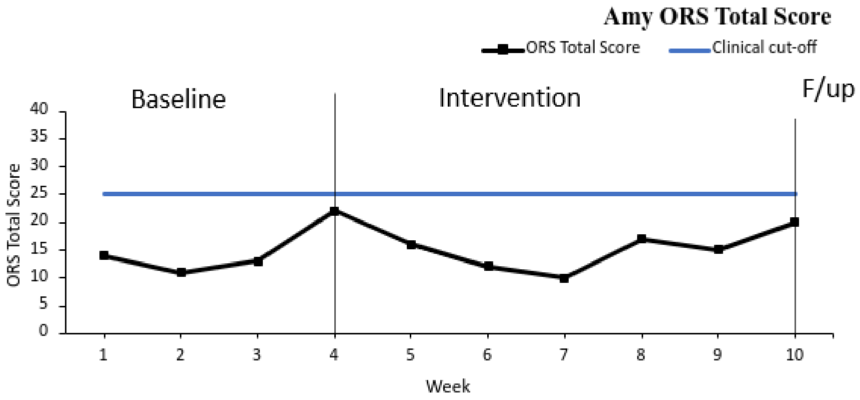
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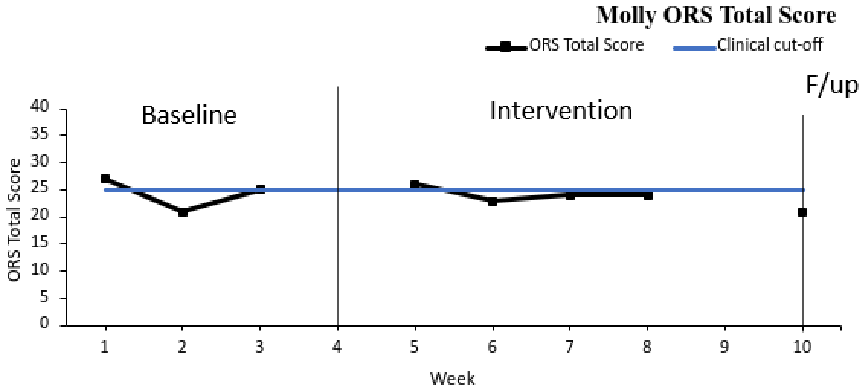
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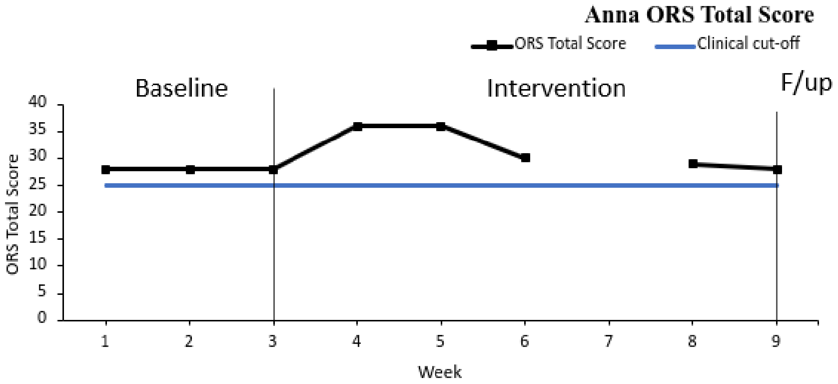
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PSI-SF Parental Distress Subscale

The PSI-SF was administered to measure changes in participants' parenting stress. Parents completed this as a weekly measure and as a repeated measure at pre-intervention, post-intervention, and follow-up. Three parents (Sarah, Lisa, Amy) demonstrated improvements in parenting stress from baseline to intervention, and five parents (Lisa, Amy, Kim, Molly, and Anna) demonstrated improvement from baseline to six-week follow-up. PBM ranged from 60-100%, indicating the degree of improvement varied across participants. Five parents' responses indicated improvements in parental distress with intervention effects, and two parents' improvements in parental distress did not indicate intervention effect as determined by PEM calculations. The Parenting Distress subscale of the PSI-SF was used to assess distress associated with perceived parenting ability. Raw scores can range from 12 – 60. Raw scores, T-scores and RCI calculations relevant to parents' Parental Distress scores are reported in Table 3, while clinically significant changes are reported in Table 4.

Table 3

Reliable Change Index Calculations - Outcome Measures: Parenting Stress, Distress, and Quality of Life

	Julie					**Sarah**					**Lisa**					**Amy**				
	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$
PS																				
PD	23/46	44/68	32/55	4.92	2.01	31/54	13/35	34/57	-4.25*	0.67	41/65	27/50	26/49	-3.35*	-3.58*	44/68	40/64	37/61	-0.89	-1.57
Distress																				
Dep	0	5	1	2.54	0.51	4	0	1	-2.03*	-1.52	7	3	5	-2.03*	-1.01	9	5	5	-2.03*	-2.03*
Anxiety	1	1	0	0	-0.51	6	1	1	-2.55*	-2.55*	4	2	0	-1.02	-2.04*	5	4	2	-0.51	-1.53
Stress	3	4	2	0.40	-0.40	7	2	2	-2.00*	-2.00*	5	1	2	-1.60	-1.20	16	10	13	-2.40*	-1.20
QoL																				
WHO-5	24%	32%	88%			60%	88%	84%			28%	28%	60%			16%	32%	24%		

	Kim					Molly					Anna				
	T1	T2	T3	$RCI_{1.2}$	$RCI_{1.3}$	T1	T2	T3	$RCI_{1.2}$	$RCI_{1.3}$	T1	T2	T3	$RCI_{1.2}$	$RCI_{1.3}$
PS															
PD	52/77	46/70	44/68	-1.57	-2.01	30/53	23/46	28/51	-1.57	-0.45	29/52	34/57	32/55	1.12	0.67
Distress															
Dep	19	20	7	0.51	-6.09	3	3	3	0	0	3	2	8	-0.51	2.54
Anxiety	17	15	4	-1.02	-6.62	1	7	5	3.05	2.04	0	3	2	1.53	1.02
Stress	20	20	8	0	-4.80	6	7	6	0.40	0	4	7	10	1.20	2.40
QoL															
WHO-5	12%	4%	60%			52%	36%	56%			48%	40%	52%		

Note: Parenting Stress = Parenting Stress Index – Short Form (PSI-SF), Distress = Depression, Anxiety, Stress Scale (DASS-21), Quality of Life = World Health Organisation 5 (WHO-5), Dep = depression, QoL = quality of life. PD scores are presented as raw score/ t-score.
* = Reliable Improvement

Table 4

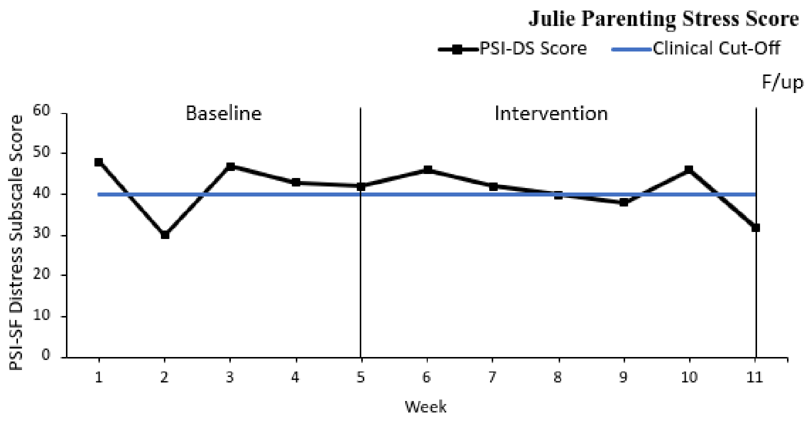
Clinically Significant Change between Pre-intervention, Post-intervention, and Follow-Up Measures

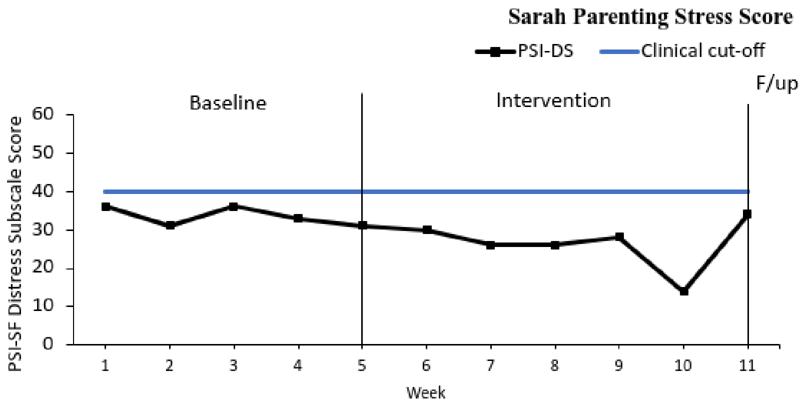
	Julie		**Sarah**		**Lisa**		**Amy**		**Kim**		**Molly**		**Anna**	
	T1-T2	**T1-T3**	**T1-T2**	**T1-T3**	**T1-T2**	**T1-T3**	**T1-T2**	**T1-T3**	**T1-T2**	**T1-T3**	**T1-T2**	**T1-T3**	**T1-T2**	**T1-T3**
PSI-SF														
Parental Distress	CSD*	NCS	NCS	NCS	CSI**	CSI**	NCS	CSI**	NCS	NCS	NCS	NCS	NCS	NCS
Quality of Life														
WHO-5	NCS	CSI**	CSI**	CSI**	NCS	CSI**	CSI**	NCS	NCS	CSI**	NCS	NCS	NCS	NCS
CBCL														
Internalising	CSD*	CSD*	CSI**	NCS	CSI**	NCS	NCS	NCS	NCS	NCS	CSI**	CSI**	CSD*	CSD*
Externalising	CSD*	NCS	NCS	CSD*	NCS	NCS	CSI**	CSI**	NCS	NCS	NCS	NCS	NCS	NCS
Total	CSD*	CSD*	NCS	CSD*	NCS	NCS	NCS	CSI**	NCS	NCS	CSI**	CSI**	NCS	NCS
DASS-21														
Depression	CSD*	NCS	NCS	NCS	CSI**	CSI**	CSI**	CSI**	NCS	CSI**	NCS	NCS	NCS	CSD*
Anxiety	NCS	NCS	CSI**	CSI**	CSI**	CSI**	NCS	CSI**	NCS	CSI**	CSD*	CSD*	NCS	NCS
Stress	NCS	NCS	NCS	NCS	NCS	NCS	CSI**	NCS	NCS	CSI**	NCS	NCS	NCS	CSD*

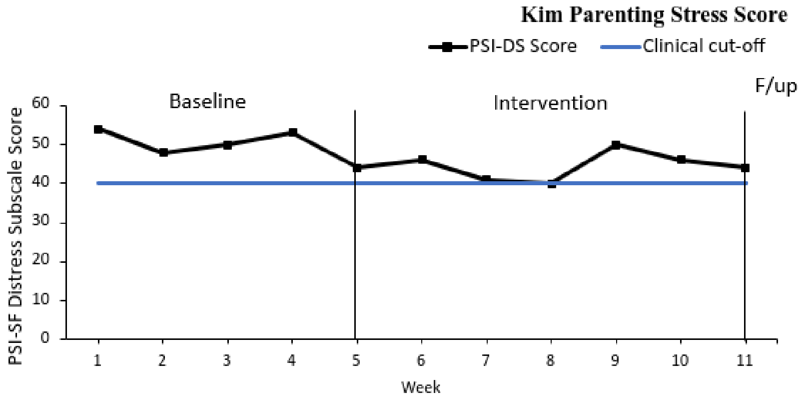
CSI = Clinically significant improvement, NCS = No clinically significant improvement, CSD = Clinically significant deterioration.
* = Clinically significant deterioration, ** = Clinically significant improvement

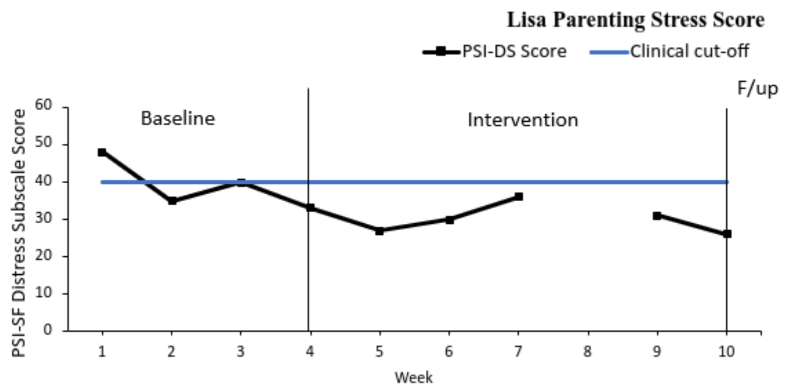
Figure 3

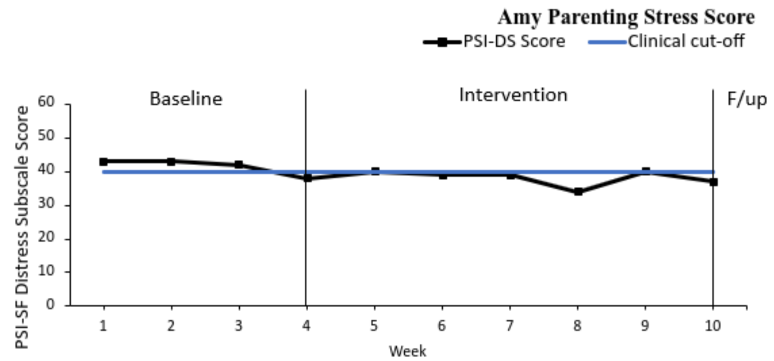
Parenting Stress Index - Short Form, Distress subscale scores across baseline, intervention and follow-up for each of the seven participants.

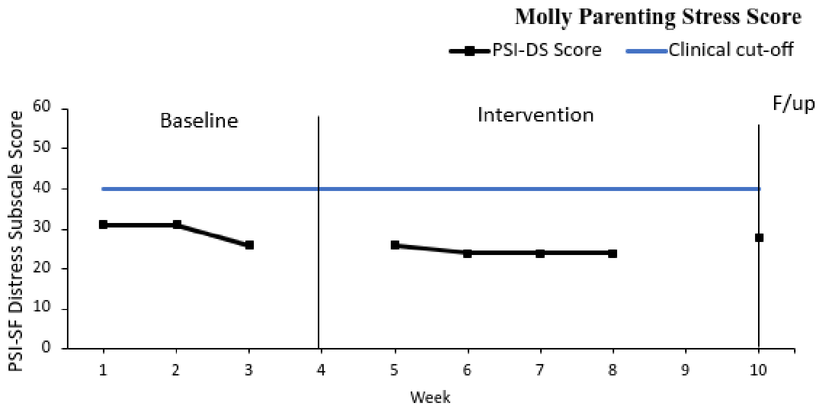


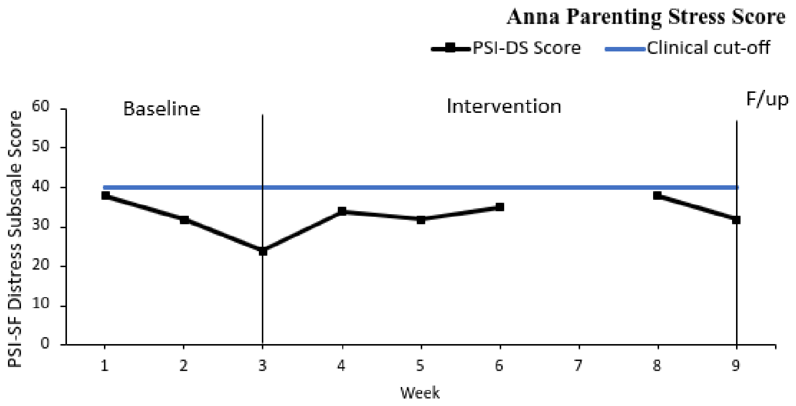





Lisa Parenting Stress Score
PSI-DS Score
Clinical cut-off
F/up
Baseline
Intervention
PSI-SF Distress Subscale Score
60
50
40
30
20
10
0
1
2
3
4
5
6
7
8
9
10
Week


Amy Parenting Stress Score
PSI-DS Score
Clinical cut-off
Baseline
Intervention
F/up
PSI-SF Distress Subscale Score
60
50
40
30
20
10
0
1
2
3
4
5
6
7
8
9
10
Week


Molly Parenting Stress Score
PSI-DS Score
Clinical cut-off
F/up
Baseline
Intervention
PSI-SF Distress Subscale Score
60
50
40
30
20
10
0
1
2
3
4
5
6
7
8
9
10
Week


Anna Parenting Stress Score
PSI-DS Score
Clinical cut-off
F/up
Baseline
Intervention
PSI-SF Distress Subscale Score
60
50
40
30
20
10
0
1
2
3
4
5
6
7
8
9
Week

Julie - PSI-SF Parental Distress Subscale Score

During baseline, Julie's parental distress scores ranged from 30 – 48 (*M* = 42) indicating stability in her parenting stress at this time. Julie's parental distress scores were largely unchanged from baseline to intervention (*M* = 42.3; range = 38 – 46). However, Julie's parental distress score decreased from baseline to six-week follow-up (32), suggesting improvement in her parenting stress. The PBM score of 67% indicated no intervention effect.

Julie's scores on the Parental Distress (PD) subscale of the PSI-SF increased from the pre-intervention phase to the post-intervention phase, and met criteria for reliable deterioration in PD at post-intervention (RCI = 4.92) which remained at six-week follow-up (RCI = 2.01). No clinically significant improvement in Julie's PD levels was identified at any phase of the study.

Sarah - PSI-SF Parental Distress Subscale Score

During baseline, Sarah's parental distress scores ranged from 31 – 36 (*M* = 34) indicating stability in her parenting stress at this time. Sarah's parental distress scores decreased from baseline to intervention (*M* = 25.8; range = 14 – 31), indicating improvement in parenting stress. Sarah's parental distress score increased at six-week follow-up (34), suggesting improvement in her parenting stress was not maintained at six-week follow-up. The PBM score of 100% indicated highly effective intervention.

Sarah demonstrated reliable improvement in PD from pre-intervention to post-intervention (RCI = -4.25), indicating a reliable reduction in parenting stress. This improvement was not maintained at six-week follow-up (RCI = 0.67). Sarah's PD scores showed no clinically significant change between pre-intervention, post-intervention, and six-week follow-up.

Lisa - PSI-SF Parental Distress Subscale Score

During baseline, Lisa's parental distress scores ranged from 35 – 48 (*M* = 41) indicating stability in her parenting stress at this time. Lisa's parental distress scores decreased from baseline to intervention (*M* = 31.4; range = 27 – 36). Lisa's parental distress score decreased from baseline to six-week follow-up (26), indicating maintained improvement in her parenting stress. The PBM score of 100% indicated highly effective intervention.

Lisa's scores demonstrated reliable improvement in PD from pre-intervention to post-intervention (RCI = -3.35). This improvement remained reliable at six-week follow-up (RCI = -3.58), indicating a reduction in parenting stress. Lisa's PD scores showed clinically significant improvement between pre and post-intervention, and pre-intervention and six-week follow-up, indicating a clinically significant improvement in parenting stress.

Amy - PSI-SF Parental Distress Subscale Score

During baseline, Amy's parental distress scores ranged from 42 – 43 (*M* = 42.7) indicating stability in her parenting stress at this time. Amy's parental distress scores decreased from baseline to intervention (*M* = 38.3; range = 34 – 40). Amy's parental distress score decreased again at six-week follow-up (37), suggesting maintained improvement in parenting stress from baseline. The PBM score of 100% indicated highly effective intervention.

Amy demonstrated a decrease in PD from pre-intervention to post-intervention but this was not a reliable change (RCI = –0.89). A decrease in PD was also present between pre-intervention and six-week follow-up, but did not indicate reliable change (RCI = –1.57). Amy's PD scores showed clinically significant improvement between pre and post-intervention, and pre-intervention and six-week follow-up, indicating a clinically significant improvement in parenting stress.

Kim - PSI-SF Parental Distress Subscale Score

During baseline, Kim's parental distress scores ranged from 48 – 54 (*M* = 51.25) indicating stability in her parenting stress at this time. Kim's parental distress scores decreased from baseline to intervention (*M* = 44.5; range = 40 – 50), indicating improvement in parenting stress. Kim's parental distress score remained lower than baseline at six-week follow-up (44), indicating maintained improvement in her parenting stress. The PBM score of 100% indicated highly effective intervention.

Kim demonstrated a decrease in PD from pre-intervention to post-intervention but this was not a reliable change (RCI = –1.57). A decrease in PD was also present between pre-intervention and six-week follow-up, which indicated reliable change (RCI = –2.01). Kim's PD scores did not indicate clinically significant improvement between pre and post-intervention, or pre-intervention and six-week follow-up, indicating no clinically significant improvement in parenting stress.

Molly - PSI-SF Parental Distress Subscale Score

During baseline, Molly's parental distress scores ranged from 26 – 31 (*M* = 29.3) indicating stability in her parenting stress at this time. Molly's parental distress scores decreased from baseline to intervention (*M* = 24.5; range = 24 – 26). Molly's parental distress score increased slightly at six-week follow-up (28), but remained lower than baseline levels, suggesting maintained improvement in her parenting stress. The PBM score of 100% indicated highly effective intervention.

Molly demonstrated a decrease in PD from pre-intervention to post-intervention but this was not a reliable change (RCI = –1.57). A decrease in PD was also present between pre-intervention and six-week follow-up, but did not indicate reliable change (RCI = –0.45). Molly's PD scores did not indicate clinically significant improvement between pre and post-intervention, or pre-intervention and six-week follow-up, indicating no clinically significant improvement in parenting stress.

Anna - PSI-SF Parental Distress Subscale Score

During baseline, Anna's parental distress scores ranged from 32 – 38 (M = 35) indicating stability in her parenting stress at this time. Lisa's parental distress scores decreased slightly from baseline to intervention (M = 32.6; range = 24 – 38), but demonstrated an upward trend throughout the intervention phase. Anna's parental distress score decreased from baseline to six-week follow-up (32), indicating maintained improvement in her parenting stress. The PBM score of 60% indicated no intervention effect.

Anna demonstrated an increase in PD from pre-intervention to post-intervention but this was not a reliable change (RCI = 1.12). An increase in PD was also present between pre-intervention and six-week follow-up, and did not indicate reliable change (RCI = 0.67). Anna's PD scores did not indicate clinically significant improvement between pre and post-intervention, or pre-intervention and six-week follow-up, indicating no clinically significant improvement in parenting stress.

Repeated Measures

Depression, Anxiety, Stress Scale - 21

The DASS-21 was administered to measure changes in parents' depression, anxiety, and stress symptoms. Five of the seven parents demonstrated reductions in depressive symptoms. Two parents' depression subscale scores decreased slightly but remained in the normal range from pre-intervention to six-week follow-up (Julie and Sarah), and three parents demonstrated clinically significant reductions in depressive symptoms from pre-intervention to six-week follow-up (Lisa, Amy, and Kim). One parent experienced no changes in depressive subscale score (Molly), and one parent demonstrated an increase in depressive symptoms (Anna). Two parents (Lisa and Amy) demonstrated a reduction in clinical range from pre-intervention to post-intervention, while three parents (Lisa, Amy, and Kim) demonstrated a reduction in clinical range from pre-intervention to six-week follow-up.

Two parents (Sarah and Lisa) demonstrated a reduction in clinical range from pre-intervention to post-intervention, while four parents (Sarah, Lisa, Amy and Kim) demonstrated a reduction in clinical range from pre-intervention to six-week follow-up. Conversely, two parents demonstrated increases in anxiety symptoms from pre-intervention to six-week follow-up, a deterioration that was only clinically significant for Molly and not Anna.

Five of the seven parents demonstrated improvements in general stress. For four of these parents this change was not clinically significant (Julie, Sarah, Lisa, and Amy). One parent (Molly) experienced no changes in stress subscale score, and one parent (Anna) demonstrated an increase in stress symptoms. One parent (Amy) demonstrated a reduction in clinical range from pre-intervention to post-intervention, and one parent (Kim) demonstrated a reduction in clinical range from pre-intervention to six-week follow-up. Raw scores and RCI calculations relevant to parents' DASS-21 scores are outlined in Table 3. Clinically significant changes in DASS-21 scores are represented in Table 4.

Julie - DASS-21 Scores

Julie demonstrated an increase in depression subscale scores from pre-intervention (normal range) to post-intervention (mild range). This indicated a clinically significant increase in depressive symptoms and was found to be a reliable deterioration (RCI = 2.54). Julie's depression subscale score decreased from post-intervention (mild range) to follow-up (normal range). Julie's depression subscale score returned to baseline levels at follow-up (normal range). A reliable change was not identified between pre-intervention and follow-up (RCI = 0.51).

Julie's anxiety subscale scores remained the same from pre-intervention (normal range) to post-intervention (normal range), indicating no reliable change in anxiety symptoms and no clinically significant change. Julie's anxiety subscale score decreased at follow-up (normal range), but did not demonstrate reliable improvement (RCI = -0.51) or a clinically significant reduction in anxiety symptoms.

Julie's stress subscale scores increased from pre-intervention (normal range) to post-intervention (normal range), although reliable change (RCI = 0.40) and clinically significant change were not identified. Julie's stress subscale score decreased from pre-intervention to follow-up (normal range). This did not indicate reliable improvement (RCI = -0.40). Julie's stress subscale scores did not demonstrate clinically significant change in stress symptoms.

Sarah - DASS-21 Scores

Sarah’s depression subscale scores decreased from pre-intervention (normal range) to post-intervention (normal range) (RCI = -2.03). This indicated a reliable improvement in depressive symptoms, although this was not a clinically significant improvement. Sarah’s depression subscale score increased from post-intervention to follow-up (RCI = -1.52), but this was not a clinically significant deterioration as Sarah’s depression subscale score remained in the normal range.

Sarah’s anxiety subscale scores decreased from pre-intervention (moderate range) to post-intervention (normal range), indicating reliable reduction in anxiety symptoms (RCI = -2.55) and clinically significant change. Julie’s anxiety subscale score remained the same at follow-up (normal range), indicating reliable improvement when compared to pre-intervention (RCI = -0.51) and a clinically significant reduction in anxiety symptoms.

Sarah’s stress subscale scores decreased from pre-intervention (normal range) to post-intervention (normal range). This indicated reliable improvement (RCI = -2.00) which was maintained at follow-up (RCI = -2.00), although no clinically significant change in stress symptoms was identified. This indicated reliable improvement (RCI = -0.40) in Sarah’s stress subscale scores, although a clinically significant improvement in stress symptoms was not identified.

Lisa - DASS-21 Scores

Lisa’s depression subscale scores decreased from pre-intervention (moderate range) to post-intervention (normal range) (RCI = -2.03). This indicated a reliable improvement in depressive symptoms and a clinically significant improvement in depression symptoms. Lisa’s depression subscale score increased from post-intervention to follow-up (mild range) but did not demonstrate reliable improvement when compared to pre-intervention (RCI = -1.01). The increase in depression subscale score and range indicated a clinically significant increase in depression symptoms from post-intervention to follow-up. However, this remained lower than pre-intervention, indicating a clinically significant decrease in depression symptoms.

Lisa’s anxiety subscale scores decreased from pre-intervention (moderate range) to post-intervention (normal range), indicating reliable reduction in anxiety symptoms (RCI = -2.03) and clinically significant change. Lisa’s anxiety subscale score increased at follow-up (mild range), no longer indicating reliable improvement when compared to pre-intervention (RCI = -1.01). Lisa demonstrated a clinically significant reduction in anxiety symptoms at post-intervention and follow-up compared to pre-intervention.

Lisa’s stress subscale scores decreased from pre-intervention (normal range) to post-intervention (normal range), although reliable change (RCI = -1.60) and clinically significant change were not identified. Julie’s stress subscale score decreased from pre-intervention to follow-up (normal range), indicating no reliable improvement (RCI = -1.20). Lisa’s stress subscale scores did not demonstrate clinically significant change in stress symptoms.

Amy - DASS-21 Scores

Amy’s depression subscale scores decreased from pre-intervention (moderate range) to post-intervention (mild range) (RCI = -2.03). This indicated a reliable improvement in depressive symptoms and a clinically significant improvement. This decrease in depression subscale score was maintained at follow-up (mild range), and demonstrated reliable improvement when compared to pre-intervention (RCI = -2.03). The maintenance of Amy’s reduction in depression subscale score and clinical range indicated a clinically significant reduction in depression symptoms at follow-up.

Amy's anxiety subscale scores decreased from pre-intervention (mild range) to post-intervention (mild range), although no reliable reduction in anxiety symptoms was found (RCI = -0.51) and no clinically significant improvement. Amy's anxiety subscale score decreased at follow-up (normal range), although no reliable improvement was indicated when compared to pre-intervention (RCI = -1.53). Amy's anxiety subscale scores demonstrated a clinically significant reduction in anxiety symptoms at follow-up compared to pre-intervention.

Amy's stress subscale scores decreased from pre-intervention (severe range) to post-intervention (moderate range), indicating reliable improvement (RCI = -2.40) and clinically significant improvement. Amy's stress subscale score decreased from pre-intervention to follow-up but increased in comparison to post-intervention back to the severe range. This did not indicate reliable improvement (RCI = -1.20). The clinically significant improvement in Amy's stress subscale scores and subsequent anxiety symptoms was not maintained at follow-up.

Kim - DASS-21 Scores

Kim's depression subscale scores increased from pre-intervention (extremely severe range) to post-intervention (extremely severe range) (RCI = 0.51). This did not indicate a reliable change in depressive symptoms or a clinically significant change. Kim's depression subscale score decreased substantially at follow-up (moderate range), demonstrating reliable improvement (RCI = -6.09) and a clinically significant reduction in depression symptoms at follow-up.

Kim's anxiety subscale scores decreased from pre-intervention (extremely severe range) to post-intervention (extremely severe range), although no reliable reduction in anxiety symptoms was found (RCI = -1.02) and no clinically significant improvement. Amy's anxiety subscale score decreased at follow-up (mild range), and indicated reliable improvement when compared to pre-intervention (RCI = -6.62). Kim's anxiety subscale scores demonstrated a clinically significant reduction in anxiety symptoms at follow-up compared to pre-intervention.

Kim's stress subscale score stayed the same between pre-intervention (extremely severe range) to post-intervention (extremely severe range), indicating no reliable change or clinically significant change in stress symptoms. Kim's stress subscale score decreased at follow-up (mild range), indicating reliable improvement when compared to pre-intervention (RCI = -4.80). Kim's anxiety subscale scores demonstrated a clinically significant reduction in anxiety symptoms at follow-up compared to pre-intervention.

Molly - DASS-21 Scores

Molly's depression subscale scores remained the same throughout pre-intervention, post-intervention and follow-up (normal range), indicating no reliable change or clinically significant change.

Molly's anxiety subscale scores increased from pre-intervention (normal range) to post-intervention (moderate range), indicating a reliable deterioration in anxiety symptoms (RCI = 3.05) and clinically significant deterioration. Molly's anxiety subscale score decreased from post-intervention to follow-up (mild range), although no reliable improvement was indicated when compared to pre-intervention (RCI = 2.04). Molly's anxiety subscale scores demonstrated a clinically significant deterioration in anxiety symptoms at follow-up compared to pre-intervention.

Molly’s stress subscale scores decreased from pre-intervention (normal range) to post-intervention (normal range), although no reliable improvement (RCI = -0.40) or clinically significant improvement was indicated. Molly’s stress subscale score returned to pre-intervention levels at follow-up (normal range). No reliable change (RCI = 0) or clinically significant change was identified in Molly’s stress subscale scores and subsequent anxiety symptoms.

Anna - DASS-21 Scores

Anna’s depression subscale scores decreased from pre-intervention (normal range) to post-intervention (normal range) (RCI = -0.51). This did not indicate a reliable change in depressive symptoms or a clinically significant change. Anna’s depression subscale score increased at follow-up (moderate range), demonstrating reliable deterioration (RCI = 2.54) and a clinically significant increase in depression symptoms at follow-up.

Anna’s anxiety subscale scores increased from pre-intervention (normal range) to post-intervention (normal range). Reliable change (RCI = 1.53) and clinically significant change were not identified. Anna’s anxiety subscale score decreased from post-intervention to follow-up (normal range. This remained higher than pre-intervention levels, indicating no reliable improvement (RCI = 1.02). Molly’s anxiety subscale scores did not demonstrate a clinically significant deterioration in anxiety symptoms at follow-up compared to pre-intervention.

Anna’s stress subscale scores increased from pre-intervention (normal range) to post-intervention (normal range). Reliable change (RCI = 1.20) and clinically significant change were not identified. Anna’s stress subscale score increased from post-intervention to follow-up (moderate range). This remained higher than pre-intervention levels, indicating a reliable deterioration in stress symptoms (RCI = 2.40). Anna's stress subscale scores demonstrated clinically significant deterioration in stress symptoms at follow-up compared to pre-intervention.

WHO-5

The WHO-5 was administered as a measure of parents' quality of life. WHO-5 scores ranged from 12 – 60% at pre-intervention, 4 – 88% at post-intervention, and 24 – 88% at six-week follow-up. Of the seven parents, two (Sarah and Amy) indicated clinically significant improvements in WHO-5 scores from pre to post-intervention, and four parents (Julie, Sarah, Lisa, and Kim) demonstrated clinically significant improvements in WHO-5 scores from pre-intervention to six-week follow-up. All parents' WHO-5 scores increased from pre-intervention to follow-up, indicating improvements in quality of life. Normative data was not available to calculate RCI for this measure, however, clinically significant change was able to be determined (see Table 4). WHO-5 scores are displayed as percentages (see Table 3).

Julie - WHO-5 Scores

Julie's WHO-5 scores increased from pre-intervention (24%) to post-intervention (32%), and again at six-week follow-up (88%), indicating an improvement in quality of life across study phases. While the increase in WHO-5 score from pre-intervention to post-intervention was not clinically significant, the increase from pre-intervention to follow-up was clinically significant.

Sarah - WHO-5 Scores

Sarah's WHO-5 scores increased from pre-intervention (60%) to post-intervention (88%), indicating a clinically significant improvement in quality of life. While this decreased slightly at follow-up (84%), Sarah's improvement in quality of life from pre-intervention to follow-up remained clinically significant.

Lisa - WHO-5 Scores

Lisa's WHO-5 scores remained the same from pre-intervention (28%) to post-intervention (28%) indicating no change in quality of life. Lisa's WHO-5 score increased at follow-up (60%), indicating a clinically significant improvement in quality of life from pre-intervention and post-intervention to follow-up.

Amy - WHO-5 Scores

Amy's WHO-5 scores increased from pre-intervention (16%) to post-intervention (32%), indicating clinically significant improvement in quality of life. A reduction in Amy's WHO-5 score at follow-up (24%) indicates the improvement in quality of life was no longer clinically significant.

Kim - WHO-5 Scores

Kim's WHO-5 scores decreased from pre-intervention (12%) to post-intervention (4%), indicating a deterioration in quality of life, although this was not clinically significant. This decrease coincided with a self-reported mental health crisis. Kim's WHO-5 score increased at follow-up (60%), demonstrating clinically significant improvement in quality of life compared to pre-intervention.

Molly - WHO-5 Scores

Molly’s WHO-5 scores decreased from pre-intervention (52%) to post-intervention (36%), indicating a clinically significant deterioration in quality of life. Molly’s WHO-5 score increased at follow-up (56%), but did not demonstrate clinically significant improvement in quality of life from pre-intervention.

Anna - WHO-5 Scores

Anna’s WHO-5 scores decreased from pre-intervention (48%) to post-intervention (40%), indicating a deterioration in quality of life, although this was not clinically significant. Anna’s WHO-5 score increased at follow-up (52%), but this did not indicate clinically significant improvement in quality of life compared to pre-intervention.

IM-P

The IMP was administered as a measure of participants’ mindful parenting. Five of the seven parents demonstrated reliable improvement in mindful parenting (Julie, Sarah, Lisa, Amy, and Anna). Two parents demonstrated a decrease in mindful parenting (Kim and Molly), although this did not indicate reliable deterioration. Normative data was not available to calculate clinically significant change for this measure. Data for this measure is presented in Table 5.

Julie - IMP Score

Julie’s IM-P score increased from pre-intervention (114) to post-intervention (124), indicating no reliable change (RCI = 1.92). Julie’s IM-P score increased from post-intervention to follow-up (134), indicating a reliable improvement in mindful parenting (RCI = 3.83).

Sarah - IMP Score

Sarah's IM-P score increased from pre-intervention (111) to post-intervention (142), but did not indicate reliable improvement (RCI = 5.94). Sarah's IM-P score decreased from post-intervention to follow-up (136), but increased from pre-intervention levels, indicating a reliable improvement in mindful parenting at follow-up (RCI = 4.79).

Lisa - IMP Score

Lisa's IM-P score increased from pre-intervention (92) to post-intervention (107), indicating reliable improvement in mindful parenting (RCI = 2.87). Lisa's IM-P score increased from post-intervention to follow-up (113), indicating a reliable improvement in mindful parenting at follow-up (RCI = 4.02).

Amy - IMP Score

Amy's IM-P score increased from pre-intervention (106) to post-intervention (116), but no reliable change was indicated (RCI = 1.92). Amy's IM-P score increased at follow-up (118), indicating a reliable improvement in mindful parenting (RCI = 2.30).

Kim - IMP Score

Kim's IM-P score decreased from pre-intervention (103) to post-intervention (92), indicating reliable deterioration (RCI = -2.11). Kim's IM-P score increased slightly from post-intervention to follow-up (93), but remained lower than pre-intervention levels. This was not a reliable deterioration in mindful parenting (RCI = -1.92).

Molly - IMP Score

Molly’s IM-P score decreased from pre-intervention (108) to post-intervention (105), but no reliable deterioration was indicated (RCI = -0.57). Kim’s IM-P score decreased again from post-intervention to follow-up (104), although this did not indicate a reliable deterioration in mindful parenting (RCI = -0.77).

Anna - IMP Score

Anna’s IM-P score increased from pre-intervention (123) to post-intervention (133), but no reliable change was indicated (RCI = 1.92). Anna’s IM-P score increased at follow-up (136), indicating a reliable improvement in mindful parenting (RCI = 2.49).

Table 5

Reliable Change Index Calculations - Outcome Measures: Mindful Parenting and Parenting Behaviour

	Julie					**Sarah**					**Lisa**					**Amy**				
	T1	T2	T3	$\text{RCI}_{1.2}$	$\text{RCI}_{1.3}$	T1	T2	T3	$\text{RCI}_{1.2}$	$\text{RCI}_{1.3}$	T1	T2	T3	$\text{RCI}_{1.2}$	$\text{RCI}_{1.3}$	T1	T2	T3	$\text{RCI}_{1.2}$	$\text{RCI}_{1.3}$
Mindful Parenting																				
IMP	114	124	134	1.92	3.83*	111	142	136	5.94*	4.79*	92	107	113	2.87*	4.02*	106	116	118	1.92	2.30*
Parenting Behaviour																				
POS	4.82	3.36	4.18	-5.73	-2.51	4.45	4.73	3.91	1.17	-2.25	2.82	3.64	4.18	3.42*	5.67*	3.55	4.45	4.27	3.76*	3.00*
MAT	2.50	2.00	3.25	-1.13	1.70	3.00	3.00	2.75	0	-0.53	1.25	1.50	1.25	0.53	0	1.25	1.25	1.50	0	0.53
RUL	4.33	2.50	3.00	-6.68	-4.86	4.00	4.50	3.00	2.03*	-4.06	3.17	4.00	4.00	3.37*	3.37*	3.17	2.67	2.50	-2.03	-2.72
DIS	2.17	1.50	2.17	-1.40	0	2.50	2.17	1.33	-0.68	-2.41	2.17	1.67	1.33	-1.03	-1.73	1.00	1.00	1.00	0	0
HAR	1.00	1.00	1.00	0	0	1.00	1.00	1.00	0	0	1.00	1.00	1.00	0	0	1.00	1.20	1.00	0.74	0
STI	4.64	3.91	4.18	-2.42	-1.52	3.45	4.73	3.82	4.51*	1.30	3.00	3.64	3.82	2.26*	2.89*	4.00	4.18	3.91	0.63	-0.32
ADA	2.33	3.22	3.78	2.17*	3.54*	3.56	4.11	3.44	1.34	-0.29	2.33	2.78	2.44	1.10	0.29	3.55	3.22	3.67	-0.81	0.29

	Kim					Molly					Anna				
	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$
Mindful Parenting															
IMP	103	92	93	-2.11	-1.92	108	105	104	-0.57	-0.77	123	133	136	1.92	2.49*
Parenting Behaviour															
POS	4.00	4.18	4.18	0.71	0.71	3.55	3.64	4.45	0.38	3.76*	4.18	4.45	4.18	1.13	0
MAT	3.50	3.25	3.25	-0.57	-0.57	3.75	4.00	4.00	0.53	0.53	3.00	2.25	1.75	-1.59	-2.65
RUL	3.50	3.83	3.83	1.20	1.20	3.33	3.33	3.83	0	2.03*	3.83	4.17	3.50	1.38	-1.34
DIS	1.83	2.17	1.67	0.71	-0.33	2.00	1.67	2.33	-0.68	0.68	1.33	1.17	1.00	-0.33	-0.68
HAR	1.00	1.20	1.00	0.74	0	1.00	1.00	1.20	0	0.74	1.00	1.00	1.00	0	0
STI	3.55	3.82	3.64	0.89	0.30	3.27	3.09	3.00	-0.63	-0.95	3.45	3.55	3.45	0.35	0
ADA	3.56	3.67	3.78	0.27	0.54	2.78	2.67	3.22	-0.27	1.07	3.11	3.22	3.00	0.27	-0.27

Note: IMP = Interpersonal Mindfulness in Parenting scale, Mindful Parenting: Dutch version of the Interpersonal Mindfulness in Parenting Scale total score. Normal M = 109.29, SD = 11.13, α = .89 (de Bruin et al., 2014). * = reliable improvement

PBS-A

From pre-intervention to six-week follow-up, four parents demonstrated improvement in positive parenting (Lisa, Amy, Kim, and Molly), while two parents demonstrated deterioration in positive parenting (Julie and Sarah), and one parent showed no changes in positive parenting (Anna). Three parents demonstrated some improvement in teaching appropriate behaviour (Sarah, Lisa, and Kim), two parents demonstrated deterioration in teaching appropriate behaviour (Julie and Amy), and the remaining parents showed no change in teaching appropriate behaviour. Sarah, Lisa, and Kim demonstrated an improved ability to stimulate their child's environment, while Julie and Molly showed a decrease in this parenting behaviour. Three parents showed increased adaptation of the environment for their adolescent (Julie, Kim, and Molly). Data for this measure is presented in Table 5.

Julie - PBS-A Subscale Scores

There was an increase in Julie's ADA subscale score from pre-intervention (2.33) to post-intervention (3.22), indicating a reliable improvement in adapting the environment for the child (RCI = 2.17). This reliable improvement was maintained at follow-up (3.78), indicating a reliable improvement in adapting the environment (RCI = 3.54). There was a decrease in Julie's POS subscale scores from pre-intervention (4.82) to post-intervention (3.36), indicating a reliable deterioration in positive parenting (RCI = -5.73). A slight increase in POS score was observed from post-intervention to follow-up (4.18), although this continued to indicate a reliable deterioration in positive parenting (RCI = -2.51). There was a decrease in Julie's RUL subscale scores from pre-intervention (4.33) to post-intervention (2.50), indicating a reliable deterioration in (RCI = -6.68). A slight increase in POS score was observed from post-intervention to follow-up (3.00), although this continued to indicate a reliable deterioration in teaching the child appropriate behaviour (RCI = -4.86). No reliable changes were observed in the HAR, DIS, or MAT subscales.

Sarah - PBS-A Subscale Scores

There was a clinically significant increase in Sarah's RUL subscale score from pre-intervention (4.00) to post-intervention (4.50), indicating a reliable improvement in teaching the child appropriate behaviour (RCI = 2.03). Sarah's RUL score decreased at follow-up (3.00), indicating reliable deterioration in teaching the child appropriate behaviour (RCI = -4.06). There was an increase in Sarah's STI subscale score from pre-intervention (3.45) to post-intervention (4.73), indicating a reliable improvement in stimulating the child's environment (RCI = 4.51). Sarah's STI score decreased from post-intervention to follow-up (3.00) but remained higher than pre-intervention levels. This did not, however, indicate reliable improvement in stimulating the child's environment (RCI = 1.30). There was a decrease in Sarah's POS subscale score from pre-intervention (4.45) to follow-up (3.91), indicating a reliable deterioration in positive parenting (RCI = -2.25). There was also a decrease in Sarah's DIS subscale score from pre-intervention (2.50) to follow-up (1.33), indicating a reliable deterioration in limit setting (RCI = -2.41). No reliable changes were observed in the HAR, MAT, or ADA subscales.

Lisa - PBS-A Subscale Scores

Lisa's POS subscale score increased from pre-intervention (2.82) to post-intervention (3.64), indicating a reliable improvement in positive parenting (RCI = 3.42). Lisa's POS score increased again at follow-up (4.18), indicating a reliable improvement in positive parenting (RCI

= 5.67). Lisa's RUL subscale score increased from pre-intervention (3.17) to post-intervention (4.00), indicating a reliable improvement in teaching the child appropriate behaviour (RCI = 3.37). Lisa's RUL score remained the same from post-intervention to follow-up (4.00), indicating this reliable improvement in teaching the child appropriate behaviour was maintained (RCI = 3.37). Lisa's STI subscale score increased from pre-intervention (3.00) to post-intervention (3.64), indicating a reliable improvement in stimulating the child's environment (RCI = 2.26). Lisa's STI score increased again at follow-up (3.82), indicating a reliable improvement in stimulating the child's environment (RCI = 5.67). No reliable changes were observed in the MAT, DIS, HAR or ADA subscales.

Amy - PBS-A Subscale Scores

Amy's POS subscale score increased from pre-intervention (3.55) to post-intervention (4.45), indicating a reliable improvement in positive parenting (RCI = 3.76). Amy's POS score decreased slightly from post-intervention to follow-up (4.27) but continued to indicate a reliable improvement in positive parenting from pre-intervention (RCI = 3.00). There was a decrease in Amy's RUL subscale scores from pre-intervention (3.17) to post-intervention (4.45), indicating a reliable deterioration in teaching the child appropriate behaviour (RCI = -2.03). A further decrease in Amy's RUL score was observed from post-intervention to follow-up (4.18), indicating a reliable deterioration in teaching the child appropriate behaviour (RCI = -2.72). No reliable changes were observed in the MAT, DIS, HAR, STI, or ADA subscales.

Kim - PBS-A Subscale Scores

No reliable changes were observed in Kim's PBS-A subscale scores across the intervention. Increases in POS subscale scores from pre-intervention (4.00) to post-intervention (4.18) (RCI = 0.71), and follow-up (4.18) (RCI = 0.71), suggest improvement in positive parenting. Increases in Kim's RUL, STI, and ADA subscales were also observed from pre-intervention to post-intervention, and maintained at follow-up, indicating improvements in teaching the child appropriate behaviour, stimulating the child's environment, and adapting the environment. Kim's MAT subscale score decreased from pre-intervention to follow-up, indicating increased material rewarding of the child. Kim's HAR subscale score increased from pre-intervention to post-intervention, indicating increased harsh punishment. This coincided with Kim's mental health crisis, and this increase was no longer present at follow-up.

Molly - PBS-A Subscale Scores

Molly's POS subscale score increased from pre-intervention (3.55) to post-intervention (3.64), although this did not indicate a reliable improvement in positive parenting (RCI = 0.38). Amy's POS score increased at follow-up (4.45) indicating reliable improvement in positive parenting from pre-intervention (RCI = 3.76). Molly's RUL subscale score remained the same from pre-intervention (3.33) to post-intervention (3.33), demonstrating no reliable change (RCI = 0). This increased at follow-up (3.83), indicating a reliable improvement in teaching the child appropriate behaviour. Increases in material rewarding (MAT), limit setting (DIS), and adapting the environment (ADA) were also observed, although these were not found to be reliable improvements (RCI < 1.94). There was a decrease in Molly's HAR subscale score from pre-intervention to follow-up, demonstrating an increase in harsh punishment, although this was not a reliable change. A decrease in Molly's STI subscale score at follow-up (not reliable) was found, demonstrating a deterioration in stimulating the child's environment.

Anna - PBS-A Subscale Scores

There was a decrease in Anna's MAT subscale score from pre-intervention (3.00) to post-intervention (2.25), indicating a reliable reduction in material rewarding (RCI = -1.59). A further decrease in Anna's MAT score was observed from post-intervention to follow-up (1.75), indicating a reliable reduction in material rewarding (RCI = -2.65). No reliable changes were observed in the POS, RUL, DIS, HAR, STI, or ADA subscales.

CBCL

The CBCL was administered to assess changes in adolescent behaviour across intervention phases. RCI data for this measure is presented in Table 6, with changes in clinical significance presented in Table 4.

Julie - CBCL Subscale Scores

Julie's CBCL internalising score increased from pre-intervention (7) to post-intervention (41), indicating reliable deterioration in reported internalising child difficulties (RCI = 7.51). Although Julie's CBCL internalising score decreased from post-intervention to follow-up (26), reliable deterioration in reported internalising child difficulties was observed from pre-intervention to follow-up (RCI = 4.20).

Julie's CBCL externalising score increased from pre-intervention (0) to post-intervention (18), indicating reliable and clinically significant deterioration in reported externalising child difficulties (RCI = 3.44). Julie's CBCL externalising score decreased from post-intervention to follow-up (10), demonstrating reliable deterioration but no clinically significant deterioration in reported externalising child difficulties from pre-intervention to follow-up (RCI = 1.91).

Julie's CBCL total score increased from pre-intervention (10) to post-intervention (97), indicating reliable and clinically significant deterioration in reported total child difficulties (RCI = 7.69). Julie's CBCL total score decreased from post-intervention to follow-up (62), but continued to demonstrate reliable deterioration and clinically significant deterioration in reported total child difficulties from pre-intervention to follow-up (RCI = 4.60).

Sarah - CBCL Subscale Scores

Sarah's CBCL internalising score decreased from pre-intervention (17) to post-intervention (7), indicating reliable and clinically significant improvement in reported internalising child difficulties (RCI = -2.62). Sarah's CBCL internalising score increased at follow-up (31), indicating reliable deterioration in reported internalising child difficulties from pre-intervention to follow-up (RCI = 3.67).

Sarah's CBCL externalising score remained the same from pre-intervention (0) to post-intervention (0), indicating no reliable and clinically significant change in reported externalising child difficulties (RCI = 0). Sarah's CBCL externalising score increased from post-intervention to follow-up (13), demonstrating reliable and clinically significant deterioration in reported externalising child difficulties from pre-intervention to follow-up (RCI = 2.48).

Sarah's CBCL total score increased from pre-intervention (25) to post-intervention (15), but did not indicate reliable or clinically significant deterioration in reported total child difficulties (RCI = -0.93). Sarah's CBCL total score increased from post-intervention to follow-up (67), demonstrating reliable and clinically significant deterioration in reported total child difficulties from pre-intervention to follow-up (RCI = 3.91).

Lisa - CBCL Subscale Scores

Lisa's CBCL internalising score decreased from pre-intervention (14) to post-intervention (11). This was a clinically significant improvement but did not indicate reliable improvement in reported internalising child difficulties (RCI = -0.79). Lisa's CBCL internalising score increased at follow-up (15), demonstrating deterioration in reported internalising child difficulties from pre-intervention to follow-up, although this was not a reliable change (RCI = 0.26).

Lisa's CBCL externalising score remained the same from pre-intervention (1) to post-intervention (1), indicating no reliable and clinically significant change in reported externalising child difficulties (RCI = 0). Lisa's CBCL externalising score increased slightly at follow-up (2), but this did not demonstrate reliable or clinically significant deterioration in reported externalising child difficulties from pre-intervention to follow-up (RCI = 0.19).

Lisa's CBCL total score remained the same from pre-intervention (37) to post-intervention (37), indicating no reliable and clinically significant change in reported total child difficulties (RCI = 0). Lisa's CBCL total score increased slightly at follow-up (38), but this did not demonstrate reliable or clinically significant deterioration in reported total child difficulties from pre-intervention to follow-up (RCI = 0.19).

Amy - CBCL Subscale Scores

Amy's CBCL internalising score increased from pre-intervention (30) to post-intervention (32), although this did not indicate reliable deterioration or clinically significant change in reported internalising child difficulties (RCI = 0.52). Amy's CBCL internalising score decreased at follow-up (25), although this did not indicate reliable improvement or clinically significant change in reported internalising child difficulties from pre-intervention to follow-up (RCI = -1.31).

Amy's CBCL externalising score decreased from pre-intervention (19) to post-intervention (15). This indicated clinically significant improvement but no reliable improvement in reported externalising child difficulties (RCI = -0.76). Amy's CBCL externalising score decreased at follow-up (4), indicating maintained clinically significant improvement and reliable improvement in reported externalising child difficulties (RCI = -2.87).

Amy's CBCL total score decreased from pre-intervention (72) to post-intervention (65), although no reliable or clinically significant improvement in reported total child difficulties was identified (RCI = -0.65). Amy's CBCL total score decreased again at follow-up (50), demonstrating reliable and clinically significant improvement in reported total child difficulties from pre-intervention to follow-up (RCI = -2.05).

Kim - CBCL Subscale Scores

Kim's CBCL internalising score decreased from pre-intervention (43) to post-intervention (42), although this did not indicate clinically significant change or reliable change in reported internalising child difficulties (RCI = -0.22). Kim's CBCL internalising score decreased at follow-up (32), indicating no clinically significant improvement but did indicate reliable improvement in reported internalising child difficulties (RCI = -2.43).

Kim's CBCL externalising score increased from pre-intervention (12) to post-intervention (14), indicating no reliable and clinically significant change in reported externalising child difficulties (RCI = 0.38). Kim's CBCL externalising score decreased at follow-up (12), demonstrating no reliable or clinically significant change in reported externalising child difficulties from pre-intervention to follow-up (RCI = 0).

Kim's CBCL total score remained the same from pre-intervention (106) to post-intervention (97), but no reliable or clinically significant improvement in reported total child difficulties (RCI = -0.80). Kim's CBCL total score decreased again at follow-up (81), demonstrating reliable but not clinically significant improvement in reported total child difficulties from pre-intervention to follow-up (RCI = -2.21).

Molly - CBCL Subscale Scores

Molly's CBCL internalising score decreased from pre-intervention (11) to post-intervention (2), indicating clinically significant and reliable improvement in reported internalising child difficulties (RCI = -2.36). Molly's CBCL internalising score increased from post-intervention to follow-up (7), indicating maintained clinically significant improvement but did not indicate maintained reliable improvement in reported internalising child difficulties (RCI = -1.05).

Molly's CBCL externalising score decreased from pre-intervention (4) to post-intervention (2), indicating no reliable and clinically significant change in reported externalising child difficulties (RCI = -0.38). This score remained the same at follow-up (2), (RCI = 0).

Molly's CBCL total score decreased from pre-intervention (42) to post-intervention (17), indicating reliable and clinically significant improvement in reported total child difficulties (RCI = -2.33). Molly's CBCL total score increased at follow-up (31), demonstrating clinically significant but not reliable improvement in reported total child difficulties from pre-intervention to follow-up (RCI = -1.02).

Anna - CBCL Subscale Scores

Anna's CBCL internalising score increased from pre-intervention (9) to post-intervention (16), although this did not indicate reliable deterioration or clinically significant change in reported internalising child difficulties (RCI = 1.83). Anna's CBCL internalising score decreased at follow-up (14), although this did not indicate reliable improvement or clinically significant change in reported internalising child difficulties from pre-intervention to follow-up (RCI = 1.31).

Anna's CBCL externalising score decreased from pre-intervention (4) to post-intervention (1), although this did not indicate reliable improvement or clinically significant change in reported externalising child difficulties (RCI = -0.57). Anna's CBCL externalising score increased at follow-up (5), although this did not indicate reliable deterioration or clinically significant deterioration in reported externalising child difficulties from pre-intervention to follow-up (RCI = 0.19).

Anna's CBCL total score increased from pre-intervention (32) to post-intervention (35), but did not indicate reliable or clinically significant deterioration in reported total child difficulties (RCI = 0.28). Anna's CBCL total score increased at follow-up (38), but this did not demonstrate reliable or clinically significant deterioration in reported total child difficulties from pre-intervention to follow-up (RCI = 0.56).

Table 6

Reliable Change Index Calculations - Outcome Measures: CBCL

	Julie					**Sarah**					**Lisa**				
	T1	T2	T3	$RCI_{1.2}$	$RCI_{1.3}$	T1	T2	T3	$RCI_{1.2}$	$RCI_{1.3}$	T1	T2	T3	$RCI_{1.2}$	$RCI_{1.3}$
CBCL															
Internalising	7	41	26	7.51	4.20	17	7	31	-2.62*	3.67	14	11	15	-0.79	0.26
Externalising	0	18	10	3.44	1.91	0	0	13	0	2.48	1	1	2	0	0.19
Total	10	97	62	7.69	4.60	25	15	67	-0.93	3.91	37	37	38	0	0.09

	Amy					**Kim**					**Molly**				
	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$
CBCL															
Internalising	30	32	25	0.52	-1.31	43	42	32	-0.22	-2.43*	11	2	7	-2.36*	-1.05
Externalising	19	15	4	-0.76	-2.87*	12	14	12	0.38	0	4	2	2	-0.38	-0.38
Total	72	65	50	-0.65	-2.05*	106	97	81	-0.80	-2.21*	42	17	31	-2.33*	-1.02

	Anna				
	T1	T2	T3	RCI$_{1.2}$	RCI$_{1.3}$
CBCL					
Internalising	9	16	14	1.83	1.31
Externalising	4	1	5	-0.57	0.19
Total	32	35	38	0.28	0.56

* = Reliable Improvement

Feasibility Outcomes

The feasibility of the current study was evaluated by examining recruitment and retention of participants, group attendance and adherence, adverse effects for participants or the facilitator, and an evaluation form completed by participants.

Initially, 21 parents emailed to express interest in participating in the mindful parenting group. Of these parents, eight consented and enrolled in the study by the end of the recruitment period, demonstrating 38% enrolment. One participant dropped out of the study in the fourth week of baseline (6th August 2022) due to work commitments. The remaining seven participants all completed the remainder of the study, demonstrating an 87.5% retention rate from those who consented.

The average group attendance rate of parent participants was 50%. Three parents (Lisa, Sarah, and Kim) were unable to attend one session each as a result of Covid-19 and child sickness. Only two participants (Julie and Lisa) attended more than 70% of group sessions.

The evaluation form was completed by parent participants six weeks after completing the intervention. All participants reported that they felt they got something of lasting value from the programme and had experienced lifestyle, relationship, and parenting changes as a result of participating in the programme. All participants also reported that they intended to keep practising mindful exercises (e.g body scan, 3 minute breathing space) and mindfulness in daily life as a parent. All participants except Sarah reported increased awareness of parenting as a result of the programme. Sarah, Molly, Amy, and Kim indicated that their thoughts or feelings about parenting had changed through the programme, while Lisa, Julie, and Amy felt this had not been the case.

Participants were asked to report how many times a week, on average, they had practised the mindfulness exercises during the programme. Julie, Sarah, and Molly reported practising the recommended frequency per week with an average of 5-7 times a week. Amy and Anna reported practising 3-4 times a week, and Lisa and Kim reported practising 1-2 times a week. When asked how often they pay attention to their child in moments together compared to before the programme, Kim, Julie, Lisa, Sarah, and Amy reported doing this more than before, Molly reported much more than before, and Anna reported no change.

Participants rated the usefulness of each mindfulness practice exercise on a scale from 1-10. In general, parents rated mindfulness exercises higher when used at home, compared to a group setting. The highest-rated mindfulness practice exercises were 3-minute breathing space ($M = 8.7$), mindful awareness in daily parenting ($M = 8$), and sitting meditation at home ($M = 7.1$). The lowest-rated mindfulness practice exercises were yoga in the group ($M = 2$), walking meditation in the group ($M = 3$), and homework logs ($M = 3.1$).

The evaluation form also explored parents' perceptions of change following the programme, asking them to indicate if they had experienced positive change, some positive change, negative change, or no change. Four parents responded that they had experienced positive change in "knowing how to take care of myself" (Julie, Sarah, Kim, and Molly), and three parents responded that they had experienced some positive change with regard to this item (Lisa, Amy, and Anna). To the item "actually taking care of myself" three parents indicated positive change (Julie, Sarah, Molly), three parents indicated some positive change (Lisa, Amy, Anna), and one parent indicated no change (Kim). To the item "how often I experience parenting stress or frustration" two parents indicated positive change (Amy and Molly), four parents indicated some positive change (Julie, Sarah, Lisa, and Kim), and one parent indicated no change

(Anna). To the item "the intensity of parenting stress or frustration" three parents indicated positive change (Sarah, Amy, and Molly), three parents indicated some positive change (Julie, Lisa, and Kim), and one parent indicated no change (Anna). To the item "believing that I can improve the relationship with my child and family" four parents indicated positive change (Julie, Sarah, Amy, and Molly), and three parents indicated some positive change (Lisa, Kim, and Anna). To the item "feeling self-confident as a parent" two parents indicated positive change (Julie and Sarah), and five parents indicated some positive change (Lisa, Kim, Amy, Molly, and Anna). To the item "feeling hopeful as a parent" three parents indicated positive change (Julie and Molly), four parents indicated some positive change (Sarag, Lisa, Amy, Kim), and one parent indicated no change (Anna). To the item "dealing with emotions (anger, sadness, fear) in parenting" one parent indicated positive change (Molly), five parents indicated some positive change (Julie, Sarah, Lisa, Amy, Kim), and one parent indicated no change (Anna). To the item "awareness of what is stressful in my life" three parents indicated positive change (Julie, Sarah, Amy, and Molly), and three parents indicated some positive change (Lisa, Kim, and Anna). To the item "awareness of stressful parenting situations in my life" four parents indicated positive change (Julie, Sarah, Amy, and Molly), three parents indicated some positive change (Lisa, Kim, and Anna). To the item "awareness of stressful parenting situations at the time they are happening" four parents indicated positive change (Julie, Sarah, Amy, and Molly), and three parents indicated some positive change (Lisa, Kim, and Anna).

Qualitative Data

The following section presents the data from qualitative interviews with five of the seven participants in this study. Two parents (Kim and Anna) chose not to take part. From this, 20 themes were initially developed from the coded parent interview data. Following a review process using thematic mapping, five main themes were identified, with several subthemes within each.

Theme 1: Social Challenges of Parenting an Autistic Adolescent

Discussions about the parents' experiences of the programme during interviews prompted parents to share their wider experiences of parenting and their interactions with society as a parent of an autistic adolescent. Parents spoke about the joys and challenges they experienced in parenting their autistic adolescent. All parents spoke of their adolescents in a loving, positive way. Two parents spoke about the joys of parenting an autistic adolescent. One parent shared that her son had taught their family so much about the world; *"He teaches us to look through the world through a different lens".* One parent spoke of her son's happy nature and the positive impact this had on her.

The majority of difficulties discussed by parents were related to barriers presented by society and systems, contributing to experiences of exclusion and discrimination. Four parents described experiencing judgement from others directed towards themselves and their child. It was shared by three parents that members of the public frequently stared or made comments about their parenting or their adolescent's behaviour associated with autism;

"The one thing, though, that is frustrating and I should be used to by now… is that when you're out, say, at the supermarket and he starts stimming or he's scripting or whatever, and all the people that just stare!" - Lisa

"And like we've had people come up to us and like, "what's wrong with him?". And it's like "nothing! Nothing's wrong with him! Something's wrong with you!" - Molly

One parent described experiencing judgement from family members; *"My dad said, he's like, "I can't talk, I can't talk to your son or, you know, I don't know what to say or it's too difficult". And it's like, well, that's your issue." - Julie*

These experiences were described by parents as frustrating and isolating. As a result, these parents described wishing for more awareness and tolerance from others towards their adolescents.

Furthermore, three parents reported negative experiences with educational and support systems. One mother described how her non-verbal adolescent had been receiving teaching at school many years below his academic level as a result of the misconceptions about his autism. This parent reported that her son's teachers seemed unaware and ill-equipped to provide appropriate support for her son, *"they were talking about him, in front of him, he understood everything"* and "*And he said… "they thought I was stupid and not worthy of an education"".* The same parent reported experiences of school exclusion as a result of her adolescent's behaviour, stating that they felt misunderstood by the school. One parent reported struggling to find appropriate support for her son's mental health through the public health system; *"We have had some pretty atrocious experiences over the last year or so with the public mental health service… It shouldn't have happened like that".* The private system had been far more accessible and suitable for this parent's family, who stated her worry for families who could not afford to seek private support services. Another parent spoke of the difficulty finding options for their son following high school graduation, with many companies or businesses not willing to be flexible for an autistic employee with additional needs.

Two mothers described their unique experiences of parenting an autistic adolescent. One parent spoke about how parenting her adolescent was very different to parenting non-autistic teenagers or parenting autistic children, with new and different needs. Another mother discussed the stress experienced while parenting her autistic adolescent, finding challenges in communication particularly difficult to navigate particularly when navigating future decisions following high school graduation.

One parent spoke about yearning for normalcy at times as a parent. She spoke of worries that her son would never do things expected of adults, such as marrying and having a family; *"Will he ever find somebody that will love him? ... What will life look like for him?"*.

Theme 2: Parents' Experiences of the Programme

Parents interviewed described largely positive experiences of the Mindful Parenting programme. Some barriers to accessing the intervention were noted, as well as suggestions for future iterations of the programme. In general, parents' experiences of the group sessions and content of the programme itself were positive.

Positive Experience

All of the five interviewed parents described positive overall experiences of the programme. Parents outlined that the experience was a valuable one, providing them with useful skills. All parents indicated in interviews that they would continue to use the skills and experiences from the programme in their lives as parents and into the future. All parents also reported that they would recommend the programme to other parents of autistic adolescents.

"I really enjoyed it" - Molly

All parents talked about the positive impacts the programme had created for them. The programme was described by parents as a great opportunity for themselves, with many explaining that they were looking forward to the programme before starting. All parents described the programme as providing them with benefits that had helped them and their family. One parent explained that she had been apprehensive as she believed making changes would be an effortful task, but was pleasantly surprised to find that small changes she made resulted in big felt differences.

"It feels like with minimal effort… I've managed to make like an 80% difference" - Amy

"It's exactly what I was looking for at that moment in time, you know. So that's perfect timing for me that… and it's worked" - Julie

Shared Connections

The group sessions were experienced positively by all parent participants. Parents described enjoying the group sessions including the content, the connections with other parents, and the support of the parent facilitator.

All parents reported positive experiences of the support of the parent facilitator. Four parents outlined that they appreciated the experience of the parent facilitator as the parent of an autistic young person herself. These parents described that being supported by someone with shared experiences made them feel understood, with two parents adding that they would not have wanted a parent of a neurotypical child to support them as they worried they would have been misunderstood. One parent described appreciating knowing that she could reach out to the parent facilitator whenever she needed.

"She was lovely… very encouraging and really allowed you to, you know, you know, express yourself and kind of share the ups and downs. And because she has … boys on the spectrum, it was really nice... you know, because she got what we were talking about." - Lisa

“I think it's probably always just nice knowing that you're talking to someone who understands rather like actually has been there rather than someone who is doing their best to empathise.” - Amy

All parents reported positive experiences of the group itself. Parents described enjoying the connections they made with other parents, specifically having similar experiences. Sharing experiences with one another was described as empowering, validating, and reduced feelings of isolation. Parents described hearing the experiences of others interesting and motivating, finding strength in the success of others. One parent noted that she did not have access to support groups for parents of autistic adolescents in her town, and therefore greatly appreciated the opportunity to hear from parents with similar experiences. One parent noted that she felt comfortable in the group and a sense of non-judgement, something that she did not often experience.

“It's nice to hear, nice to talk to or hear from other parents who don't judge in those kind of ways. Because I've been there.” - Amy

“You know, you're not, you're not completely alone in this journey. Yeah. There are people going through the same similar things that you are”. - Molly

Experiences of Programme Content

Parents were asked about their experiences of different components of the programme including the website, videos, audio recordings, and workbook. In interviews, parents described different aspects as more useful and applicable than others.

All parents reported that the videos posted on the website were one of the most helpful resources. Three of the five parents reported finding the workbook helpful, stating that having a physical copy of the written content helped when wanting to refer back to a specific skill or concept.

"I did like having it printed out so that I could read it and really read things" - Amy

Two parents described the audio meditations as helpful, adding that they enjoyed being able to come back to their favourites whenever they needed. Two parents reported enjoying the body scan exercise the most as it helped them to develop an awareness of themselves.

It was noted by one parent that the workbook appeared to address issues that were more relevant to parents of autistic children rather than adolescents. This parent was disappointed about this, feeling that they had already moved through the challenges and techniques described in the workbook. Additionally, two parents mentioned that they would have appreciated the inclusion of mindfulness techniques to try with their adolescent. Parents reported that anxiety and emotional regulation could be difficult for their adolescents, and felt that being able to work through mindfulness practice alongside their child would have been beneficial. Both parents suggested that this be explored for future practice.

"The parent and the adolescent can chat about, what it means to them and what they struggle with or what they find easy. And that could be a real, really good thing." - Lisa

There were a handful of less positive experiences of the programme reported by parents. One parent reported that attending the Zoom sessions was difficult for her as she became anxious about speaking and being in front of others. She indicated wanting to partake more in the Zoom group sessions but felt unable to do so because of this anxiety. One parent reported that the Zoom group sessions took place too late in the evening, making it difficult to manage the needs of her family simultaneously. Two parents indicated disappointment in the small number of parents who attended the group sessions after the first session, demonstrating a desire for a larger group in order to have more discussions and experiences connecting with others.

Experiences of Practice

When not engaging in the group sessions, parents were encouraged to practise mindfulness at home with the assistance of the provided resources. In general, parents found this a positive experience, with some barriers reported.

Four parents described mindfulness practice as something that became easier with time. Parents appreciated that only small moments were needed, enjoying the flexibility of being able to practise whenever a spare moment presented itself. Two parents noted that forming a routine for mindfulness practice helped them to practise consistently. One parent explained that she no longer needed the resources such as videos or audio recordings, instead being able to practise mindfulness independently. Two parents described finding it difficult to find the motivation to maintain consistent mindfulness practice once the programme ended.

Other Impacting Factors on Parent Outcomes

External factors that may have impacted wellbeing and stress during the programme were identified by all parents. One parent described how they had recently taken a job transcribing interviews around the subject of grounding and supporting wellbeing, stating that this may also have contributed to her reduced stress. One parent had entered a new relationship during the programme and subsequently reported feeling more supported. It was noted by one parent that having a bad day impacted her answers to survey questions despite the surveys asking about the last week. Another parent mentioned that she had had previous experience with some basic mindfulness skills, and felt that the programme had helped her further develop this. Finally, one parent reported that her autistic adolescent had experienced a recent worsening of mental health and that this had greatly impacted her own wellbeing and stress levels.

Theme 3: Skills Acquired by Parents during the Programme

This theme demonstrates the several skills and qualities developed by parents during the Mindful Parenting programme. Parents were asked to discuss their experience of taking part in the programme and any changes they had noticed in their parenting or their own stress or emotional wellbeing.

Being Mindful

Four of the five parents interviewed reported feeling more mindful in parenting and daily life. These parents reflected that they used mindfulness often during the day in regular activities such as parenting or in their interactions with others. Two parents reported that they felt more grounded and present as a result of this skill.

"It's just you know, you're centred. You're grounded. Then you can cope with whatever comes along in a more mindful way" - Lisa

Parents noted that they were able to apply mindfulness in daily life and stressful parenting situations. Subsequently, they were able to react in a more appropriate way to their child and respond in a measured way. One parent reported an increase in mindful listening that had helped communication with her autistic and neurotypical adolescents, noting that this had made a difference in their communication with one another. Two parents explained that beginning their day with mindfulness practice helped them to start the day positively. Another parent indicated that mindful practice had subsequently become an important part of her life that was enjoyable;

"And now it's just not "I have to do this". It's just like, "Ah, I'm actually just doing it now". - Julie

Awareness of Self

Four of the five parents interviewed reported increased awareness of their own feelings and inner state as a result of the programme. Parents reported that the programme had made them aware of how they had been functioning prior to taking part in the programme. Two parents indicated that they had been previously unaware of their own feelings and emotions in stressful moments and that this lack of awareness would previously lead to emotional responses;

"It seems so crazy to actually think that I wasn't noticing how I was feeling" - Amy

Parents reported that they now recognised and were more aware of their own emotions and mental state. Two parents noted that this skill had helped them to recognise when their own emotions were becoming overwhelming. As a result, they were able to prevent anger and parenting responses they felt they would have regretted, particularly yelling. One parent recognised the impact suppressing and ignoring her own emotions had on her and her family;

"I think the biggest difference is noticing when I'm getting to the point where I'm about to explode... I think even just noticing that it's really hard and that I might lose my temper, seems to manage to mean that I don't". - Amy

Within this theme, parents also reported noticing that they had been operating on autopilot. Prior to the programme, parents had been focused on getting through the day's challenges, surviving, and repeating the same process through the days and weeks. One parent was amazed that she had been operating in this way for years.

“You can get kind of caught up in the day-to-day dealing with everything. It feels like I was always in crisis mode” - Amy

“I was like, just autopilot, get through the day… Start again tomorrow, you know. And realising that that's all that we were doing. There was not really any extra joy or anything like that.” - Julie

Self-Care and Compassion

All parents described a newfound ability to take care of their own support needs as a result of the programme. It was noted by all that they were able to now recognise the importance of taking time for themselves, particularly emphasising that this did not have to be great lengths of time. Parents found that taking a few minutes for a cup of tea or a moment alone was a beneficial skill that they had developed. Parents reported recognising that this helped them to reset and care for their own needs, and subsequently helped them to support their adolescent and family. One parent noted that giving herself permission to admit that the situation she found herself in was stressful was validating. They reported becoming more aware of the importance of looking after themselves;

“I do need to take more time for myself just to keep me going, keep my battery charged.” - Julie

It was shared by one parent that she had begun taking more time to do things that made her happy, such as visiting friends or going shopping. She added that she is going on a holiday away with a friend for the first time in a long time, recognising the importance of taking care of herself.

Pausing

All parents described an increased ability to pause before reacting in parenting situations. When managing challenging behaviour, parents reported that it could be easy to react first before thinking due to the stress of the situation. Following the programme, all described a new ability to stop, evaluate or think about the situation, and either respond in a more measured, appropriate way, or remove themselves and take a moment away. As a result, parents felt they were able to handle difficult situations more easily and respond in the way that they wanted. Consequently, they felt that these responses were less stressful and more manageable for themselves and their adolescent. This was referred to often as "stepping back" and "pausing before reacting";

"finding that in those stressful situations, you can stop and think… before you actually do something." - Sarah

New Perspective

Following the programme, four parents expressed that they had developed a new perspective and acceptance of their lives as parents. The general attitude developed amongst these parents was acceptance of the reality they faced every day, including the challenges and stress.

"What's going to be is going to be". - Molly

Theme 4: Parental Outcomes

During interviews, parents were asked about any changes they had experienced in their wellbeing, stress levels, or parenting. It was shared by all parents that they had experienced an improvement in emotional wellbeing, and a reduction in stress and other negative wellbeing and parenting outcomes. Within this theme, parental outcomes have been divided into increased positive outcomes, and reduced negative outcomes for parents' own stress and wellbeing.

Benefits for Parents Following Intervention

Each parent interviewed shared that they had experienced some improvements in emotional wellbeing since taking part in the mindful parenting programme. One parent explained that she had begun spending more time outdoors as a result of the programme. She went on to add that mindfulness practice had contributed to a greater sense of calm in her life. This was echoed by two other parents who noted that they felt calmer and more relaxed in general. Three of the five parents interviewed added that they were happier as a result of the programme. One parent noted that she was more at peace with the reality of parenting an autistic adolescent, stating that his happiness was the most important.

Further positive changes were made by one parent, including starting to exercise and trying new things more often. She noted that these positive changes had even been noticed by others in her life;

"She sees the difference that it's made for me, you know, when they come to visit" - Julie

An increase in social wellbeing was experienced by two parents. One parent described making an effort to see her friends more often since the programme. Since engaging in the programme another parent reported that she had gone out of her way to make friends with her new neighbours, something that she would not have done prior to the programme; "*I'd be like,* *you know, whatever, you know, can't be bothered. But we've actually made friends with them and we've invited them over which is not something that we do… I haven't done that in a long time"*.

One parent described feeling increased self-confidence and feelings of achievement since completing the programme; *"There's a confidence that comes with knowing you can actually do something that you didn't think was achievable"*.

Fewer Challenges

In interviews, parents were asked if they had noticed any changes in their emotional wellbeing and stress. Four of five parents reported a reduction in negative mental health outcomes and parenting stress. Reported changes in stress varied from small changes to significant differences noticed. Two parents described experiencing little to no changes in their stress. One parent noted that she felt less stressed but would not have described herself as a stressed person before the programme. Another mother commented that her stress levels had been very high recently as a result of her son's worsening mental health, but noted that without the programme, *"In fact, it could have been worse"*. This parent explained that prior to the programme she would frequently become overwhelmed by parenting and stressful situations; *"I would kind of have my own little mini meltdown"*. She reported, however, that since the programme she had only felt seriously overwhelmed once which was far less than previously.

Three parents noticed significant reductions in their stress levels. Two parents noted that before the programme, in stressful parenting situations, their stress levels would be at an 8 out of 10, while after the programme they would be at a 4 out of 10. Another mother reported that previous situations she would find stressful with her son no longer impacted her in the same way, particularly to her son's discomfort leaving the house. Following the programme, this mother reported not feeling stressed when her son would want to stay at home, describing more acceptance in conjunction with this. Three parents discussed reduced anxiety and low mood since taking part in the programme. One parent noted feeling less worried about her adolescent's future, and also experiencing less low mood; *"I don't think I get as down about things as I used to".*

"I'm not so uptight about when things aren't working out… I don't really worry about it… I'm just like, "it is what it is". - Julie

Changes in Parenting

A common experience amongst parents was a new sense of awareness of their adolescents' perspective. Three parents reported becoming more aware of the difficulties and challenges their adolescent experienced, creating an increased sense of empathy for their child. One parent commented, *"It's just being mindful that what I think is a rough day, could be 1000 times worse for him".* Another parent reported feeling increased empathy for her daughter's challenges that she previously found difficult to understand, *"she's pretty up and down at the moment, so I'm just being tolerant of that… without, you know, being judgy of what she's feeling at that particular second in time".* Another parent was able to reflect that she felt she understood her adolescents' perspectives more; *"They have got a lot of stress as well".*

All parents described positive changes in their parenting behaviours. Pausing before reacting in stressful situations was noted by all parents as a skill that had improved their parenting. One parent explained that by practising this skill, she felt she was a better role model for her children by demonstrating positive ways to handle big emotions. Instead of becoming overwhelmed during stressful parenting situations, she explained that she was now able to respond in a way that she wanted to as opposed to becoming overwhelmed; "*I guess it has obviously affected my parenting because I've lost my temper when I run out of patience ... less often*". This was echoed by other parents, describing calmer and more tolerant attitudes during stressful parenting situations. Within this, parents reported being more flexible and adaptable in stressful parenting situations. Instead of becoming frustrated and emotional in these instances, parents noted that they were able to use mindfulness techniques to stay calm and practise patience with their adolescents; "*Now it's just like, just, just breathe and just move on to something else*".

"It feels really good to not lose it. Yeah. You know. And so if I'm feeling more like I'm doing a better job of parenting, it's probably helping everybody." - Amy

As a result of these changes in parenting, parents noticed that their children were positively impacted. It was noted by one parent that by practising mindful parenting, she would not become overwhelmed in difficult situations. With an adolescent who was very affected by the emotions of others, this meant that he experienced better emotional regulation; *"We've been on a much more even keel"*.

Three of the parents interviewed had also practised mindfulness exercises together with their adolescent since engaging in the programme. These parents noted that not only was this helpful for grounding and calming their adolescents, but also a way for parent and child to spend time together.

Theme 5: Adolescent and Family Outcomes

Changes in Adolescents

Parents noted varying degrees of change in their child’s behaviour during and after the programme. Two parents noted that their ability to be calm and not react during stressful parenting situations ensured that their adolescents also stayed calm.

“If I’m calm they’re calm. So, you know, it's important to remain calm, otherwise everything just turns to crap” - Julie

Two parents who reported that self-isolation was a challenge for their adolescents identified that this had since improved. Both parents reported responding more flexibly when managing their adolescents' desire not to leave the house. As a result, both parents described their adolescents leaving the house for small periods of time, something that they viewed as a great success. Unfortunately, the adolescent of one parent experienced a mental health crisis while the programme was taking place, although this parent made it clear that this was unrelated to the programme.

Changes in Parent-Child Relationship

Some parents noted positive changes in their relationship with their adolescent, while others felt that no change had occurred. Three parents reported fewer negative parent-adolescent interactions, adding that this had helped to increase positive interactions with their adolescent. Increased listening and better connection reported by one parent had contributed to a greater understanding of her adolescent’s experiences.

“So it's actually taking a step back, and thinking about how they are in that situation and being mindful of what they're going through.” - Lisa

Parents noticed that the time they spent together with their child was more positive, making it easier to spend time with one another and connect.

Changes in Family Dynamics

All parents reflected that the changes they had made as a result of the programme had also impacted their family as a whole. The culmination of fewer negative interactions, less stress, and increases in positive interactions meant that parents felt calmer, and more positive family dynamics.

"I'm just like happy with the changes that I've been… I've been able to see… that we've been able to bring into our family". - Molly

Chapter 5: Discussion

Research Objectives

The aims of this study were to explore the feasibility and preliminary effects of an online MP programme delivered by a parent facilitator for parents of autistic adolescents. Three hypotheses were put forward related to quantitative outcomes; (1) Participation in the mindful parenting programme will be associated with improvements in parenting stress, distress (anxiety, depression symptoms), parenting behaviours, mindful parenting, and quality of life immediately post-intervention and at six-week follow-up; (2) Parents taking part in the mindful parenting programme will report fewer adolescent behaviour problems as measured by the Child Behaviour Checklist (CBCL) immediately following the online MP intervention and at six-week follow-up; (3) Parents' responses to the programme evaluation survey will support the acceptability, social validity, and feasibility of the online Mindful Parenting programme. Two research questions were posed in relation to the qualitative data; (1) How do parents who choose to participate in the follow-up interview perceive the intervention?; (2) How do parents' perceptions of their parenting change through the course of and after the programme?

The current study used a single case design to examine the impacts of an online MP intervention for seven mothers of autistic adolescents aged 12-18 years using a single case design. During the six-week programme, participants took part in self-directed online lessons separated into three learning modules via a dedicated website. In addition, parents took part in four group sessions delivered via Zoom led by a trained parent facilitator. This chapter will discuss the findings of this study in relation to the aims outlined above, and the significance of these findings in relation to previous research.

Effects of an Online, Parent-Facilitated MP Programme in Improving Wellbeing and Stress in Parents of Autistic Adolescents

The effectiveness of an online, parent-facilitated MP programme on parent wellbeing and stress was assessed using quantitative outcomes measuring parent wellbeing and distress (ORS), parenting stress (PSI-SF), mental health (DASS-21), quality of life (WHO-5), mindful parenting (IM-P), parenting behaviour (PBS-A), and child behaviour (CBCL). The ORS and PSI-SF findings were assessed using the SCED guidelines with visual analysis across intervention phases, and the repeated measures were assessed using RCI and clinical significance calculations for change between baseline, post-intervention and follow-up.

Parental Wellbeing and Distress

The single-case design analyses indicated mixed findings in relation to the effectiveness of the MP programme on measures of parental wellbeing and distress as indicated by the ORS. Six of the seven parents demonstrated improvement in ORS overall scores during the intervention, with three parents indicating improved ORS overall scores from baseline to intervention, and three parents showing maintained improvements from baseline to six-week follow-up with moderate to high intervention effects. The most improvement in the ORS was demonstrated in parents' personal wellbeing, with all seven parents demonstrating a degree of improvement in this domain. Positive change was observed in parents' interpersonal wellbeing, with six parents demonstrating improvement in this domain, while one of the seven parents demonstrated deterioration in interpersonal wellbeing from baseline to follow-up. The least improvement was observed in parents' social functioning. Although five parents' demonstrated improvement in social functioning from baseline to intervention, only three parents indicated maintained improvement in social functioning at six-week follow-up with high intervention effects.

Varying effect sizes were observed for each domain of the ORS. Three of the seven parents' (Sarah, Lisa, and Kim) scores on the overall domain indicated a moderate to high intervention effect. Intervention effects for the same three parents were found across personal and social wellbeing domains, with moderate to highly effective intervention and highly effective intervention effects respectively. Three parents' (Sarah, Lisa, and Amy) scores on the interpersonal domain indicated moderate to highly effective intervention effects, and four parents' (Sarah, Lisa, Kim and Anna) scores demonstrated moderate to high intervention effects for total wellbeing. Of the seven parents, five (Sarah, Lisa, Amy, Kim, and Anna) demonstrated improvement with intervention effect in at least one of the ORS domains assessed, with the most improvement observed in parents' total wellbeing. However, two parents (Julie and Molly) did not demonstrate improvement with intervention effects in any ORS domain. As these two parents had the greatest variability in their baseline phase data, increased baseline length to attain stability may have produced results with intervention effects. Despite this, all parents indicated some improvement from baseline to six-week follow-up in two or more ORS domains.

The results of visual analysis indicated that parents with lower baseline levels of wellbeing experienced the greatest improvements, while the parents with higher levels of wellbeing at baseline demonstrated less improvement over the course of the intervention. These findings suggest that this intervention is most effective for parents with clinically low levels of wellbeing at baseline. This study provides preliminary evidence to indicate the effectiveness of an online, parent-facilitated MP programme as a successful intervention for distress and wellbeing in parents of autistic adolescents. Approximately 50% of parents in the current study demonstrated improvement with intervention effect from baseline to follow-up in each of the ORS domains. As the ORS has been shown to effectively demonstrate intervention effect (Miller et al., 2003), these results indicate the preliminary effectiveness of this intervention for improving wellbeing in this population. While these results are variable, as no previous studies have examined intervention effect on wellbeing directly in this manner, this study provides a foundation for future research in this domain.

Parenting Stress

Five parents demonstrated improvements in parenting stress (Sarah, Lisa, Amy, Kim, and Molly) as measured by the PSI-SF subscale, while two parents demonstrated worsening parenting stress (Julie and Anna). However, Anna's worsening parenting stress was not clinically significant. Neither parent reported any events that may have contributed to this increase in parenting stress, however, Julie's increased parenting stress coincided with an increase in adolescent externalising behaviour challenges as indicated by the CBCL. Increased externalising behaviour in young people has been shown to be associated with increased parenting stress (Bonis, 2016; Ooi et al., 2016), providing a possible reason for increased stress for this parent. Visual analysis indicated that parents with higher baseline levels of parenting stress experienced the greatest improvements, while the parents with lower levels of parenting stress at baseline demonstrated less improvement over the course of the intervention. These findings suggest that this intervention is most effective for parents with clinically high levels of parenting stress prior to intervention.

The findings related to participants' parenting stress are partially consistent with findings of previous studies implementing MP programmes as in Bögels et al. (2014) and Emerson et al.

(2019), who found significant reductions in parenting stress at 8-weeks and 1-year follow-up respectively. The use of quasi-experimental designs and larger sample sizes in Emerson et al. (2019) and Bögels et al. (2014) allow for the generalisability of results to the larger population. While the use of a single case design in the current study may limit generalisability, this method ensured the stability of parenting stress prior to intervention could be determined, allowing for direct observation of the changes occurring as the intervention was introduced. Subsequently, the current results demonstrate that for six of the seven parents, an immediate downward trend in parenting stress is observed at the beginning of the intervention phase, indicating improvement beginning with the introduction of the intervention. The lack of a baseline or control period in Emerson et al. (2019) makes it difficult to determine the stability of parenting stress prior to the intervention, and therefore reducing the strength of conclusions made about the impact of the intervention on parenting stress. The current study adds to the previous research by demonstrating the immediate improvement effect of the MP programme on parenting stress. The results of the current study add to existing research by confirming that MP interventions reduce parenting stress in parents of autistic adolescents as well as children as demonstrated in previous studies.

The results of the current study also indicated similar effects on parenting stress compared to previous MBI studies. Past research has identified significant reductions in PSI-SF scores at post-intervention (Dykens et al., 2014; Ferraioli & Harris, 2013), and at six-month follow-up (Dykens et al., 2014). While parents in Ferraioli & Harris (2013) displayed greater improvement in parenting stress immediately post-intervention compared to three-month follow-up, parents in the current study demonstrated significant improvement in parenting stress at six-week follow-up. Although the follow-up period for the current study was shorter, this provides preliminary evidence for the positive long-term effects of this programme on parenting stress in this population. However, it cannot be assumed that an increased follow-up period would yield maintained improvements, limiting the conclusions that can be drawn.

The population used in Dykens et al. (2014) included parents of children and adults with unspecified developmental disabilities (35%), as well as parents of autistic children and adults (65%). As parents of autistic young people have been shown to experience higher levels of parenting stress than parents of children with other developmental difficulties (Craig et al., 2016; Estes et al., 2009), it is possible that the parenting stress of parents of autistic was qualitatively different to that of the other parents in the sample. This may have impacted to what extent parents of different children responded to the intervention. As the sample was not solely parents of autistic young people, this may have impacted the generalisability of these results to parents of autistic young people. In addition, the broad age range (2 – 54 years) of children and adults in Dykens et al. (2014) does not provide specific data for parents of autistic adolescents. Subsequently, the results of the current study add to the literature by providing specific data related to parents of autistic young people, in particular, autistic adolescents.

Parents who attended fewer group sessions and parents who practised less than twice a week still demonstrated improvements in parenting stress following the MP programme. It is noteworthy that parents' with low group session attendance reported higher frequency of weekly practice and vice versa. Parents who practised only 1-2 times a week (Kim and Lisa) attended two and three group sessions respectively and still demonstrated significant improvements in parenting stress with an intervention effect. Similarly, the three parents who only attended one of the four group sessions (Sarah, Molly, and Anna) reported practising more than three times a week and demonstrated improvements in parenting stress, two with intervention effect (Sarah and Molly). It is possible that the benefits of parents' higher attendance or practice frequency counterbalanced the lost benefits of low attendance or practice frequency. This may indicate that even a small amount of participation in this programme positively impacts this outcome for parents of autistic adolescents, or that changes may be attributable to increased engagement in either group sessions or home practice. The findings related to parenting stress are promising, providing preliminary evidence in support of online MP programmes for parents of autistic adolescents as an effective intervention to reduce parenting stress in this population.

Parental Mental Health

The MP programme in the current study was found to positively impact some dimensions of parents' mental health, although there was a degree of variability observed in these findings. All parents except Anna and Molly demonstrated reductions in depressive symptoms from pre-intervention to six-week follow-up, with three parents demonstrating clinically significant reductions in depressive symptoms from pre-intervention to six-week follow-up. All parents except Anna and Molly demonstrated reductions in anxiety symptoms. Four parents demonstrated clinically significant improvement in anxiety symptoms from pre-intervention to six-week follow-up. In the current study, fewer parents experienced clinically significant improvement in stress symptoms than anxiety and depressive symptoms. All parents except Anna and Molly demonstrated reductions in general stress symptoms. One parent demonstrated clinically significant improvement in stress symptoms from pre-intervention to six-week follow-up, and one parent demonstrated clinically significant improvement in stress symptoms from pre-intervention to post-intervention, but not at six-week follow-up.

Results in this thesis related to parental mental health add to the findings of previous research. In their controlled trial of MP, Salem-Guirgis et al. (2019) also reported changes in parents' DASS-21 subscale scores, indicating no significant decrease in parents' stress subscale scores from 10-weeks pre-intervention to one-week post-intervention, or at 10-week follow-up. The lack of change in parents' stress in Salem-Guirgis et al. (2019) may stem from the intervention design in which both parents and adolescents took part in concurrent 10-session mindfulness programmes, which may have impacted parents' general stress unexpectedly. The current study indicated similar results, with only two parents demonstrating significant improvement in general stress from baseline to post-intervention or six-week follow-up. The MP programme is targeted towards improving parenting stress (Bögels & Resifo, 2013). It is therefore understandable that parents' general stress would remain largely similar to baseline levels, particularly considering the continuing impacts of the Covid-19 pandemic and the rise in living costs in Aotearoa at the time this study took place.

Salem-Guirgis et al. (2019) reported no significant reductions in parents' anxiety or depression subscale scores from baseline to post-intervention, or 10-week follow-up. In contrast, approximately half the parents in the current study displayed clinically significant improvement from baseline to six-week follow-up. While not observed in the majority of participants, this provides preliminary evidence for the positive effect of MP programmes on the mental health of parents of autistic adolescents. As only one other study has evaluated the impacts of an MP programme on parent mental health using the DASS-21, the current study provides new evidence of the specific positive impacts such programmes can have for mental health in parents of autistic adolescents.

Previous studies have used alternate measures to assess changes in parents' mental health following involvement in MP programmes. Parents' internalising difficulties (e.g anxiety, withdrawal, somatic complaints) as measured by the ASR were found to decrease significantly following MP programme participation at 8-week follow-up in Emerson et al. (2019) and 1-year follow-up in Ridderinkhof et al. (2018). The internalising difficulties subscale of the ASR is comparable to the DASS-21 as both assess difficulties related to symptoms associated with anxiety and depression. The findings of the current study do not align with this previous evidence, as although some parents demonstrated clinically significant improvements with intervention effects in mental health during the intervention, approximately half did not. It should be noted, however, that the ASR and DASS-21 are different measures despite their similarities. The ASR is a much broader measure of emotional, social, and behavioural difficulties experienced by adults, while the DASS-21 is specifically designed to assess mental health. In addition, the ASR asks participants to consider their responses based on the past six months (Achenbach & Rescola, 2003), while the DASS-21 uses a one week period of recall (Lovibond & Lovibond, 1995). Therefore, the use of the DASS-21 in the current study may allow for more in-depth analysis of changes in mental health. The use of a single case design along with this measure also ensures that the changes in parents' mental health can be more accurately attributed to the intervention itself through visual analysis. As a result, the current study adds to the previous evidence of this effect with greater detail.

Studies implementing MBPBS interventions identified significant reductions in the mental health of parents of autistic young people. Lunksy et al. (2021) reported significant reductions in parents' DASS-14 (stress and depression) scores following participation in an online delivered, parent-facilitated MP programme. This improvement was maintained at three-month follow-up (Lunsky et al., 2021). The current findings partially support these results, finding similar reductions in parents’ depression scores, but not stress scores. The design and MP programme delivery methods used by Lunsky et al. (2021) were very similar to those implemented in the current study. When comparing these studies, the apparent differences are the older age range of autistic children and adults (16 – 39 years), the use of MBCT, and the additional parent facilitators taking part in Lunksy et al. (2021). It may be that additional parent facilitators provided parents with further support, translating into reduced general stress. Conversely, the findings of the current study and Lunsky et al. (2021) are at odds with those of Salem-Guirgis et al. (2019), in which no significant reductions in anxiety or depression were identified from baseline to post-intervention. Although not reported, it may be that parents in Salem-Guirgis et al. (2019) began with fewer mental health difficulties at baseline, leading to less noticeable improvement following intervention.

The results of the current study provide preliminary evidence for the effectiveness of an online MP intervention for reducing anxiety and depression in parents of autistic adolescents, producing similar results to previous MP studies (Emerson et al., 2019; Ridderinkhof et al., 2018). The findings of the current study suggest that MP programmes do not affect general stress in parents of autistic adolescents, aligning with one previous MP study (Salem-Guirgis et al., 2019). The findings of the current study provide preliminary support for MP programmes' positive impact on mental health in parents of autistic adolescents specifically.

Parental Quality of Life

The MP intervention was found to positively impact parents’ quality of life. All parents’ responses to the WHO-5 in the present study indicated improvements in quality of life from pre-intervention to six-week follow-up, with clinically significant improvements experienced by five of the seven participants. In addition, parents' attendance and frequency of home practice of mindfulness did not appear to correspond with improvements in quality of life. As stated above, it is likely that less home practice or fewer group sessions attended were counterbalanced by higher group session attendance or increased home practice respectively (e.g Lisa practised 1-2 times a week but attended three group sessions).

These results demonstrate greater improvement in quality of life than parents of autistic young people (11-23 years) taking part in a MYmind intervention implemented by de Bruin et al. (2015). Contrary to the present study, parents' responses following the MYmind programme indicated that significant improvements in WHO-5 scores post-intervention were not maintained at nine-week follow-up (de Bruin et al., 2015). The MYmind programme measured follow-up outcomes three weeks later than in the present study. Although it is unknown if these improvements would have been maintained at a later follow-up period, the trajectory of parents' WHO-5 scores indicated positive change. However, as in other studies, it is possible that reduced effects on quality of life would be observed as follow-up periods increase. Although the parent programme used in this previous study was based on the same Bögels & Restifo (2013) format as the present study, the MYmind programme included a concurrent mindfulness intervention for the adolescents with a larger age range than the current study (11 – 23 years). The MP intervention alone in the current study produced improvements in parents' quality of life, while the intervention for both parents and adolescents in de Bruin et al. (2015) did not produce maintained improvements in parents' quality of life. As a result, this indicates preliminary evidence of the positive impact of an MP programme for parental quality of life. As very few studies have explored this outcome, this finding provides new evidence to support this intervention as an effective method of improving parental quality of life. As improvements in quality of life have wide-reaching positive impacts on parent wellbeing (Cappe et al., 2011), the effects of the current intervention on this outcome have promising implications for future use with parents of autistic adolescents who typically have low quality of life (Vasilopoulou & Nisbet, 2016).

Mindful Parenting

Mixed findings were observed in parents' changes in mindful parenting over the programme. Five of the seven parents demonstrated reliable improvement in mindful parenting from pre-intervention to six-week follow-up. Two parents (Kim and Molly) demonstrated a decrease in mindful parenting, although this did not indicate reliable deterioration. One of the two parents who demonstrated reduced mindful parenting (Kim) had experienced a mental health crisis at the same time, a factor which may have impacted her responses to parenting situations. It is unknown why Molly's mindful parenting decreased, although these changes were very small. Both Kim and Molly demonstrated the least improvement in wellbeing and parenting stress, which has been shown to negatively correspond with mindful parenting (Duncan et al., 2009), a factor that may account for the decrease in these parents' mindful parenting.

The improvements observed in parents' ability to parent mindfully are similar to that of other studies implementing MP programmes with parents of autistic young people. Parents of autistic young people demonstrated significant improvements in mindful parenting at varying follow-up lengths (8 weeks - 1 year) (de Bruin et al., 2015; Emerson et al., 2019; Ridderinkhof et al., 2018; Salem-Guirgis et al., 2019). While two parents did show reduced mindful parenting, these changes were small and explained by extraneous circumstances. The majority of parents demonstrated reliable, maintained improvements in mindful parenting. This indicates that the MP programme in the current study had some effect on participants' mindful parenting, although the impact on mindful parenting may be determined by the changes in parenting stress experienced.

Parenting Behaviour

Some improvement in participants' parenting behaviour was observed, although mixed results were found. From pre-intervention to six-week follow-up, four parents demonstrated improvement in positive parenting, three of whom demonstrated reliable improvement. Two parents demonstrated deterioration in positive parenting and one parent showed no changes in positive parenting. Both Julie and Sarah who demonstrated decreased positive parenting also reported increases in their adolescents' challenging externalising behaviour, which corresponded with their decreases in positive parenting. Increased externalising behaviour in young people has been shown to be associated with reduced positive parenting behaviour as measured by the PBS-A (Van Leeuwen & Vermulst, 2004) suggesting that increased positive parenting contributes to fewer child externalising behaviour difficulties.

Three parents demonstrated some improvement in teaching appropriate behaviour (Sarah, Lisa, and Kim), two parents demonstrated deterioration in teaching appropriate behaviour (Julie and Amy), and the remaining parents showed no change in teaching appropriate behaviour. The deterioration demonstrated by Julie in this domain may have been due to the increase in her adolescents' externalising behaviour, as this has been shown to be associated with reduced time spent teaching appropriate behaviour to one's child (Van Leeuwen & Vermulst, 2004). This aligns with previous studies of MP interventions with parents of neurotypical young people, which has demonstrated an association between MP interventions and appropriate discipline and teaching of behaviour (Shorey & Ng, 2021). Amy experienced a worsening in her adolescent's mental health and general functioning at this time which may also account for this decrease.

Previous MP studies have used similar measures to assess changes in parenting behaviour. Parents in Bögels et al., (2014) demonstrated significant improvement in adaptive parenting behaviours such as acceptance and reductions in harmful parenting behaviours such as overprotection and rejection. The current findings do not align with this previous research, as while improvements in adaptive parenting behaviours such as positive parenting were observed in half of the parents, this was not consistent across participants. It may be that the parents in the current study began the intervention with high levels of adaptive parenting behaviours compared to the sample in Bögels et al. (2014), therefore limiting the degree of improvement observed. This cannot be ascertained, however, as this data is unavailable for Bögels et al. (2014). This difference may also be due to the longer eight-session MP programme implemented by Bögels et al. (2014), providing parents with additional learning and support, thereby increasing adaptive parenting behaviours. As there are currently no other MP studies that have used the PBS-A to assess changes in parenting behaviour following engagement in an MP programme, the results provide some preliminary insight into the mixed effects of the MP programme on parenting behaviour in parents of autistic adolescents.

Qualitative analysis of follow-up interviews with parents six-weeks following the intervention partially aligned with the quantitative findings of this study. Although some parents did not demonstrate improvement in some outcomes, all parents reported experiencing improvements in parenting stress, mental health, and wellbeing in qualitative interviews. All parents reported experiencing positive changes in their parenting, stress, and general wellbeing, demonstrating the positive impact of the MP programme for these parents. Parents may have reported more positive outcomes in the interviews than were reflected in outcome measures as a result of social desirability bias. Alternatively, this may be due to differences in parents' perspectives of improvement compared to improvement quantified by the outcome measures.

Effects of an Online MP Programme on Challenging Behaviour in Autistic Adolescents

The CBCL was used to assess changes in adolescents' internalising, externalising, and total difficulties. RCI and clinical significance calculations indicated that approximately half the parents (Sarah, Lisa and Molly) in the present study reported clinically significant improvement in their adolescents' internalising difficulties from pre-intervention to post-intervention, while only Molly's responses indicated maintenance of this improvement at six-week follow-up. Approximately half the parents (Julie, Sarah, Lisa, and Anna) reported deterioration in their adolescents' internalising difficulties from pre-intervention to six-week follow-up, with two parents' responses demonstrating clinically significant deterioration (Julie and Anna). From pre-intervention to six-week follow-up only Amy's responses indicated reliable improvement, and only Molly's responses demonstrated clinically significant improvement. Parents' responses indicated mixed changes in adolescent externalising difficulties. It was hypothesised that this would be the subscale that would demonstrate the most improvement across parents as mindful parenting has been shown to impact child externalising difficulties. However, only two parents' responses demonstrated improvement in adolescent externalising difficulties, while the remaining parents either reported no change or a worsening of adolescent externalising difficulties. Parents' CBCL responses also corresponded with their perceptions of changes in child behaviour in the follow-up interviews. Only two parents noted changes in externalising behaviour, such as attention difficulties or rule-breaking behaviour. Of the seven participants, three parents' responses indicated improvement in CBCL total difficulties, while three parents' responses indicated deterioration in their child's total difficulties.

These results differ from previous studies implementing MP programmes with parents of autistic young people aged 2-21 years (Bögels et al., 2014) and 1.5-18 years (Emerson et al., 2019). Both studies reported significant reductions in child internalising and externalising difficulties at post-intervention and eight-week follow-up (Bögels et al., 2014; Emerson et al., 2019). Although the MP programmes implemented in these studies were similar to that of the current study, differing study designs were used and target populations were reported. As no age comparison was used in these previous studies to ascertain if children or adolescents demonstrated differing changes in behaviour (Bögels et al., 2014; Emerson et al., 2019), the current study provides evidence specific to autistic adolescents. Consequently, this study adds to previous research demonstrating that an MP programme has similar effects for parents of children as parents of adolescents, providing evidence for future use with this population. Furthermore, only a quarter of the young people in one study had an autism diagnosis, while other young people had other diagnoses such as ADHD (Emerson et al., 2019). Therefore, the current study may be more representative of the impact of an MP programme on autistic adolescent behaviour due to the nature of the sample population.

Similarly to the findings of Bögels et al. (2014) and Emerson et al. (2019), parents of autistic children (4-6 years) taking part in a 12-session MP intervention conducted by Singh et al. (2006) reported significant reductions in aggressive, non-compliant, and self-injurious behaviours from baseline to 1-year follow-up. This study used a single case design, as in the current study, although the MP intervention used was delivered to parents individually for a longer period of time, as opposed to in a group setting over six weeks in the current study. The longer, more intensive delivery of the intervention may have allowed for greater specification to each parent, contributing to the positive impacts on child behaviour reported by parents in Singh et al. (2006). While the results from this previous study demonstrate positive effects on child behaviour, this is a time and resource-consuming method of delivery as opposed to a group setting in which the intervention is delivered to multiple parents at one time. It is possible that a longer group MP programme may result in greater improvement in parent-reported adolescent behaviour as in previous studies (Bögels et al., 2014; Emerson et al., 2019; Singh et al., 2006).

Previous research has found that the mindful parenting techniques taught in MP programmes are associated with reduced parenting stress, helpful coping in stressful situations, and subsequent reductions in challenging child behaviour in autistic young people (Duncan et al., 2009). Despite parents in the current study reporting greater mindful parenting, reduced stress, and improved wellbeing, little improvement in adolescent behaviour was observed. These differing findings may be the result of the different age groups of children in these studies and the current study. Autistic children experience qualitatively different challenges to autistic adolescents (McGovern & Sigman, 2005), which may be more receptive to mindful parenting interventions. In addition, the use of longer delivery (Bögels et al., 2014; Emerson et al., 2019) and intensive one-on-one training (Singh et al., 2006) may have allowed parents in these previous studies to learn more material or have access to more tailored support, contributing to greater improvements in adolescent behaviour.

Feasibility of an Online MP programme for Parents of Autistic Adolescents

In this study, data pertaining to the feasibility and acceptability of the programme were gathered using an evaluation survey and a semi-structured interview with participating parents. The evaluation survey asked parents to rate different components of the programme, perceived helpfulness, changes experienced, and rates of home practice. During interviews, parents were asked about their experience of the programme itself, and about any changes they had observed since taking part.

Feasibility

The feasibility of the online MP programme was assessed using participant adherence, attendance at group Zoom sessions, and retention of participants. An enrolment rate of 38% was identified, a result comparable to previous parenting programmes (Finan et al., 2018). Only one parent dropped out of the current study following enrolment, producing a high retention rate of 87.5%. Comparable retention rates were identified by the current study and in previous face-to-face interventions conducted by Bögels et al. (2014) (98%), de Bruin et al. (2015) (83.3%), and Ridderinkhof et al., (2018) (84%). This suggests that the online delivery format of the MP programme in the current study did not negatively impact retention rates as similar rates have been found in face-to-face MP studies (Bögels et al., 2014; de Bruin et al., 2015; Ridderinkhof et al., 2018). This may have been due to the ease of accessing the programme without needing to travel, source childcare, or other barriers noted by parents in in-person parenting programmes (Roberts & Neece, 2015; Siebelink et al., 2021). Notably, the retention rate in the present study was greater than that reported by Lunsky et al. (2021) (54% completed the post-intervention measures) who implemented an online, parent-cofacilitated MBCT intervention. This difference may have been due to the different programmes used. While both studies both implemented online, parent-facilitated interventions, the current study used an MP programme with an introductory group Zoom session before the programme began. The use of an introductory online group session was noted by Lunsky et al. (2021) as a possible method of increasing participant retention in future studies. This may have been a factor that ensured high retention in the current study.

Six parents reported practising mindfulness at home three or more times a week, and three parents reported practising five or more times per week, compared to the recommended practice frequency of five times per week. Similar results were reported by Bögels et al., (2014) in which most parents reported practising between one and four times a week. This shared finding indicates that this needs to be addressed in future MP studies. It is unclear if home practice or group session attendance was associated with parent and adolescent outcomes as parents with varying attendance and adherence had different outcomes with no discernable pattern. Parent attendance of group sessions in the current study was (50%), partially impacted by child and family sickness. While this was lower than attendance rates reported by previous studies implementing face-to-face MP interventions with parents of autistic young people (87 – 91.3%) (de Bruin et al., 2015; Salem-Guirgis et al., 2019), it is comparable to attendance rates of other parenting programmes (Finan et al., 2018). Lower levels of attendance did not appear to correspond with higher levels of stress at baseline, increased depression, anxiety or stress symptoms, lower wellbeing, or adolescent challenging behaviour. Reasons for missed sessions included adolescent and parent sickness, and anxiety. The literature highlights that numerous factors can impact participant attendance at parenting interventions, particularly limited self-belief, and poor health (Whittaker & Cowley, 2012). To address this in future, facilitators of MP programmes could speak privately with parents prior to the programme about any worries they may have about the group sessions, putting strategies in place to increase attendance. The low attendance of the current study impacts the conclusions able to be drawn as it is unknown if the attendance at group sessions produced the outcomes observed.

A novel element of the current study was the inclusion of a parent facilitator of the programme who herself had an autistic adolescent. This component was positively experienced by both the parents and the parent facilitator. Parents did not report any difficulties with any elements of the technology used, indicating the feasibility of this delivery format. The retention rate in the current study (87.5%) was higher than those reported by Flynn et al. (2020) (80%), Dykens et al. (2014) (83%), and Lunsky et al. (2021) (54%). The key differences between the current study and previous studies were that a different programme of MP was used as opposed to MBIs, a smaller group size was used, and one trained parent-facilitator alone delivered the intervention as opposed to two. This may suggest that one parent facilitator with a smaller group is able to better connect with the group. Although there is no literature currently exploring this, it is possible that a smaller, more intimate group size leads to increased connection and identification with the group facilitator. However, this should be explored further in future research.

The parent facilitator in the current study did not report any adverse effects as a result of her involvement in the MP programme. Similarly to previous studies, she did report that facilitating the programme could, at times, elicit previous emotional memories of her own experiences, but that this was a learning opportunity as opposed to an adverse effect of the programme. This was also observed by Thomson et al. (2015), in which it was identified that the empathy and personal connection of parent facilitators strengthened their practice and own experiences of the programme.

The online, parent-facilitated MP programme in this study produced mixed findings with regard to feasibility. While this study demonstrated a high retention rate and feasibility of a parent facilitator, low attendance and home practice rates were also observed. While the positive reception of the parent facilitator by parents and the high retention rate are promising findings for future replications of this programme, the low attendance and adherence to practice do not support the feasibility of this method of delivery. As this is the first known study to examine the feasibility of an online, parent-facilitated MP programme, the preliminary evidence gathered from this study can inform future replications and address the limitations reported presently.

Acceptability

Overall results suggest that the online, parent-facilitated MP programme was acceptable to all parents taking part, with some suggestions for future implementation. Acceptability was assessed using the evaluation survey and qualitative interviews. Parents were asked to respond to questions about areas of their life in the evaluation survey, reporting positive change, some positive change, no change, or negative change.

All seven parents reported feeling they had gained something of lasting value from taking part in the programme and intended to keep practising mindfulness. Over 90% of parents' responses to the evaluation survey indicated some positive or positive change had been experienced. This was further supported by the information parents provided in the follow-up interviews. This illustrated more positive feedback than that identified by the evaluation survey by Bögels et al. (2014). This finding indicates that the online and parent-facilitated adaptation of the MP programme used in the current study did not impact acceptability, as parents' reported high value of the programme and intentions for continued practice as observed in face-to-face delivery (Bögels et al., 2014).

The evaluation survey and qualitative interviews with parents following the MP programme highlighted parents' largely positive perceptions and experiences of the MP programme. The qualitative interviews with five of the parent participants provided valuable insight into the useful components of the programme, skills developed, changes observed, and the experiences of parents overall. Parents' responses to the evaluation survey indicated that the most beneficial components of the MP programme were the 3-minute breathing space, mindful awareness in daily parenting, and sitting meditation at home. This sentiment was echoed in the qualitative interviews, as parents noted that these elements were the easiest to incorporate into their busy daily lives. Similarly, parents in Bögels et al. (2014), rated awareness in daily parenting and sitting meditation at home as the most useful components.

All parents described enjoying the MP programme, providing overwhelmingly positive feedback for the content, parent facilitator, and programme as a whole. Although one parent reported frustration with the content of the workbook, she reported being satisfied with the programme as a whole. As in other studies of MP programmes, parents described the positive experiences of the group sessions. The unity and validation provided by shared parenting experiences were palpable in all parent interviews. This may have contributed to the increase in social wellbeing noted in some participants. As it is reported in the literature that parents of autistic young people often feel socially isolated from their peers (Nealy et al., 2012), the positive impacts on parents' connections with others following the intervention are notable. However, it was also noted by one parent that the time of 7 pm for the group Zoom sessions was too late in the evening. Two parents also reported that the low attendance at group Zoom sessions detracted from their experience of the group.

In interviews, parents also reported increases in mindful parenting skills including pausing before reacting, awareness of self and child, and acceptance. The content of the interviews suggested that the majority of parents interviewed had experienced increased self-regulation in stressful parenting situations, a skill that has been theorised to correspond with increased tolerance and lower reactivity in stressful parenting situations (Duncan et al., 2009). Parents reported spending more time with their adolescents and more positive interactions between them. As adolescence can be a particularly challenging period for autistic young people (Cresswell et al., 2019; DePape & Lindsay, 2016), the increased connection between parent and adolescent allows for effective support during this time (Duncan et al., 2009; Stafford et al., 2015).

Parents' responses to the evaluation survey and qualitative interviews indicated the acceptability of the parent-facilitation component of the MP programme. Thematic analysis of the qualitative interviews revealed that parents felt the parent facilitator provided valuable insight and a shared perspective of parenting an autistic young person. Additionally, parents noted a sense of authenticity from a peer, feeling as though a parent without an autistic child as a facilitator would not have understood their experiences. The findings related to parents' acceptability of the current study align with previous research exploring the acceptability of a parent or peer facilitator in parenting programmes. The wider literature indicates that the involvement of a peer facilitator role in programmes for parents increases participants' trust in the facilitator, and increases the perceived credibility of the facilitator (Mytton et al., 2014; Thomson et al., 2015). This subsequently improves parent involvement and a sense of shared identity towards the facilitator (Mytton et al., 2014; Thomson et al., 2015). Parents in the current study reported these perceptions of increased facilitator credibility and shared experiences, although it was not assessed if this increased parent involvement in the study.

Parents' responses in interviews also demonstrated preliminary acceptability of the online delivery element of the MP programme. All five parents interviewed noted that the website and the online resources it provided were helpful and easy to use, with particular emphasis on the videos and audio recordings. Some barriers were identified that impacted parents' experiences of the online delivery of the MP programme. One parent reported anxiety about being on Zoom in a group setting, a common barrier reported by other parenting programmes in the literature (Mytton et al., 2014).

Strengths and Limitations

The single case design used in the present study poses both strengths and limitations. ABA designs have the benefit of clearly demonstrating the impact of interventions, by comparing a baseline phase, intervention phase, and follow-up phase with one another directly (Dallery & Raiff, 2014). As a result, the ongoing influence of the intervention can be examined, providing a broader picture of the effectiveness of the intervention (Lillie et al., 2011). As the current study aimed to assess an adapted intervention, the single-case experimental design allows greater depth of information related to participant outcomes (Rassafiani & Sahaf, 2010). Consequently, this study was able to gather evidence related to the effectiveness of an online, parent-facilitated version of an MP programme for parents of autistic young people. Conversely, it can be difficult to generalise the results of single-case design studies to the rest of the population (Evers & Wu, 2006). While the results of this study indicate the preliminary effectiveness and feasibility of the intervention for the seven participating parents, further replications of this research are required before generalisation to other parents of autistic adolescents can be made. It is important to acknowledge that the parents who signed up for this form of study may have been more motivated or had lower stress than parents who did not sign up for this study, impacting generalisability.

The low dropout rate in this study acts as a strength, allowing the collection of sufficient data and further indicating the acceptability of the MP programme. This is also a strength when considering the small sample size of this study, as much more data was provided by the retention of the majority of participants. It is important to note, however, that 19.3% of data were missing across repeated and weekly measures. Of particular significance is that the stability of outcome measures at baseline was unable to be ascertained in Anna's case due to missing data. Only two baseline data points were available for Anna, as opposed to the typically expected three baseline data points. As a result, it could not be established if Anna's single case outcome measures were stable at baseline, impacting the internal validity of her data (Rassafiani & Sahaf, 2010). As a result, it is difficult to draw conclusions about treatment effects for this parent. In addition, one weekly single case data point was missing for two parents (Lisa and Anna), and two weekly single case data points were missing for one parent (Molly). Despite this, trends in the data were still able to be identified, although with less certainty.

Inconsistent evidence of treatment effects was identified for some outcomes. Aside from consistent improvements in quality of life observed across all seven parents, parent outcomes in distress, wellbeing, parenting stress, mindful parenting, and parenting behaviours were mixed. As some of the results between parents differ, generalising the results to other parents of autistic adolescents should be done with caution. Additionally, no fathers were included in this study, making it difficult to generalise the results to all parents. Previous research has demonstrated that there are qualitative differences between parenting stress in mothers and fathers of autistic young people (Bonis et al., 2016). Therefore, fathers may respond differently to the intervention used in this study.

There are some possible limitations associated with the measures used in the current study. It is possible that the self-report measures used in this study may have been impacted by social desirability bias. Two parents noted in follow-up interviews that they were conscious that their survey answers would be seen and evaluated by researchers. This may have impacted their answers to surveys, creating biased and inaccurate results. In the interviews themselves, it is possible that parents' answers were also influenced by social desirability bias, impacting the accuracy of the interview data in relation to their experience.

As no comparison was made between the MP programme and another, alternative parenting or mindfulness-based intervention, it is difficult to draw conclusions about the effectiveness of the current intervention compared to others. As a result, it cannot be concluded how this intervention format and delivery is effective in comparison to face-to-face or other intervention formats. The lack of a longer follow-up period such as 6 months to a year also prevents conclusions about long-term effectiveness from being drawn.

Future Directions

The findings of the current study present opportunities for new directions in this field of research. The effectiveness of the intervention implemented lends support for future exploration of online, parent-facilitated delivery of MP interventions and MBIs for parents of autistic adolescents. The findings demonstrated preliminary evidence that this length of MP intervention can be effective with parents of autistic adolescents.

A consideration for future studies implementing MP programmes is the inclusion of a session or component teaching parents mindfulness skills to impart to their adolescents. This was noted by multiple parents in the present study as something that would be valuable for connection with their autistic adolescent, as well as an opportunity to teach new skills for stressful situations for their autistic adolescents. A similar note was made by parents in Lunsky et al. (2021), suggesting that this is an element parents would value. This may also have a positive impact on adolescents' challenging externalising behaviour. As opposed to the MYmind intervention in which parents and young people both take part in separate sessions of intervention, parents in the current study suggested a session be added teaching parents how to work through mindfulness exercises with their adolescents.

Future randomised control trials comparing the impacts of online MP interventions with face-to-face MP interventions or alternative MBIs would provide further insight into the efficacy of this intervention compared to others. Further single-case design studies would also be beneficial to replicate the design and format of this study in order to determine if similar results would be produced. In future replications, it would be helpful to increase the enrolment of fathers in the programme. Previous evidence suggests that methods to increase recruitment of fathers to parenting programmes include targeted advertisement to fathers and word-of-mouth recruitment (Stahlschmidt et al., 2013). As well as providing a more representative sample of the population for the purposes of generalisability, the inclusion of fathers avoids the reinforcement of gender roles in parenting as mothers are typically seen as the main carer of children (Mahalik et al., 2005), and creates opportunities for better relationships between father and adolescent (Stahlschmidt et al., 2013).

Two of the key issues impacting feasibility in the current study were the low levels of parent practice at home and low attendance at group Zoom sessions. Targeting these aspects in future research would be beneficial for parent outcomes. The literature indicates that possible methods of increasing attendance in parenting programmes include check-in phone calls from the group facilitator (Whittaker & Cowley, 2012). This provides parents with support between group sessions and an opportunity to discuss successes and challenges (Whittaker & Cowley, 2012). Koha or incentives given to parents based on attendance to group Zoom sessions may also increase attendance in future reiterations of this programme (Whittaker & Cowley, 2012). As previous MBI studies indicate that increased home practice has been associated with positive outcomes (Parsons et al., 2017), this should be addressed in future research. Increased emphasis on the benefits of home practice and focusing on building parent self-efficacy through the parent facilitator are possible methods that may increase home practice for future parent participants (Masheder et al., 2020).

Clinical Implications

Parents of autistic adolescents face a myriad of unique challenges (Bonis, 2016; DePape & Lindsay, 2015; Woodgate et al., 2008), yet receive reduced support for themselves and their adolescents compared to autistic children (Cidav et al., 2013; Friedman et al., 2013; Ludlow et al., 2011; Tehee et al., 2009). Previous studies have demonstrated the efficacy of mindfulness-based interventions for parents of autistic young people (Bögels et al., 2014; de Bruin et al., 2015; Emerson et al., 2019; Ridderinkhof et al., 2018), yet this research is still in its early stages of development and does not yet paint a full picture of the effect or suitability of these interventions for this population due to conflicting findings in different studies. However, the current study provides further support for the use of Mindful Parenting programmes for parents of autistic adolescents as an intervention to improve parenting stress, distress, and wellbeing. The mixed methods utilised in this study provide a depth of evidence supporting an online, parent-facilitated Mindful Parenting programme, as told by the participants themselves. The single case data indicated that the intervention was most beneficial for parents with lower levels of wellbeing and higher levels of parenting stress at baseline.

The findings from parent interviews and the evaluation survey suggest that online delivery is a feasible, acceptable platform of delivery for parents, providing a more accessible, affordable option for parents that may not otherwise receive the support they seek. Parents from across Aotearoa took part in the MP programme. Consequently, the feasibility findings from the current study indicate that parents who may not have access to appropriate interventions in their area would be able to have access to the MP programme through online delivery. Parents' appreciation of the flexibility offered by the online intervention suggests that this delivery may be helpful for parents with busy lives. Low-income families and families living outside of the main centres would benefit, as the costs and distance of travel are eliminated through the online delivery of this programme. As a result, this form of delivery would act as a more equitable support service for those families who may have been unable to access this previously. It is important to acknowledge, however, that this method of delivery may still pose some financial barriers for low-income families due to the cost of the internet and devices such as computers.

Conclusion

The current study provides some evidence to support the use of an online, parent-facilitated Mindful Parenting programme with parents of autistic adolescents (12 – 18 years). Seven parents took part in a six-week, adapted MP programme from the established programme developed by Bögels & Restifo (2013), involving four Zoom group sessions with a parent facilitator supported by online resources and home practice. Following the intervention, parents demonstrated reduced parenting stress, distress, and improved quality of life, much of which was maintained at six-week follow-up. Fewer improvements were observed in adolescent behaviour. Qualitative interviews provided further support for this intervention and delivery method, providing insight into the unique experiences of parents of autistic adolescents and the positive changes they experienced. This new adaptation of the MP programme was found to be acceptable and feasible for parents in the study, providing support for further exploration of such methods of intervention delivery for parents of autistic adolescents

References

Abidin, R. R. (2012). Parenting Stress Index (PSI) Professional Manual (4th ed.). Lutz, FL: PAR Inc.

Achenbach, T.M., & Rescorla, L.A. (2001). Manual for the ASEBA School‑Age Forms & Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.

Achenbach, T. M., & Rescola, L. A. (2003). Manual for the ASEBA adult forms & profiles. Burlington: University of Vermont, Research Center for Children, Youth, & Families.

Allison, C., Ph.D, Auyeung, B., Ph.D, & Baron-Cohen, S., Ph.D. (2012). Toward brief "Red flags" for autism screening: The short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(2), 202-212.e7. https://doi.org/10.1016/j.jaac.2011.11.003

Altiere, M. J., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual & Developmental Disability, 34*(2), 142-152. https://doi.org/10.1080/13668250902845202

Altmaier, E., & Maloney, R. (2007). An initial evaluation of a mindful parenting programme. Journal of Clinical Psychology, 63, 1231–1238.

American Psychiatric Association, & American Psychiatric Association. DSM-5 Task Force. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th;Fifth; ed.). American Psychiatric Association. ProQuest Ebook Central, https://ebookcentral.proquest.com/lib/canterbury/detail.action?docID=1811753

Amundson, R. (2000). Against normal function. *Studies in History and Philosophy of Science. Part C, Studies in History and Philosophy of Biological and Biomedical Sciences, 31*(1), 33-53. https://doi.org/10.1016/S1369-8486(99)00033-3

Anastasiou, D., & Kauffman, J. M. (2013). The social model of disability: Dichotomy between impairment and disability. *The Journal of Medicine and Philosophy, 38*(4), 441-459. https://doi.org/10.1093/jmp/jht026

Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics (Evanston), 141*(Suppl 4), S300-S305. https://doi.org/10.1542/peds.2016-4300G

Anderson-Chavarria, M. (2022;2021;). The autism predicament: Models of autism and their impact on autistic identity. *Disability & Society, 37*(8), 1321-1341. https://doi.org/10.1080/09687599.2021.1877117

Andreou, M., & Skrimpa, V. (2020). Theory of mind deficits and neurophysiological operations in autism spectrum disorders: A review. *Brain Sciences, 10*(6), 393. https://doi.org/10.3390/brainsci10060393

Andrews, J. L., Ahmed, S. P., & Blakemore, S. (2021). Navigating the social environment in adolescence: The role of social brain development. *Biological Psychiatry (1969), 89*(2), 109-118. https://doi.org/10.1016/j.biopsych.2020.09.012

Antshel, K. M., Polacek, C., McMahon, M., Dygert, K., Spenceley, L., Dygert, L., Miller, L., & Faisal, F. (2011). Comorbid ADHD and anxiety affect social skills group intervention treatment efficacy in children with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 32*(6), 439-446. https://doi.org/10.1097/DBP.0b013e318222355d

Aquilino, W. S., & Supple, A. J. (2001). Long-term effects of parenting practices during adolescence on well-being outcomes in young adulthood. *Journal of Family Issues, 22*(3), 289-308. https://doi.org/10.1177/019251301022003002

Ashburner, J., Bennett, L., Rodger, S., & Ziviani, J. (2013). Understanding the sensory experiences of young people with autism spectrum disorder: A preliminary investigation. *Australian Occupational Therapy Journal, 60*(3), 171-180. https://doi.org/10.1111/1440-1630.12025

Aubé, B., Follenfant, A., Goudeau, S., & Derguy, C. (2021;2020;). Public stigma of autism spectrum disorder at school: Implicit attitudes matter. *Journal of autism and*

Developmental Disorders, 51(5), 1584-1597. https://doi.org/10.1007/s10803-020-04635-9

Austriaco, K., Aban, I., Willig, J., & Kong, M. (2019). Contemporary trainee knowledge of autism: How prepared are our future providers? *Frontiers in Pediatrics, 7*, 165-165. https://doi.org/10.3389/fped.2019.00165

Autistica (2015). *Your Questions: Shaping Future Autism Research*. Available online at: https://www.autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf

Argumedes, M., Lanovaz, M. J., & Larivée, S. (2018). Brief report: Impact of challenging behavior on parenting stress in mothers and fathers of children with autism spectrum disorders. *Journal of autism and Developmental Disorders, 48*(7), 2585-2589. https://doi.org/10.1007/s10803-018-3513-1

Arnold, D. S., O'Leary, S. G., Wolff, L. S., & Acker, M. M. (1993). The parenting scale: A measure of dysfunctional parenting in discipline situations. *Psychological Assessment, 5*(2), 137-144. https://doi.org/10.1037/1040-3590.5.2.137

Ashburner, J., Bennett, L., Rodger, S., & Ziviani, J. (2013). Understanding the sensory experiences of young people with autism spectrum disorder: A preliminary investigation. *Australian Occupational Therapy Journal, 60*(3), 171-180. https://doi.org/10.1111/1440-1630.12025

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217-230. https://doi.org/10.1046/j.1365-2788.2003.00484.x

Baumrind, D. (1971). Current patterns of parental authority. *Developmental Psychology, 4*(1p2), 1-103. https://doi.org/10.1037/h0030372

Baumrind, D. (1966). Effects of authoritative parental control on child behavior. Child Development, 37, 887-907.

Barroso, N. E., Hungerford, G. M., Garcia, D., Graziano, P. A., & Bagner, D. M. (2016;2015;). Psychometric properties of the parenting stress index-short form (PSI-SF) in a high-risk sample of mothers and their infants. *Psychological Assessment, 28*(10), 1331-1335. https://doi.org/10.1037/pas0000257

Bech. P. Measuring the dimensions of psychological general well-being by the WHO-5. QoL Newsletter 2004; 32; 15-16.

Beer, M., Ward, L., & Moar, K. (2013). The relationship between mindful parenting and distress in parents of children with an autism spectrum disorder. *Mindfulness, 4*(2), 102-112. https://doi.org/10.1007/s12671-012-0192-4

Behbahani, M., Zargar, F., Assarian, F., & Akbari, H. (2018). Effects of mindful parenting training on clinical symptoms in children with attention deficit hyperactivity disorder and parenting stress: Randomized controlled trial. *Iranian Journal of Medical Sciences, 43*(6), 596-604.

Bellini, S. (2004). Social skill deficits and anxiety in high-functioning adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 19*(2), 78-86. https://doi.org/10.1177/10883576040190020201

Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of the self*. Free Press

Bevan-Brown, J. (2013). Including people with disabilities: An indigenous perspective. *International Journal of Inclusive Education, 17*(6), 571-583. https://doi.org/10.1080/13603116.2012.694483

Blakemore, S. (2008). The social brain in adolescence. *Nature Reviews. Neuroscience, 9*(4), 267-277. https://doi.org/10.1038/nrn2353

Bögels, S. M., Hellemans, J., van Deursen, S., Römer, M., & van der Meulen, R. (2014). Mindful parenting in mental health care: Effects on parental and child psychopathology, parental stress, parenting, coparenting, and marital functioning. *Mindfulness, 5*(5), 536-551. https://doi.org/10.1007/s12671-013-0209-7

Bögels, S., & Restifo, K. (2013). *Mindful parenting: A guide for mental health practitioners*. Springer Science & Business Media.

Bohlmeijer, E. T., ten Klooster, P. M., Fledderus, M., Veehof, M. M., & Baer, R. (2011). Psychometric properties of the five facet mindfulness questionnaire in depressed adults and development of a short form. *Assessment (Odessa, Fla.), 18*(3), 308-320. https://doi.org/10.1177/1073191111408231

Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing, 37*(3), 153-163. https://doi.org/10.3109/01612840.2015.1116030

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child : Care, Health & Development, 42*(6), 784-797. https://doi.org/10.1111/cch.12383

Botha, M., Hanlon, J., & Williams, G. L. (2021). Does language matter? identity-first versus person-first language use in autism research: A response to vivanti. *Journal of autism and Developmental Disorders,* , 1-9. https://doi.org/10.1007/s10803-020-04858-w

Boyd, B. A., McDonough, S. G., & Bodfish, J. W. (2012). Evidence-based behavioral interventions for repetitive behaviors in autism. *Journal of Autism and Developmental Disorders, 42*(6), 1236-1248. https://doi.org/10.1007/s10803-011-1284-z

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208-215. https://doi.org/10.1177/10883576020170040301

Brandmeyer, T., Delorme, A., & Wahbeh, H. (2019). The neuroscience of meditation: Classification, phenomenology, correlates, and mechanisms. *Progress in Brain Research, 244*, 1. https://doi.org/10.1016/bs.pbr.2018.10.020

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Grief experiences in family caregivers of children with autism spectrum disorder (ASD). *International Journal of Environmental Research and Public Health, 16*(23), 4821. https://doi.org/10.3390/ijerph16234821

Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E. (2017). Excluded from school: autistic students' experiences of school exclusion and subsequent re-integration into school. *Autism & Developmental Language Impairments, 2*, 239694151773751. https://doi.org/10.1177/2396941517737511

Broady, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: The voice of families with a child on the autism spectrum. *Health & Social Care in the Community, 25*(1), 224-233. https://doi.org/10.1111/hsc.12297

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *autism : The International Journal of Research and Practice, 8*(4), 409-423. https://doi.org/10.1177/1362361304047224

Browning, J., Osborne, L. A., & Reed, P. (2009). A qualitative comparison of perceived stress and coping in adolescents with and without autistic spectrum disorders as they approach leaving school. *British Journal of Special Education, 36*(1), 36-43. https://doi.org/10.1111/j.1467-8578.2008.00400.x

de Bruin, E. I., Zijlstra, B. J. H., Geurtzen, N., Zundert, R. M. P. v., Weijer-Bergsma, E. v. d., Hartman, E. E., Nieuwesteeg, A. M., Duncan, L. G., & Bögels, S. M. (2014). Mindful parenting assessed further: Psychometric properties of the dutch version of the interpersonal mindfulness in parenting scale (IM-P). *Mindfulness, 5*(2), 200-212. https://doi.org/10.1007/s12671-012-0168-4

Buescher, A. V. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the united kingdom and the united states. *JAMA Pediatrics, 168*(8), 721. https://doi.org/10.1001/jamapediatrics.2014.210

Burgdorf, V., Szabó, M., & Abbott, M. J. (2019). The effect of mindfulness interventions for parents on parenting stress and youth psychological outcomes: A systematic review and meta-analysis. *Frontiers in Psychology, 10*, 1336-1336. https://doi.org/10.3389/fpsyg.2019.01336

Cappe, E., Wolff, M., Bobet, R., & Adrien, J. (2011). 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. *Quality of Life Research, 20*(8), 1279-1294. https://doi.org/10.1007/s11136-011-9861-3

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research : Strengthening its practice. *Annual Review of Public Health, 29*(1), 325-350. https://doi.org/10.1146/annurev.publhealth.29.091307.083824

Caruth, G. D., & Amberton University, Garland, Texas USA. (2013). Demystifying mixed methods research design: A review of the literature. *Mevlana International Journal of Education, 3*(2), 112-122. https://doi.org/10.13054/mije.13.35.3.2

Cascio, M. A. (2012). Neurodiversity: Autism pride among mothers of children with autism spectrum disorders. *Intellectual and Developmental Disabilities, 50*(3), 273-283. https://doi.org/10.1352/1934-9556-50.3.273

Cavell, T. A., Harrist, A. W., & Del Vecchio, T. (2013). Working with parents of aggressive children: Ten principles and the role of authoritative parenting. In R. E. Larzelere, A. W. Harrist & A. S. Morris (Eds.), *Authoritative parenting: Synthesizing nurturance and discipline for optimal child development* (pp. 165-188). American Psychological Association. https://doi.org/10.1037/13948-008

Chaplin, T. M., Turpyn, C. C., Fischer, S., Martelli, A. M., Ross, C. E., Leichtweis, R. N., Miller, A. B., & Sinha, R. (2021). Parenting-focused mindfulness intervention reduces stress and improves parenting in highly stressed mothers of adolescents. *Mindfulness, 12*(2), 450-462. https://doi.org/10.1007/s12671-018-1026-9

Cheak-Zamora, N. C., & Teti, M. (2015). “You think it’s hard now … it gets much harder for our children”: Youth with autism and their caregiver’s perspectives of health care transition services. *Autism: The International Journal of Research and Practice, 19*(8), 992-1001. https://doi.org/10.1177/1362361314558279

Chiang, H., & Gau, S. S. (2016). Comorbid psychiatric conditions as mediators to predict later social adjustment in youths with autism spectrum disorder. *Journal of Child Psychology and Psychiatry, 57*(1), 103-111. https://doi.org/10.1111/jcpp.12450

Cidav, Z., Lawer, L., Marcus, S. C., & Mandell, D. S. (2013). Age-related variation in health service use and associated expenditures among children with autism. *Journal of Autism and Developmental Disorders, 43*(4), 924-931. https://doi.org/10.1007/s10803-012-1637-2

Clauser, P., Ding, Y., Chen, E. C., Cho, S., Wang, C., & Hwang, J. (2021). Parenting styles, parenting stress, and behavioral outcomes in children with autism. *School Psychology International, 42*(1), 33-56. https://doi.org/10.1177/0143034320971675

Cleary, M., West, S., & Mclean, L. (2022). From 'refrigerator mothers' to empowered advocates: The evolution of the autism parent. *Issues in Mental Health Nursing, ahead-of-print*(ahead-of-print), 1-7. https://doi.org/10.1080/01612840.2022.2115594

Close, H. A., Lee, L., Kaufmann, C. N., & Zimmerman, A. W. (2012). Co-occurring conditions and change in diagnosis in autism spectrum disorders. *Pediatrics (Evanston), 129*(2), e305-e316. https://doi.org/10.1542/peds.2011-1717

Collis, E., Gavin, J., Russell, A., & Brosnan, M. (2022). Autistic adults’ experience of restricted repetitive behaviours. *Research in Autism Spectrum Disorders, 90*, 101895. https://doi.org/10.1016/j.rasd.2021.101895

Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *Journal of Intellectual Disabilities, 19*(4), 356-366. https://doi.org/10.1177/1744629515577876

Craig, F., Fanizza, I., Russo, L., Lucarelli, E., Alessandro, L., Pasca, M. G., & Trabacca, A. (2017). Social communication in children with autism spectrum disorder (asd): Correlation between DSM‐5 and autism classification system of functioning—social communication (ACSF:SC). *Autism Research, 10*(7), 1249-1258. https://doi.org/10.1002/aur.1772

Craig, F., Operto, F. F., De Giacomo, A., Margari, L., Frolli, A., Conson, M., Ivagnes, S., Monaco, M., & Margari, F. (2016). Parenting stress among parents of children with neurodevelopmental disorders. *Psychiatry Research, 242*, 121-129. https://doi.org/10.1016/j.psychres.2016.05.016

Cresswell, L., Hinch, R., & Cage, E. (2019). The experiences of peer relationships amongst autistic adolescents: A systematic review of the qualitative evidence. *Research in autism Spectrum Disorders, 61*, 45-60. https://doi.org/10.1016/j.rasd.2019.01.003

Crnic, K. A., Gaze, C., & Hoffman, C. (2005). Cumulative parenting stress across the preschool period: Relations to maternal parenting and child behaviour at age 5. *Infant and Child Development, 14;7;*(4;2;), 117-132. https://doi.org/10.1002/icd.384

Cupples, M. E., Stewart, M. C., Percy, A., Hepper, P., Murphy, C. & Halliday, H. L. (2011) A RCT of peer-mentoring for first-time mothers in socially disadvantaged areas (The MOMENTS Study). Archives of Disease in Childhood, 96, 252–258. doi: 10.1136/ adc.2009.167387

Dallery, J., & Raiff, B. R. (2014). Optimizing behavioral health interventions with single-case designs: From development to dissemination. *Translational Behavioral Medicine, 4*(3), 290-303. https://doi.org/10.1007/s13142-014-0258-z

Darling, N., & Steinberg, L. (1993). Parenting style as context: An integrative model. *Psychological Bulletin, 113*(3), 487-496. https://doi.org/10.1037/0033-2909.113.3.487

D'Astous, V., Manthorpe, J., Lowton, K., & Glaser, K. (2016). Retracing the historical social care context of autism: A narrative overview. *The British Journal of Social Work, 46*(3), 789-807. https://doi.org/10.1093/bjsw/bcu131

Davey, L. (2020). Using the special interests of autistic children to facilitate meaningful engagement and learning. *Good Autism Practice, 21*(1), 43-64.

Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology, 20*(3), 775-803. https://doi.org/10.1017/S0954579408000370

Deater-Deckard, K. (1998). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical Psychology (New York, N.Y.), 5*(3), 314-332. https://doi.org/10.1111/j.1468-2850.1998.tb00152.x

de Bruin, E. I., Blom, R., Smit, F. M. A., van Steensel, F. J. A., & Bögels, S. M. (2015). MYmind: Mindfulness training for youngsters with autism spectrum disorders and their parents. *Autism: The International Journal of Research and Practice, 19*(8), 906-914. https://doi.org/10.1177/1362361314553279

den Houting, J. (2019). Neurodiversity: An insider’s perspective. *Autism : The International Journal of Research and Practice, 23*(2), 271-273. https://doi.org/10.1177/1362361318820762

DeFilippis, M. (2018). Depression in children and adolescents with autism spectrum disorder. *Children (Basel), 5*(9), 112. https://doi.org/10.3390/children5090112

DePape, A., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research, 25*(4), 569-583. https://doi.org/10.1177/1049732314552455

DePape, A., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities, 31*(1), 60-71. https://doi.org/10.1177/1088357615587504

De Young, M. (2015). *Encyclopedia of asylum therapeutics, 1750-1950s*. McFarland and Company, Incorporated, Publishers. https://ebookcentral.proquest.com/lib/canterbury/detail.action?docID=1953256

Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Focus On Practice: Living with children diagnosed with autistic spectrum disorder: Parental and professional views. *British Journal of Special Education, 37*(1), 13-23. https://doi.org/10.1111/j.1467-8578.2010.00455.x

Dinishak, J., & Akhtar, N. (2013). A critical examination of mindblindness as a metaphor for autism. *Child Development Perspectives, 7*(2), 110-114. https://doi.org/10.1111/cdep.12026

Djela, M. (2021). Change of autism narrative is required to improve employment of autistic people. *Advances in Autism, 7*(1), 86-100. https://doi.org/10.1108/AIA-11-2019-0041

Doja, A., & Roberts, W. (2006). Immunizations and autism: A review of the literature. *Canadian Journal of Neurological Sciences, 33*(4), 341. https://doi.org/10.1017/S031716710000528X

Dooley, C. (2011). The end of the asylum (town): Community responses to the depopulation and closure of the Saskatchewan hospital, weyburn. *Histoire Sociale, 44*(2), 331-354. https://doi.org/10.1353/his.2011.0015

Dovgan, K., & Mazurek, M. O. (2019). Impact of multiple co‐occurring emotional and behavioural conditions on children with autism and their families. *Journal of Applied Research in Intellectual Disabilities, 32*(4), 967-980. https://doi.org/10.1111/jar.12590

Dreeben, S. J., Mamberg, M. H., & Salmon, P. (2013). The MBSR body scan in clinical practice. *Mindfulness, 4*(4), 394-401. https://doi.org/10.1007/s12671-013-0212-z

Drysdale, H., & van der Meer, L. (2020). Rates of autism spectrum disorder diagnoses for children and adolescents in the hutt valley region of new zealand between 2012 and 2016. *Research in autism Spectrum Disorders, 73*, 101547. https://doi.org/10.1016/j.rasd.2020.101547

Duncan, L.G. (2007). Assessment of mindful parenting among parents of early adolescents: Development and validation of the Interpersonal Mindfulness in Parenting Scale. Unpublished dissertation. The Pennsylvania State University.

Duncan, L. G., Coatsworth, J. D., & Greenberg, M. T. (2009). A model of mindful parenting: Implications for Parent–Child relationships and prevention research. *Clinical Child and Family Psychology Review, 12*(3), 255-270. https://doi.org/10.1007/s10567-009-0046-3

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39-52. https://doi.org/10.1023/A:1026592305436

Durukan, İ., Kara, K., Almbaideen, M., Karaman, D., & Gül, H. (2018). Alexithymia, depression and anxiety in parents of children with neurodevelopmental disorder: Comparative study of autistic disorder, pervasive developmental disorder not otherwise specified and attention deficit–hyperactivity disorder. *Pediatrics International, 60*(3), 247-253. https://doi.org/10.1111/ped.13510

Dutra, L., Campbell, L., & Westen, D. (2004). Quantifying clinical judgment in the assessment of adolescent psychopathology: Reliability, validity, and factor structure of the child behavior checklist for clinician report. *Journal of Clinical Psychology, 4;60;*(4;1;), 65-85. https://doi.org/10.1002/jclp.10234

Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics (Evanston), 134*(2), e454-e463. https://doi.org/10.1542/peds.2013-3164

Eggleston, M. J. F., Thabrew, H., Frampton, C. M. A., Eggleston, K. H. F., & Hennig, S. C. (2019). Obtaining an autism spectrum disorder diagnosis and supports: New zealand parents' experiences. *Research in autism Spectrum Disorders, 62*, 18-25. https://doi.org/10.1016/j.rasd.2019.02.004

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(10), 1274-1284. https://doi.org/10.1007/s10803-010-0986-y

Ekas, N., & Whitman, T. L. (2010). ASD symptom topography and maternal socioemotional functioning. American Journal on Intellectual and Developmental Disabilities, 115, 234–249. doi:10.1352/1944-7558-115.3.234

Emerson, L. M., Aktar, E., de Bruin, E., Potharst, E., & Bögels, S. (2019). Mindful parenting in secondary child mental health: Key parenting predictors of treatment effects. *Mindfulness, 12*(2), 532-542. https://doi.org/10.1007/s12671-019-01176-w

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism: The International Journal of Research and Practice, 13*(4), 375-387. https://doi.org/10.1177/1362361309105658

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., & Munson, J. (2012). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain & Development (Tokyo. 1979), 35*(2), 133-138. https://doi.org/10.1016/j.braindev.2012.10.004

Estes, A., Zwaigenbaum, L., Gu, H., St John, T., Paterson, S., Elison, J. T., Hazlett, H., Botteron, K., Dager, S. R., Schultz, R. T., Kostopoulos, P., Evans, A., Dawson, G., Eliason, J., Alvarez, S., Piven, J., & IBIS network. (2015). Behavioral, cognitive, and adaptive development in infants with autism spectrum disorder in the first 2 years of life. *Journal of Neurodevelopmental Disorders, 7*(1), 7-24. https://doi.org/10.1186/s11689-015-9117-6

Evans, S., Ferrando, S., Findler, M., Stowell, C., Smart, C., & Haglin, D. (2008). Mindfulness-based cognitive therapy for generalized anxiety disorder. *Journal of Anxiety Disorders, 22*(4), 716-721. https://doi.org/10.1016/j.janxdis.2007.07.005

Evers, C. W., & Wu, E. H. (2006). On generalising from single case studies: Epistemological reflections. *Journal of Philosophy of Education, 40*(4), 511-526. https://doi.org/10.1111/j.1467-9752.2006.00519.x

Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders, 44*(12), 3185-3203. https://doi.org/10.1007/s10803-014-2189-4

Feldman, J. I., Cassidy, M., Liu, Y., Kirby, A. V., Wallace, M. T., & Woynaroski, T. G. (2020). Relations between sensory responsiveness and features of autism in children. *Brain Sciences, 10*(11), 1. https://doi.org/10.3390/brainsci10110775

Ferraioli, S. J., & Harris, S. L. (2013). Comparative effects of mindfulness and skills-based parent training programmes for parents of children with autism: Feasibility and preliminary outcome data. *Mindfulness, 4*(2), 89-101. https://doi.org/10.1007/s12671-012-0099-0

Finan, S. J., Swierzbiolek, B., Priest, N., Warren, N., & Yap, M. (2018). Parental engagement in preventive parenting programs for child mental health: A systematic review of predictors and strategies to increase engagement. *PeerJ (San Francisco, CA), 6*, e4676-e4676. https://doi.org/10.7717/peerj.4676

Finch, T. L., Mackintosh, J., Petrou, A., McConachie, H., Le Couteur, A., Garland, D., & Parr, J. R. (2022). "we couldn't think in the box if we tried. we can't even find the damn box": A qualitative study of the lived experiences of autistic adults and relatives of autistic adults. *PloS One, 17*(3), e0264932-e0264932. https://doi.org/10.1371/journal.pone.0264932

Fisher, M. H., & Taylor, J. L. (2016). Let's talk about it: Peer victimization experiences as reported by adolescents with autism spectrum disorder. *Autism: The International Journal of Research and Practice, 20*(4), 402-411. https://doi.org/10.1177/1362361315585948

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2018). Making the future together: Shaping autism research through meaningful participation. *Autism: The International Journal of Research and Practice, 23*(4), 943-953. https://doi.org/10.1177/1362361318786721

Flynn, S., Hastings, R. P., Burke, C., Howes, S., Lunsky, Y., Weiss, J. A., & Bailey, T. (2020). Online mindfulness stress intervention for family carers of children and adults with intellectual disabilities: Feasibility randomized controlled trial. *Mindfulness, 11*(9), 2161-2175. https://doi.org/10.1007/s12671-020-01436-0

Fonseca, A., Moreira, H., & Canavarro, M. C. (2020). Uncovering the links between parenting stress and parenting styles: The role of psychological flexibility within parenting and global psychological flexibility. *Journal of Contextual Behavioral Science, 18*, 59-67. https://doi.org/10.1016/j.jcbs.2020.08.004

Friedman, N. D., Warfield, M. E., & Parish, S. L. (2013). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry, 3*(2), 181-192. https://doi.org/10.2217/npy.13.13

Gast, D. L. (2009). In Ledford J. R., Gast D. L.(Eds.), *Single subject research methodology in behavioral sciences*. Routledge. https://doi.org/10.4324/9780203877937

Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2013). Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. *Autism : The International Journal of Research and Practice, 17*(4), 465-480. https://doi.org/10.1177/1362361311416830

Goldin, P. R., Morrison, A. S., Jazaieri, H., Heimberg, R. G., & Gross, J. J. (2017). Trajectories of social anxiety, cognitive reappraisal, and mindfulness during an RCT of CBGT versus

MBSR for social anxiety disorder. *Behaviour Research and Therapy, 97*, 1-13. https://doi.org/10.1016/j.brat.2017.06.001

Goodall, C. (2018). ‘I felt closed in and like I couldn’t breathe’: A qualitative study exploring the mainstream educational experiences of autistic young people. *Autism & Developmental Language Impairments, 3*, 239694151880440. https://doi.org/10.1177/2396941518804407

Graham, R., & Masters‑Awatere, B. (2020). Experiences of māori of aotearoa new zealand's public health system: A systematic review of two decades of published qualitative research. *Australian and New Zealand Journal of Public Health, 44*(3), 193-200. https://doi.org/10.1111/1753-6405.12971

Grant, A., & Kara, H. (2021). Considering the autistic advantage in qualitative research: The strengths of autistic researchers. *Contemporary Social Science, 16*(5), 589-603. https://doi.org/10.1080/21582041.2021.1998589

Gray, D. E. (2002). ‘Everybody just freezes. everybody is just embarrassed’: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*(6), 734-749. https://doi.org/10.1111/1467-9566.00316

Grinker, R. R. (2020). Autism, “Stigma,” disability: A shifting historical terrain. *Current Anthropology, 61*(S21), S55-S67. https://doi.org/10.1086/705748

Gu, J., Strauss, C., Bond, R., & Cavanagh, K. (2015). How do mindfulness-based cognitive therapy and mindfulness-based stress reduction improve mental health and wellbeing? A systematic review and meta-analysis of mediation studies. *Clinical Psychology Review, 37*, 1-12. https://doi.org/10.1016/j.cpr.2015.01.006

Hamlin, A., & Oakes, P. (2008). Reflections on deinstitutionalization in the united kingdom. *Journal of Policy and Practice in Intellectual Disabilities, 5*(1), 47-55. https://doi.org/10.1111/j.1741-1130.2007.00139.x

Harris, J. (2018). Leo kanner and autism: A 75-year perspective. *International Review of Psychiatry (Abingdon, England), 30*(1), 3-17. https://doi.org/10.1080/09540261.2018.1455646

Hartley, M., Due, C., & Dorstyn, D. (2021). Barriers and facilitators to engaging individuals and families with autism spectrum disorder in mindfulness and acceptance-based therapies: A meta-synthesis. *Disability and Rehabilitation,* , 1-12. https://doi.org/10.1080/09638288.2021.1921859

Hayes, S. A., & Watson, S. L. (2012). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of autism and Developmental Disorders, 43*(3), 629-642. https://doi.org/10.1007/s10803-012-1604-y

Hebron, J., & Humphrey, N. (2014). Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study. *Journal of Research in Special Educational Needs, 14*(1), 22-32. https://doi.org/10.1111/j.1471-3802.2012.01246.x

Helmes, E., & Ward, B. G. (2017). Mindfulness-based cognitive therapy for anxiety symptoms in older adults in residential care. *Aging & Mental Health, 21*(3), 272-278. https://doi.org/10.1080/13607863.2015.1111862

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the depression anxiety stress scales (DASS-21): Construct validity and normative data in a large non-clinical sample.

British Journal of Clinical Psychology, 44(2), 227-239. https://doi.org/10.1348/014466505X29657

Hickey, H., Wilson, D. (2017). Whānau Hauā: Reframing disability from an Indigenous perspective. *MAI Journal, 6(1),* 82-94. https://doi.org/10.20507/MAIJournal.2017.6.1.7

Hofmann, S. G., & Gómez, A. F. (2017). Mindfulness-based interventions for anxiety and depression. *The Psychiatric Clinics of North America, 40*(4), 739. https://doi.org/10.1016/j.psc.2017.08.008

Hofmann, S. G., Sawyer, A. T., Witt, A. A., & Oh, D. (2010). The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *Journal of Consulting and Clinical Psychology, 78*(2), 169-183. https://doi.org/10.1037/a0018555

Hoover, D. W., & Kaufman, J. (2018). Adverse childhood experiences in children with autism spectrum disorder. *Current Opinion in Psychiatry, 31*(2), 128. https://doi.org/10.1097/YCO.0000000000000390

den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2021). 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. *autism : The International Journal of Research and Practice, 25*(1), 148-163. https://doi.org/10.1177/1362361320951696

Howe, F. E. J., & Stagg, S. D. (2016). How sensory experiences affect adolescents with an autistic spectrum condition within the classroom. *Journal of autism and Developmental Disorders, 46*(5), 1656-1668. https://doi.org/10.1007/s10803-015-2693-1

Humphrey, N., & Lewis, S. (2008). Make me normal: The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism : The International*

Journal of Research and Practice, 12(1), 23-46. https://doi.org/10.1177/1362361307085267

Humphrey, N., & Symes, W. (2010). Responses to bullying and use of social support among pupils with autism spectrum disorders (ASDs) in mainstream schools: A qualitative study. *Journal of Research in Special Educational Needs, 10*(2), 82-90. https://doi.org/10.1111/j.1471-3802.2010.01146.x

Ibrahim, I. (2020). Specific learning disorder in children with autism spectrum disorder: Current issues and future implications. *Advances in Neurodevelopmental Disorders, 4*(2), 103-112. https://doi.org/10.1007/s41252-019-00141-x

Interagency Autism Coordinating Committee [IACC]. Autism Spectrum Disorder Research Publications Analysis Report: The Global Landscape of Autism Research. *Office of Autism Research Coordination and Thomson Reuters, Inc. on behalf of the Interagency Autism Coordinating Committee.* https://iacc.hhs.gov/publications/publications-analysis/2012/publications_analysis_2012.pdf

Ismael, N., Lawson, L. M., & Hartwell, J. (2018). Relationship between sensory processing and participation in daily occupations for children with autism spectrum disorder: A systematic review of studies that used dunn's sensory processing framework. *The American Journal of Occupational Therapy, 72*(3), 7203205030p1-4A. https://doi.org/10.5014/ajot.2018.024075

Ivankova, N., & Wingo, N. (2018). Applying mixed methods in action research: Methodological potentials and advantages. The American Behavioral Scientist (Beverly Hills), 62(7), 978-997. https://doi.org/10.1177/0002764218772673

Jaarsma, P., & Welin, S. (2012). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health Care Analysis, 20*(1), 20-30. https://doi.org/10.1007/s10728-011-0169-9

Jacobson, N. S., & Truax, P. (1991). Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology, 59*(1), 12-19. https://doi.org/10.1037/0022-006X.59.1.12

Jaffey, S., & Ashwin, C. (2022). Exploring antecedents and outcomes of restricted and repetitive behaviours in autistic children: A thematic analysis of teacher interviews. *Research in Autism Spectrum Disorders, 97*, 102021. https://doi.org/10.1016/j.rasd.2022.102021

Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2022). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic People's experiences. *Journal of autism and Developmental Disorders, 52*(3), 1131-1142. https://doi.org/10.1007/s10803-021-04998-7

Jones, E. K., Hanley, M., & Riby, D. M. (2020). Distraction, distress and diversity: Exploring the impact of sensory processing differences on learning and school life for pupils with autism spectrum disorders. *Research in Autism Spectrum Disorders, 72*, 101515. https://doi.org/10.1016/j.rasd.2020.101515

Jones, R., Quigney, C., & Huws, J. (2003). First-hand accounts of sensory perceptual experiences in autism: A qualitative analysis. *Journal of Intellectual & Developmental Disability, 28*(2), 112-121. https://doi.org/10.1080/1366825031000147058

Joyce, C., Honey, E., Leekam, S. R., Barrett, S. L., & Rodgers, J. (2017). Anxiety, intolerance of uncertainty and restricted and repetitive behaviour: Insights directly from young people with ASD. *Journal of autism and Developmental Disorders, 47*(12), 3789-3802. https://doi.org/10.1007/s10803-017-3027-2

Kabat-Zinn, J. (1982). An outpatient programme in behavioral medicine for chronic pain patients based on the practice of mindfulness meditation: Theoretical considerations and preliminary results. *General Hospital Psychiatry, 4*(1), 33. https://doi.org/10.1016/0163-8343(82)90026-3

Kabat-Zinn, J. (2015). mindfulness. *Mindfulness, 6*(6), 1481-1483. https://doi.org/10.1007/s12671-015-0456-x

Kanner, L. (1943). Autistic Disturbances of Affective Contact. *Nervous Child* 2 217–250. http://mail.neurodiversity.com/library_kanner_1943.pdf

Kapp, S. (2019). How social deficit models exacerbate the medical model: Autism as case in point. *Autism Policy & Practice*, *2*(1), 3-28. https://www.researchgate.net/profile/Steven-Kapp/publication/338986384_How_social_deficit_models_exacerbate_the_medical_model_Autism_as_case_in_point/links/5e36da93a6fdccd965819ecf/How-social-deficit-models-exacerbate-the-medical-model-Autism-as-case-in-point.pdf

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). ‘People should be allowed to do what they like’: Autistic adults’ views and experiences of stimming. *Autism: The International Journal of Research and Practice, 23*(7), 1782-1792. https://doi.org/10.1177/1362361319829628

Kazdin, A. E. (2019). Single-case experimental designs. evaluating interventions in research and clinical practice. *Behaviour Research and Therapy, 117*, 3-17. https://doi.org/10.1016/j.brat.2018.11.015

Keenan, B. M., Newman, L. K., Gray, K. M., & Rinehart, N. J. (2016). Parents of children with ASD experience more psychological distress, parenting stress, and attachment-related anxiety. *Journal of autism and Developmental Disorders, 46*(9), 2979-2991. https://doi.org/10.1007/s10803-016-2836-z

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? perspectives from the UK autism community. *Autism : The International Journal of Research and Practice, 20*(4), 442-462. https://doi.org/10.1177/1362361315588200

Kern, J. K., Trivedi, M. H., Garver, C. R., Grannemann, B. D., Andrews, A. A., Savla, J. S., Johnson, D. G., Mehta, J. A., & Schroeder, J. L. (2006). The pattern of sensory processing abnormalities in autism. *autism : The International Journal of Research and Practice, 10*(5), 480-494. https://doi.org/10.1177/1362361306066564

Kim, E., Krägeloh, C. U., Medvedev, O. N., Duncan, L. G., & Singh, N. N. (2018;2019;). Interpersonal mindfulness in parenting scale: Testing the psychometric properties of a korean version. *Mindfulness, 10*(3), 516-528. https://doi.org/10.1007/s12671-018-0993-1

Kingston, T., Dooley, B., Bates, A., Lawlor, E., & Malone, K. (2007). Mindfulness-based cognitive therapy for residual depressive symptoms. *Psychology and Psychotherapy, 80*(2), 193-203. https://doi.org/10.1348/147608306X116016

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of autism and Developmental Disorders, 46*(3), 942-953. https://doi.org/10.1007/s10803-015-2637-9

Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society, 15*(1), 25-47. https://doi.org/10.1080/09687590025757

Kuhaneck, H. M., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. R. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. *Physical & Occupational Therapy in Pediatrics, 30*(4), 340-350. https://doi.org/10.3109/01942638.2010.481662

Kuusikko, S., Pollock-Wurman, R., Jussila, K., Carter, A. S., Mattila, M., Ebeling, H., Pauls, D. L., & Moilanen, I. (2008). Social anxiety in high-functioning children and adolescents with autism and asperger syndrome. *Journal of Autism and Developmental Disorders, 38*(9), 1697-1709. https://doi.org/10.1007/s10803-008-0555-9

Lai, M., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet. Psychiatry,* https://doi.org/10.1016/S2215-0366(19)30289-5

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology, 12*, 635690-635690. https://doi.org/10.3389/fpsyg.2021.635690

Ledesma, D., & Kumano, H. (2009). Mindfulness-based stress reduction and cancer: A meta-analysis. *Psycho-Oncology, 18*(6), 571-579. https://doi.org/10.1002/pon.1400

Lee, M., Nayar, K., Maltman, N., Hamburger, D., Martin, G. E., Gordon, P. C., & Losh, M. (2020;2019;). Understanding social communication differences in autism spectrum disorder and first-degree relatives: A study of looking and speaking. *Journal of autism* *and Developmental Disorders, 50*(6), 2128-2141. https://doi.org/10.1007/s10803-019-03969-3

Lee, S. M., Daniels, M. H., & Kissinger, D. B. (2006). Parental influences on adolescent adjustment: Parenting styles versus parenting practices. *The Family Journal (Alexandria, Va.), 14*(3), 253-259. https://doi.org/10.1177/1066480706287654

Leekam, S. R., Nieto, C., Libby, S. J., Wing, L., & Gould, J. (2007). Describing the sensory abnormalities of children and adults with autism. *Journal of Autism and Developmental Disorders, 37*(5), 894-910. https://doi.org/10.1007/s10803-006-0218-7

Leekam, S. R., Prior, M. R., & Uljarevic, M. (2011). Restricted and repetitive behaviors in autism spectrum disorders: A review of research in the last decade. *Psychological Bulletin, 137*(4), 562-593. https://doi.org/10.1037/a0023341

Leitch, S., Sciberras, E., Post, B., Gerner, B., Rinehart, N., Nicholson, J. M., & Evans, S. (2019). Experience of stress in parents of children with ADHD: A qualitative study. *International Journal of Qualitative Studies on Health and Well-being, 14*(1), 1690091-1690091. https://doi.org/10.1080/17482631.2019.1690091

Leitner, Y. (2014). The co-occurrence of autism and attention deficit hyperactivity disorder in children - what do we know? *Frontiers in Human Neuroscience, 8*, 268-268. https://doi.org/10.3389/fnhum.2014.00268

Leonard, H., Dixon, G., Whitehouse, A. J. O., Bourke, J., Aiberti, K., Nassar, N., Bower, C., & Glasson, E. J. (2010). Unpacking the complex nature of the autism epidemic. *Research in Autism Spectrum Disorders, 4*(4), 548-554. https://doi.org/10.1016/j.rasd.2010.01.003

Lester, J. N., & Lester. (2021). *Social, cultural, and political discourses of autism*. Springer.

Levy, S. E., Giarelli, E., Lee, L., Schieve, L. A., Kirby, R. S., Cunniff, C., Nicholas, J., Reaven, J., & Rice, C. E. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the united states. *Journal of Developmental and Behavioral Pediatrics, 31*(4), 267-275. https://doi.org/10.1097/DBP.0b013e3181d5d03

Leysen, J., Jacobs, D., & Ramaekers, S. (2021). The red fish in a shoal of Greenish‐Blue fish? A critique of the biomedical model of autism spectrum disorder. *Educational Theory, 71*(4), 435-454. https://doi.org/10.1111/edth.12494

Lillie, E. O., Patay, B., Diamant, J., Issell, B., Topol, E. J., & Schork, N. J. (2011). The n-of-1 clinical trial: The ultimate strategy for individualizing medicine? *Personalized Medicine, 8*(2), 161-173. https://doi.org/10.2217/pme.11.7

Lindsay, S., Proulx, M., Thomson, N., & Scott, H. (2013). Educators' challenges of including children with autism spectrum disorder in mainstream classrooms. *International Journal of Disability, Development, and Education, 60*(4), 347-362. https://doi.org/10.1080/1034912X.2013.846470

Liu, K., King, M., & Bearman, P. S. (2010). Social influence and the autism epidemic. *The American Journal of Sociology, 115*(5), 1387-1434. https://doi.org/10.1086/651448

Livingston, L. A., Shah, P., & Happé, F. (2019). Compensatory strategies below the behavioural surface in autism: A qualitative study. *The Lancet. Psychiatry, 6*(9), 766-777. https://doi.org/10.1016/S2215-0366(19)30224-X

Lorenz, T., Brüning, C. R., Waltz, M., & Fabri, M. (2021). Not a stranger to the dark: Discrimination against autistic students and employees. *Advances in Autism, 7*(1), 60-72. https://doi.org/10.1108/AIA-10-2019-0036

Lovibond, S. H., & Lovibond, P. F. (1995). Manual for the Depression Anxiety Stress Scales (DASS). New South Wales: Psychology Foundation Monograph.

Luberto, C. M., Perez, G. K., Finkelstein-Fox, L., Millstein, R. A., Fell, L., Chad-Friedman, E., Park, E. R., & Kuhlthau, K. A. (2021). Acceptability of a virtual Mind–Body intervention for parents of children with autism or learning disabilities. *Global Advances in Health and Medicine, 10*, 21649561211047804-21649561211047804. https://doi.org/10.1177/21649561211047804

Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 17*(5), 702-711. https://doi.org/10.1177/1359105311422955

Lyons, A. M., Leon, S. C., Roecker Phelps, C. E., & Dunleavy, A. M. (2010). The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies, 19*(4), 516-524. https://doi.org/10.1007/s10826-009-9323-5

MacLennan, K., O'Brien, S., & Tavassoli, T. (2022). In our own words: The complex sensory experiences of autistic adults. *Journal of Autism and Developmental Disorders, 52*(7), 3061-3075. https://doi.org/10.1007/s10803-021-05186-3

Mahalik, J. R., Morray, E. B., Coonerty-Femiano, A., Ludlow, L. H., Slattery, S. M., & Smiler, A. (2005). Development of the conformity to feminine norms inventory. *Sex Roles, 52*(7-8), 417-435. https://doi.org/10.1007/s11199-005-3709-7

Maïano, C., Normand, C. L., Salvas, M., Moullec, G., & Aimé, A. (2016). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. *Autism Research, 9*(6), 601-615. https://doi.org/10.1002/aur.1568

Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2022;2021;). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatric Research, 91*(5), 1028-1035. https://doi.org/10.1038/s41390-021-01465-y

Maljaars, J., Boonen, H., Lambrechts, G., Van Leeuwen, K., & Noens, I. (2014). Maternal parenting behavior and child behavior problems in families of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(3), 501-512. https://doi.org/10.1007/s10803-013-1894-8

Mansell, J. (2006). Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disability, 31*(2), 65-76. https://doi.org/10.1080/13668250600686726

Marco, E. J., Hinkley, L. B. N., Hill, S. S., & Nagarajan, S. S. (2011). Sensory processing in autism: A review of neurophysiologic findings. *Pediatric Research, 69*(5 Pt 2), 48R-54R. https://doi.org/10.1203/PDR.0b013e3182130c54

Masheder, J., Fjorback, L., & Parsons, C. E. (2020). "I am getting something out of this, so I am going to stick with it": Supporting participants' home practice in mindfulness-based programmes. *BMC Psychology, 8*(1), 91-91. https://doi.org/10.1186/s40359-020-00453-x

Matson, J. L., & Goldin, R. L. (2013). Comorbidity and autism: Trends, topics and future directions. *Research in Autism Spectrum Disorders, 7*(10), 1228-1233. https://doi.org/10.1016/j.rasd.2013.07.003

Mayes, S. D., & Calhoun, S. L. (2006). Frequency of reading, math, and writing disabilities in children with clinical disorders. *Learning and Individual Differences, 16*(2), 145-157. https://doi.org/10.1016/j.lindif.2005.07.004

McCormack, L., Wong, S. W., & Campbell, L. E. (2022). ‘If I don’t do it, I’m out of rhythm and I Can’t focus as well’: Positive and negative adult interpretations of therapies aimed at ‘Fixing’ their restricted and repetitive behaviours in childhood. *Journal of Autism and Developmental Disorders,* https://doi.org/10.1007/s10803-022-05644-6

McGovern, C. W., & Sigman, M. (2005). Continuity and change from early childhood to adolescence in autism. *Journal of Child Psychology and Psychiatry, 46*(4), 401-408. https://doi.org/10.1111/j.1469-7610.2004.00361.x

McGregor, E. M. C., & Campbell, E. (2001). The attitudes of teachers in scotland to the integration of children with autism into mainstream schools. *Autism : The International Journal of Research and Practice, 5*(2), 189-207. https://doi.org/10.1177/1362361301005002008

McPherson, A., Lewis, K. M., Lynn, A. E., Haskett, M. E., & Behrend, T. S. (2009). Predictors of parenting stress for abusive and nonabusive mothers. Journal of Child and Family Studies, 18, 61–69. doi:10.1007/s10826-008-9207-0

McPhilemy, C., & Dillenburger, K. (2013). Parents' experiences of applied behaviour analysis (ABA)-based interventions for children diagnosed with autistic spectrum disorder. *British Journal of Special Education, 40*(4), 154-161. https://doi.org/10.1111/1467-8578.12038

McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of autism and Developmental Disorders, 44*(12), 3101-3118. https://doi.org/10.1007/s10803-014-2178-7

McStay, R. L., Dissanayake, C., Scheeren, A. M., Koot, H. M., & Begeer, S. M. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *autism : The International Journal of Research and Practice, 18*(5), 502-510. https://doi.org/10.1177/1362361313485163

Meadan, H., Halle, J. W., & Ebata, A. T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children, 77*(1), 7-36. https://doi.org/10.1177/001440291007700101

Miller, S., Duncan, B., & Brown, Jeb. (2003). The Outcome Rating Scale: A Preliminary Study of the Reliability, Validity, and Feasibility of a Brief Visual Analog Measure. *Journal of Brief Therapy*. 2. 91-100.

Ming, X., Brimacombe, M., Chaaban, J., Zimmerman-Bier, B., & Wagner, G. C. (2008). Autism spectrum disorders: Concurrent clinical disorders. *Journal of Child Neurology, 23*(1), 6-13. https://doi.org/10.1177/0883073807307102

Miranda, A., Tárraga, R., Fernández, M. I., Colomer, C., & Pastor, G. (2015). Parenting stress in families of children with autism spectrum disorder and ADHD. *Exceptional Children, 82*(1), 81-95. https://doi.org/10.1177/0014402915585479

Mount, N., & Dillon, G. (2014). Parents' experiences of living with an adolescent diagnosed with an autism spectrum disorder. *Educational and Child Psychology, 31*(4), 72–81

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heart ache:” parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *Research in Autism Spectrum Disorders, 3*(3), 670-684. https://doi.org/10.1016/j.rasd.2009.01.004

Mytton, J., Ingram, J., Manns, S., & Thomas, J. (2014). Facilitators and barriers to engagement in parenting programs: A qualitative systematic review. *Health Education & Behavior, 41*(2), 127-137. https://doi.org/10.1177/1090198113485755

Nealy, C. E., O'Hare, L., Powers, J. D., & Swick, D. C. (2012). The impact of autism spectrum disorders on the family: A qualitative study of mothers' perspectives. *Journal of Family Social Work, 15*(3), 187-201. https://doi.org/10.1080/10522158.2012.675624

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities, 117*(1), 48-66. https://doi.org/10.1352/1944-7558-117.1.48

Nicholas, D. B., Zwaigenbaum, L., Zwicker, J., Clarke, M. E., Lamsal, R., Stoddart, K. P., Carroll, C., Muskat, B., Spoelstra, M., & Lowe, K. (2018). Evaluation of employment-support services for adults with autism spectrum disorder. *Autism : The International Journal of Research and Practice, 22*(6), 693-702. https://doi.org/10.1177/1362361317702507

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Kapp, S. K., Weiner, M., & Boisclair, W. C. (2015). “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism : The International Journal of Research and Practice, 19*(7), 824-831. https://doi.org/10.1177/1362361315576221

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013;2012;). Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine : JGIM, 28*(6), 761-769. https://doi.org/10.1007/s11606-012-2262-7

Oakley, B. F., Tillmann, J., Ahmad, J., Crawley, D., Cáceres, A. S. J., Holt, R., Charman, T., Banaschewski, T., Buitelaar, J. K., Simonoff, E., Murphy, D., & Loth, E. (2021). How do core autism traits and associated symptoms relate to quality of life? findings from the longitudinal european autism project. *Autism : The International Journal of Research and Practice, 25*(2), 389-404. https://doi.org/10.1177/1362361320959959

Ochs, E., Kremer-Sadlik, T., Solomon, O., & Sirota, K. G. (2001). Inclusion as social practice: Views of children with autism. *Social Development (Oxford, England), 10*(3), 399-419. https://doi.org/10.1111/1467-9507.00172

Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment, 12*, 745-762. https://doi.org/10.2147/NDT.S100634

O'Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2018;2017;). How do parents manage irritability, challenging behaviour, non-compliance and anxiety in children with autism spectrum disorders? A meta-synthesis. *Journal of autism and Developmental Disorders, 48*(4), 1272-1286. https://doi.org/10.1007/s10803-017-3361-4

van der Oord, S., Bögels, S. M., & Peijnenburg, D. (2012;2011;). The effectiveness of mindfulness training for children with ADHD and mindful parenting for their parents. *Journal of Child and Family Studies, 21*(1), 139-147. https://doi.org/10.1007/s10826-011-9457-0

Osborne, L. A., & Reed, P. (2010). Stress and self-perceived parenting behaviors of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders, 4*(3), 405-414. https://doi.org/10.1016/j.rasd.2009.10.011

Ozturk, Y., Riccadonna, S., & Venuti, P. (2014). Parenting dimensions in mothers and fathers of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 8*(10), 1295-1306. https://doi.org/10.1016/j.rasd.2014.07.001

Parsons, C. E., Crane, C., Parsons, L. J., Fjorback, L. O., & Kuyken, W. (2017). Home practice in mindfulness-based cognitive therapy and mindfulness-based stress reduction: A systematic review and meta-analysis of participants' mindfulness practice and its association with outcomes. *Behaviour Research and Therapy, 95*, 29-41. https://doi.org/10.1016/j.brat.2017.05.004

Peacock, G., Amendah, D., Ouyang, L., & Grosse, S. D. (2012). Autism spectrum disorders and health care expenditures: The effects of co-occurring conditions. *Journal of Developmental and Behavioral Pediatrics, 33*(1), 2-8. https://doi.org/10.1097/DBP.0b013e31823969de

Pellicano, E., & den Houting, J. (2022). Annual research review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry, 63*(4), 381-396. https://doi.org/10.1111/jcpp.13534

Phetrasuwan, S., & Shandor Miles, M. (2009). Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Pediatric Nursing, 14*(3), 157-165. https://doi.org/10.1111/j.1744-6155.2009.00188.x

Phelps, K. W., Hodgson, J. L., McCammon, S. L., & Lamson, A. L. (2009). Caring for an individual with autism disorder: A qualitative analysis. *Journal of Intellectual & Developmental Disability, 34*(1), 27-35. https://doi.org/10.1080/13668250802690930

Piet, J., & Hougaard, E. (2011). The effect of mindfulness-based cognitive therapy for prevention of relapse in recurrent major depressive disorder: A systematic review and meta-analysis. *Clinical Psychology Review, 31*(6), 1032-1040. https://doi.org/10.1016/j.cpr.2011.05.002

Pinquart, M., & Gerke, D. (2019). Associations of parenting styles with self-esteem in children and adolescents: A meta-analysis. *Journal of Child and Family Studies, 28*(8), 2017-2035. https://doi.org/10.1007/s10826-019-01417-5

Potharst, E. S., Aktar, E., Rexwinkel, M., Rigterink, M., & Bögels, S. M. (2017). Mindful with your baby: Feasibility, acceptability, and effects of a mindful parenting group training for mothers and their babies in a mental health context. *Mindfulness, 8*(5), 1236-1250. https://doi.org/10.1007/s12671-017-0699-9

Potharst, E. S., Boekhorst, M. G. B. M., Cuijlits, I., van Broekhoven, K. E. M., Jacobs, A., Spek, V., Nyklíček, I., Bögels, S., & Pop, V. (2019). A randomized control trial evaluating an online mindful parenting training for mothers with elevated parental stress. *Frontiers in Psychology, 10*(JULY), 1550-1550. https://doi.org/10.3389/fpsyg.2019.01550

Potter, C. A. (2016). 'I accept my son for who he is - he has incredible character and personality': Fathers' positive experiences of parenting children with autism. *Disability & Society, 31*(7), 948-965. https://doi.org/10.1080/09687599.2016.1216393

Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology, 22*(6), 855-864. https://doi.org/10.1037/a0013604

Puka, K., Bax, K., Andrade, A., Devries-Rizzo, M., Gangam, H., Levin, S., Nouri, M. N., Prasad, A. N., Secco, M., Zou, G., & Speechley, K. N. (2020). A live-online mindfulness-based intervention for children living with epilepsy and their families: Protocol for a randomized controlled trial of making mindfulness matter[c]. *Trials, 21*(1), 922-922. https://doi.org/10.1186/s13063-020-04792-3

Punshon, C., Skirrow, P., & Murphy, G. (2009). The `not guilty verdict: Psychological reactions to a diagnosis of asperger syndrome in adulthood. *Autism : The International Journal of Research and Practice, 13*(3), 265-283. https://doi.org/10.1177/1362361309103795

Rassafiani, M., & Sahaf, R. (2010). Single case experimental design: An overview. *International Journal of Therapy and Rehabilitation, 17*(6), 285-289. https://doi.org/10.12968/ijtr.2010.17.6.48151

Rayan, A., & Ahmad, M. (2016). Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder. *Research in Developmental Disabilities, 55*, 185-196. https://doi.org/10.1016/j.ridd.2016.04.002

Raymaker, D., & Nicolaidis, C. (2013). Participatory research with autistic communities: Shifting the system. In Joyce Davidson, & Michael Orsini (Eds.), *Worlds of autism* (pp. 169). University of Minnesota Press. https://doi.org/10.5749/j.ctt4cggsn.11

Reaven, J. A. (2009). Children with high-functioning autism spectrum disorders and co-occurring anxiety symptoms: Implications for assessment and treatment. *Journal for Specialists in Pediatric Nursing, 14*(3), 192-199. https://doi.org/10.1111/j.1744-6155.2009.00197.x

Reid, J., Taylor-Moore, K., & Varona, G. (2014). Towards a social-structural model for understanding current disparities in maori health and well-being. *Journal of Loss & Trauma, 19*(6), 514-536. https://doi.org/10.1080/15325024.2013.809295

Remington, A., & Fairnie, J. (2017). A sound advantage: Increased auditory capacity in autism. *Cognition, 166*, 459-465. https://doi.org/10.1016/j.cognition.2017.04.002

Richdale, A. L., & Schreck, K. A. (2009). Sleep problems in autism spectrum disorders: Prevalence, nature, & possible biopsychosocial aetiologies. *Sleep Medicine Reviews, 13*(6), 403-411. https://doi.org/10.1016/j.smrv.2009.02.003

Ridderinkhof, A., de Bruin, E. I., Blom, '., & Bögels, S. M. (2018). Mindfulness-based programme for children with autism spectrum disorder and their parents: Direct and long-term improvements. *Mindfulness, 9*(3), 773-791. https://doi.org/10.1007/s12671-017-0815-x

Ridderinkhof, A., de Bruin, E. I., Blom, R., Singh, N. N., & Bögels, S. M. (2019). Mindfulness-based programme for autism spectrum disorder: A qualitative study of the experiences of children and parents. *Mindfulness, 10*(9), 1936-1951. https://doi.org/10.1007/s12671-019-01202-x

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of autism and Developmental Disorders, 44*(7), 1609-1620. https://doi.org/10.1007/s10803-013-2028-z

Roberts, L. R., & Neece, C. L. (2015). Feasibility of mindfulness-based stress reduction intervention for parents of children with developmental delays. *Issues in Mental Health Nursing, 36*(8), 592-602. https://doi.org/10.3109/01612840.2015.1017063

Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception (London), 44*(5), 569-586. https://doi.org/10.1068/p7833

Rodriguez, G., Hartley, S. L., & Bolt, D. (2019). Transactional relations between parenting stress and child autism symptoms and behavior problems. *Journal of autism and Developmental Disorders, 49*(5), 1887-1898. https://doi.org/10.1007/s10803-018-3845-x

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology, 37*(1), 8-38. https://doi.org/10.1080/15374410701817808

Rosen, T. E., Mazefsky, C. A., Vasa, R. A., & Lerner, M. D. (2018). Co-occurring psychiatric conditions in autism spectrum disorder. *International Review of Psychiatry (Abingdon, England), 30*(1), 40-61. https://doi.org/10.1080/09540261.2018.1450229

Ruiz-Robledillo, N., Sariñana-González, P., Pérez-Blasco, J., González-Bono, E., & Moya-Albiol, L. (2014;2015;). A mindfulness-based programme improves health in caregivers of people with autism spectrum disorder: A pilot study. *Mindfulness, 6*(4), 767-777. https://doi.org/10.1007/s12671-014-0316-0

Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism in Adulthood, 1*(2), 124.

Ryan, S., & Salisbury, H. (2012). 'you know what boys are like': Pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice, 62*(598), e378-e383. https://doi.org/10.3399/bjgp12X641500

Saggers, B. (2015). Student perceptions: Improving the educational experiences of high school students on the autism spectrum. *Improving Schools, 18*(1), 35-45. https://doi.org/10.1177/1365480214566213

Salem-Guirgis, S., Albaum, C., Tablon, P., Riosa, P. B., Nicholas, D. B., Drmic, I. E., & Weiss, J. A. (2019). MYmind: A concurrent group-based mindfulness intervention for youth with autism and their parents. *Mindfulness, 10*(9), 1730-1743. https://doi.org/10.1007/s12671-019-01107-9

Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *autism : The International Journal of Research and Practice, 15*(3), 373-389. https://doi.org/10.1177/1362361310386505

Schnabel, A., Youssef, G. J., Hallford, D. J., Hartley, E. J., McGillivray, J. A., Stewart, M., Forbes, D., & Austin, D. W. (2020). *Psychopathology in parents of children with autism spectrum disorder: A systematic review and meta-analysis of prevalence*. SAGE Publications. https://doi.org/10.1177/1362361319844636

Schopler, E., & Reichler, R. J. (1971). Parents as cotherapists in the treatment of psychotic children. *Journal of Autism and Childhood Schizophrenia, 1*(1), 87-102. https://doi.org/10.1007/BF01537746

Schroeder, J. H., Cappadocia, M. C., Bebko, J. M., Pepler, D. J., & Weiss, J. A. (2014). Shedding light on a pervasive problem: A review of research on bullying experiences among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(7), 1520-1534. https://doi.org/10.1007/s10803-013-2011-8

Searing, B. M. J., Graham, F., & Grainger, R. (2015). Support needs of families living with children with autism spectrum disorder. *Journal of autism and Developmental Disorders, 45*(11), 3693-3702. https://doi.org/10.1007/s10803-015-2516-4

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2002). *Mindfulness-based cognitive therapy for depression: A new approach to preventing relapse*. Guilford Press.

Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews, 10*(4), 234-247. https://doi.org/10.1002/mrdd.20038

Serpa, J. G., Taylor, S. L., & Tillisch, K. (2014). Mindfulness-based stress reduction (MBSR) reduces anxiety, depression, and suicidal ideation in veterans. *Medical Care, 52*(12), S19-S24. https://doi.org/10.1097/MLR.0000000000000202

Shapiro, S. L., Carlson, L. E., Astin, J. A., & Freedman, B. (2006). Mechanisms of mindfulness. *Journal of Clinical Psychology, 4;62;*(4;3;), 373-386. https://doi.org/10.1002/jclp.20237

Shapiro, S. L. (2009). The integration of mindfulness and psychology. *Journal of Clinical Psychology, 4;65;*(4;6;), 555-560. https://doi.org/10.1002/jclp.20602

Shepherd, D., Landon, J., Taylor, S., & Goedeke, S. (2018). Coping and care-related stress in parents of a child with autism spectrum disorder. *Anxiety, Stress, and Coping, 31*(3), 277-290. https://doi.org/10.1080/10615806.2018.1442614

Shorey, S., & Ng, E. D. (2021). The efficacy of mindful parenting interventions: A systematic review and meta-analysis. *International Journal of Nursing Studies, 121*, 103996-103996. https://doi.org/10.1016/j.ijnurstu.2021.103996

Siebelink, N. M., Kaijadoe, S. P. T., van Horssen, F. M., Holtland, J. N. P., Bögels, S. M., Buitelaar, J. K., Speckens, A. E. M., & Greven, C. U. (2021). Mindfulness for children with ADHD and mindful parenting (MindChamp): A qualitative study on feasibility and effects. *Journal of Attention Disorders, 25*(13), 1931-1942. https://doi.org/10.1177/1087054720945023

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*(1), 9-22. https://doi.org/10.1016/j.ridd.2005.09.003

Simonoff, Emily, M.D., F.R.C.Psych, Pickles, A., Ph.D, Charman, T., Ph.D, Chandler, S., Ph.D, Loucas, T., Ph.D, & Baird, G., F.R.C.P.C.H. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921-929. https://doi.org/10.1097/CHI.0b013e318179964f

Singh, J., Illes, J., Lazzeroni, L., & Hallmayer, J. (2009). Trends in US autism research funding. *Journal of Autism and Developmental Disorders, 39*(5), 788-795. https://doi.org/10.1007/s10803-008-0685-0

Singh, N. N., Lancioni, G. E., Karazsia, B. T., Myers, R. E., Hwang, Y., & Anālayo, B. (2019). Effects of mindfulness-based positive behavior support (MBPBS) training are equally beneficial for mothers and their children with autism spectrum disorder or with intellectual disabilities. *Frontiers in Psychology, 10*, 385-385. https://doi.org/10.3389/fpsyg.2019.00385

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Fisher, B. C., Wahler, R. G., Mcaleavey, K., Singh, J., & Sabaawi, M. (2006). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders, 14*(3), 169-177. https://doi.org/10.1177/10634266060140030401

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Karazsia, B. T., Myers, R. E., Latham, L. L., & Singh, J. (2014). Mindfulness-based positive behavior support (MBPBS) for mothers of adolescents with autism spectrum disorder: Effects on adolescents' behavior and parental stress. *Mindfulness, 5*(6), 646-657. https://doi.org/10.1007/s12671-014-0321-3

Sipe, W. E. B., & Eisendrath, S. J. (2012). Mindfulness-based cognitive therapy: Theory and practice : Mindfulness. *Canadian Journal of Psychiatry, 57*(2), 63-69.

Sipowicz, K., Pietras, T., Podlecka, M., & Mokros, Ł. (2022). The association between depression and perceived stress among parents of autistic and non-autistic children-the role of loneliness. *International Journal of Environmental Research and Public Health, 19*(5), 3019. https://doi.org/10.3390/ijerph19053019

Smetana, J. G. (2017). Current research on parenting styles, dimensions, and beliefs. *Current Opinion in Psychology, 15*, 19-25. https://doi.org/10.1016/j.copsyc.2017.02.012

Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of autism and Developmental Disorders, 38*(5), 876-889. https://doi.org/10.1007/s10803-007-0461-6

Smith-Young, J., Chafe, R., & Audas, R. (2020). “Managing the wait”: Parents’ experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with autism spectrum disorder. *Health Services Insights, 13*, 1178632920902141-1178632920902141. https://doi.org/10.1177/1178632920902141

Smith-Young, J., Chafe, R., Audas, R., & Gustafson, D. L. (2022). "I know how to advocate": Parents' experiences in advocating for children and youth diagnosed with autism spectrum disorder. *Health Services Insights, 15*, 11786329221078803-11786329221078803. https://doi.org/10.1177/11786329221078803

Soulières, I., Zeffiro, T. A., Girard, M. L., & Mottron, L. (2011). Enhanced mental image mapping in autism. *Neuropsychologia, 49*(5), 848-857. https://doi.org/10.1016/j.neuropsychologia.2011.01.027

Sperry, L. A., & Mesibov, G. B. (2005). Perceptions of social challenges of adults with autism spectrum disorder. *Autism : The International Journal of Research and Practice, 9*(4), 362-376. https://doi.org/10.1177/1362361305056077

Stahlschmidt, M. J., Threlfall, J., Seay, K. D., Lewis, E. M., & Kohl, P. L. (2013). Recruiting fathers to parenting programs: Advice from dads and fatherhood program providers. *Children and Youth Services Review, 35*(10), 1734-1741. https://doi.org/10.1016/j.childyouth.2013.07.004

Stafford, M., Kuh, D. L., Gale, C. R., Mishra, G., & Richards, M. (2015). Parent-child relationships and offspring's positive mental wellbeing from adolescence to early older age. *The Journal of Positive Psychology, 11*(3), 326-337. https://doi.org/10.1080/17439760.2015.1081971

van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review, 14*(3), 302-317. https://doi.org/10.1007/s10567-011-0097-0

Streit, C., & Davis, A. N. (2022). The longitudinal links between parenting stress, harsh parenting, and adolescents' social behaviors in latinx families. *Journal of Latinx Psychology, 10*(2), 128-139. https://doi.org/10.1037/lat0000203

Tager-Flusberg, H. (1999). A psychological approach to understanding the social and language impairments in autism. *International Review of Psychiatry (Abingdon, England), 11*(4), 325-334. https://doi.org/10.1080/09540269974203

Tate, R. L., Perdices, M., Rosenkoetter, U., Shadish, W., Vohra, S., Barlow, D. H., Horner, R., Kazdin, A., Kratochwill, T., McDonald, S., Sampson, M., Shamseer, L., Togher, L., Albin, R., Backman, C., Douglas, J., Evans, J. J., Cast, D., Manolov, R., . . . Wilson, B. (2016). The single-case reporting guideline in BEhavioural interventions (SCRIBE) 2016 statement. *Physical Therapy, 96*(7), 932. https://doi.org/10.1177/0008417416648124

Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 34-42. https://doi.org/10.1111/j.1468-3148.2008.00437.x

Te Pou o te Whakaaro Nui. (2019). Te Tau Tītoki: A framework for supporting people on the autism spectrum. https://www.tepou.co.nz/resources/te-tau-titoki-a-framework-forsupporting-people-on-the-autism-spectrum/915

Thabrew, H., & Eggleston, M. (2018). Spectrum of care: Current management of childhood autism spectrum disorder (ASD) in new zealand. *Australasian Psychiatry : Bulletin of the Royal Australian and New Zealand College of Psychiatrists, 26*(3), 294-298. https://doi.org/10.1177/1039856217716290

Thompson, T. (2013). Autism research and services for young children: History, progress and challenges. *Journal of Applied Research in Intellectual Disabilities, 26*(2), 81-107. https://doi.org/10.1111/jar.1202

Thomson, S., Michelson, D., & Day, C. (2015). From parent to 'peer facilitator': A qualitative study of a peer-led parenting programme: From parent to 'peer facilitator': A qualitative study. *Child : Care, Health & Development, 41*(1), 76-83. https://doi.org/10.1111/cch.12132

Topp, C. W., Østergaard, S. D., Søndergaard, S., & Bech, P. (2015). The WHO-5 well-being index: A systematic review of the literature. *Psychotherapy and Psychosomatics, 84*(3), 167-176. https://doi.org/10.1159/000376585

Tucker, V., & Schwartz, I. (2013). Parents' perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with ASD. *School Mental Health, 5*(1), 3-14. https://doi.org/10.1007/s12310-012-9102-0

Tupou, J., Curtis, S., Taare-Smith, D., Glasgow, A., & Waddington, H. (2021). *Māori and autism: A scoping review*. SAGE Publications. https://doi.org/10.1177/13623613211018649

Van Leeuwen, K. & Noens, I. (2013). Parental Behaviour Scale for Autism Spectrum Disorders. Unpublished document, Leuven: KU Leuven.

Van Leeuwen, K. G., & Vermulst, A. A. (2004). Some psychometric properties of the ghent parental behavior scale. *European Journal of Psychological Assessment : Official Organ of the European Association of Psychological Assessment, 20*(4), 283-298. https://doi.org/10.1027/1015-5759.20.4.283

Van der Oord, S., Bögels, S. M., & Peijnenburg, D. (2012). The effectiveness of mindfulness training for children with ADHD and mindful parenting for their parents. Journal of Child and Family studies, 21, 139–147.

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in autism Spectrum Disorders, 23*, 36-49. https://doi.org/10.1016/j.rasd.2015.11.008

Vogan, V., Lake, J. K., Tint, A., Weiss, J. A., & Lunsky, Y. (2017). Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal, 10*(2), 264-270. https://doi.org/10.1016/j.dhjo.2016.11.002

Voulgarakis, H. M., Lisa, J. A. S., Conde, K. A., & Davies, E. A. (2021). The experience of parenting children with autism spectrum disorder: A qualitative content analysis. *Child Care in Practice : Northern Ireland Journal of Multi-Disciplinary Child Care Practice, ahead-of-print*(ahead-of-print), 1-13. https://doi.org/10.1080/13575279.2021.1939655

Waltz, M. (2008). Autism = death: The social and medical impact of a catastrophic medical model of autistic spectrum disorders. *Popular Narrative Media, 1*(1), 13-23. https://doi.org/10.3828/pnm.1.1.4

WHO Regional Office for Europe. Health for all targets. The health policy for Europe. (1984, updated edition 1991). Copenhagen, WHO Regional Office for Europe, 1991 (European Health for All Series, No. 4).

Whittaker, K. A., & Cowley, S. (2012). An effective programme is not enough: A review of factors associated with poor attendance and engagement with parenting support programmes. *Children & Society, 26*(2), 138-149. https://doi.org/10.1111/j.1099-0860.2010.00333.x

Wilkinson, E., Vo, L. T. V., London, Z., Wilson, S., & Bal, V. H. (2022). Parent-reported strengths and positive qualities of adolescents and adults with autism spectrum disorder and/or intellectual disability. *Journal of autism and Developmental Disorders,* https://doi.org/10.1007/s10803-021-05405-x

Williams, J. M. G., Alatiq, Y., Crane, C., Barnhofer, T., Fennell, M. J. V., Duggan, D. S., Hepburn, S., & Goodwin, G. M. (2008). Mindfulness-based cognitive therapy (MBCT) in bipolar disorder: Preliminary evaluation of immediate effects on between-episode functioning. *Journal of Affective Disorders, 107*(1), 275-279. https://doi.org/10.1016/j.jad.2007.08.022

Winter-Messiers, M. A., Herr, C. M., Wood, C. E., Brooks, A. P., Gates, M. A. M., Houston, T. L., & Tingstad, K. I. (2007). How far can brian ride the daylight 4449 express?: A strength-based model of asperger syndrome based on special interest areas. *Focus on Autism and Other Developmental Disabilities, 22*(2), 67-79. https://doi.org/10.1177/10883576070220020701

Wolff, S. (2004). The history of autism. *European Child & Adolescent Psychiatry, 13*(4), 201-208. https://doi.org/10.1007/s00787-004-0363-5

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075-1083. https://doi.org/10.1177/1049732308320112

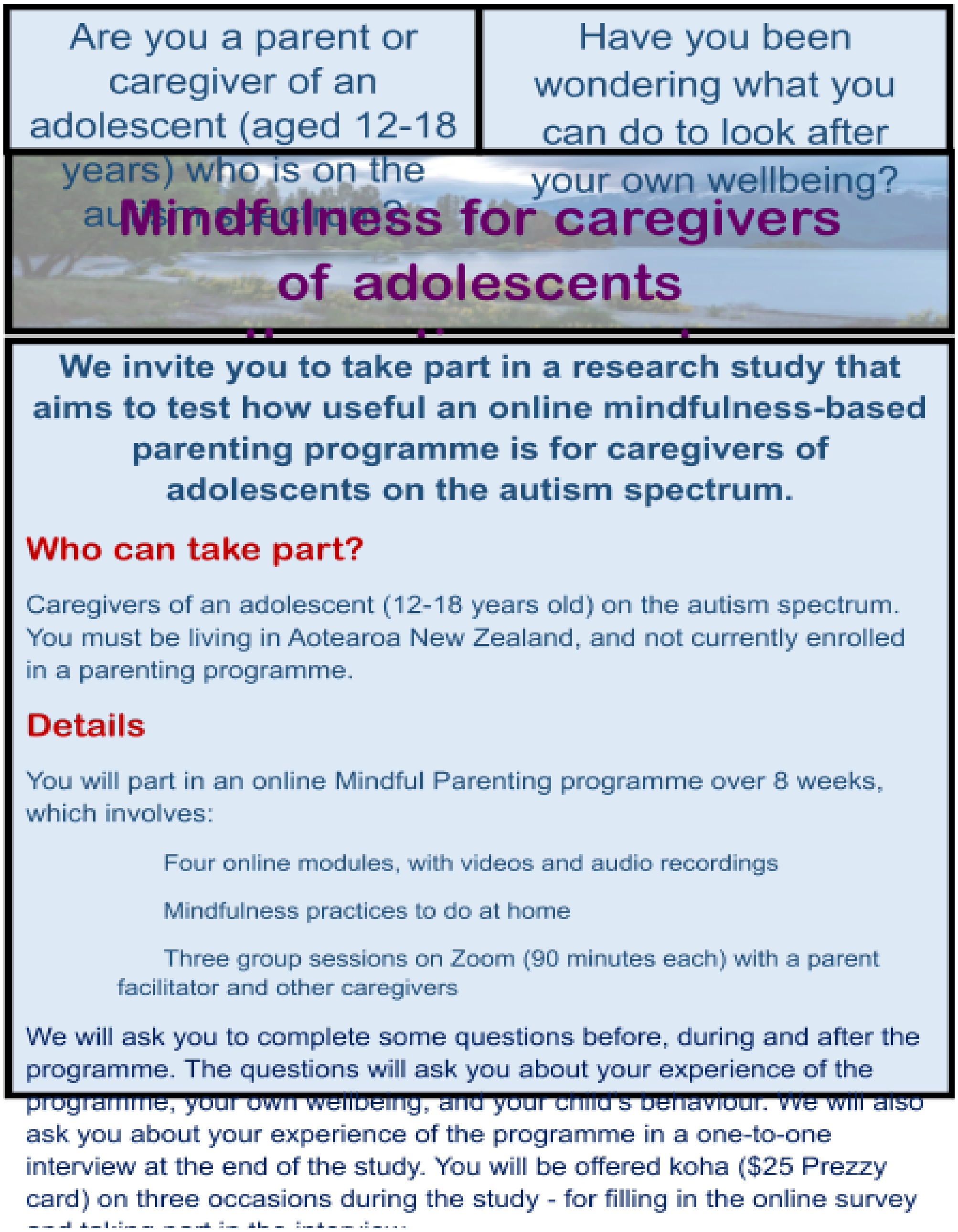
Wright, D. (2019). The metamorphosis of autism: A history of child development in britain by bonnie evans (review). *Bulletin of the History of Medicine, 93*(1), 140-142. https://doi.org/10.1353/bhm.2019.0020

Zaidman-Zait, A., Mirenda, P., Zumbo, B. D., Wellington, S., Dua, V., & Kalynchuk, K. (2010). An item response theory analysis of the parenting stress index-short form with parents of children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry, 51*(11), 1269-1277. https://doi.org/10.1111/j.1469-7610.2010.02266.x

Zhang, D., Lee, E. K. P., Mak, E. C. W., Ho, C. Y., & Wong, S. Y. S. (2021). Mindfulness-based interventions: An overall review. *British Medical Bulletin, 138*(1), 41-57. https://doi.org/10.1093/bmb/ldab005

Appendices

Appendix A. Advertisement poster and recruitment email



Are you a parent or caregiver of an adolescent (aged 12-18 years) who is on the autism spectrum?

Have you been wondering what you can do to look after your own wellbeing?

Mindfulness for caregivers of adolescents

We invite you to take part in a research study that aims to test how useful an online mindfulness-based parenting programme is for caregivers of adolescents on the autism spectrum.

Who can take part?

Caregivers of an adolescent (12-18 years old) on the autism spectrum. You must be living in Aotearoa New Zealand, and not currently enrolled in a parenting programme.

Details

You will part in an online Mindful Parenting programme over 8 weeks, which involves:

Four online modules, with videos and audio recordings

Mindfulness practices to do at home

Three group sessions on Zoom (90 minutes each) with a parent facilitator and other caregivers

We will ask you to complete some questions before, during and after the programme. The questions will ask you about your experience of the programme, your own wellbeing, and your child's behaviour. We will also ask you about your experience of the programme in a one-to-one interview at the end of the study. You will be offered koha ($25 Prezzy card) on three occasions during the study - for filling in the online survey

If you are interested in taking part, or have any questions about the study, please contact [Masters student contact]

Appendix B

Information Sheet

UC
UNIVERSITY OF
CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Te Rāngai Ako me to Hauora | College of Education, Health and Human Development
Te Kura Mātai Hauora | School of Health Sciences
University of Canterbury
Private Bag 4800
Christchurch
New Zealand

PARTICIPANT INFORMATION SHEET

Study title:
Mindfulness-based parenting support for parents of adolescents on the autism spectrum

Principal investigator:
Dr Lisa Marie Emerson, University of Canterbury
Phone: 03 369 4398
Email: lisa.emerson@canterbury.ac.nz

Co-investigators:
A/Prof Laurie McLay, University of Canterbury, laurie.mclay@canterbury.ac.nz
A/Prof Dawn Adams, Griffith University, dawn.adams@griffith.edu.au
Dr Jessica Paynter, Griffith University, j.paynter@griffith.edu.au

Student researcher :
Madeline Groom, Masters student, University of Canterbury, msg62@uclive.ac.nz

Research assistant :
Juliana Edwards, parent facilitator, University of Canterbury, juliana.edwards@pg.canterbury.ac.nz

Locality: University of Canterbury, Christchurch, New Zealand

Ethics ref: 2021/167

Kia ora,

Thank you for your interest in our study. I am Madeline Groom, a student studying for a Masters in Child and Family Psychology. I am carrying out this research under the supervision of Dr Lisa Marie Emerson, who is the Principal Investigator, Senior Lecturer in the School of Health Sciences at the University of Canterbury, a registered Clinical Psychologist and mindfulness teacher.

We are inviting parents and caregivers of adolescents (aged 12-18 years) on the autism spectrum to take part in this study. Parents and caregivers of the same adolescent are welcome to take part together. This information sheet (3 pages) will help you decide if you would like to take part. It will tell you why we are doing the study and what we will ask you to do.

Whether or not you take part is your choice. If you choose to take part in this study, we will ask you to complete a consent form, and a brief screening questionnaire. Please make sure you have read and understood all of the pages of this information sheet. Please contact us if you would like to talk more about the study to help you make your decision about whether to take part.

If you decide you would like to take part, then please follow the link provided in the email to fill in the consent form and screening questionnaire.

What is the aim of this research?

In this research, we are aiming to find out whether an online mindfulness-based parenting group will be useful for parents and caregivers of adolescents on the autism spectrum.

Mindfulness involves paying attention to the here-and-now, in a non-judgmental way. We use this skill in parenting to attend to the needs of our children, and ourselves.

What does taking part involve?

If you choose to take part in this study, you will first be asked to answer some questions in a screening questionnaire, via an online survey. This survey will include questions about your child, their diagnosis and autism characteristics. We will use your responses to these questions to confirm that your child is 12-18 years old, and has a diagnosis of autism, and characteristics consistent with autism. You will also be asked to confirm that you are not currently enrolled in another parenting support programme. This will allow us to confirm that you are eligible to take part in the study.

After you have completed the online screening questionnaire, then Madeline Groom will contact you to confirm whether you are eligible to take part. If you are eligible, then Madeline will provide you with information about completing the questionnaires, and arrange a time when you can talk with the parent facilitator about the mindful parenting programme.

You will be invited to complete an online mindful parenting programme for 8 weeks. The mindful parenting programme will involve:

- Four online modules, which include written content, videos and audio recordings.
- Home practice of mindfulness skills, supported by video and audio recordings, and a workbook.
- Three group Zoom sessions, with up to 6 other parents and caregivers. The group will be facilitated by Juliana Edwards, who is a trained parent facilitator with experience of parenting an adolescent on the autism spectrum, and mindfulness.

Through the mindful parenting programme you will learn mindful parenting skills. Learning the mindful parenting skills will include some meditation and imagination practices. Through these practices you will learn to direct your awareness to what is happening in the present moment; to be aware of your own thoughts and emotions; and to respond rather than react in challenging parenting situations.

You will be asked to complete a set of questionnaires via an online survey on three occasions: before starting the programme, after completing the programme and again 8 weeks after the programme finishes. While you are taking part in the mindful parenting programme, you will be asked to complete a few questions online each week. These questions will ask about your wellbeing and your child's behaviour, as well as what you think about the mindful parenting group sessions.

You will also be invited to take part in an individual interview with Madeline Groom 8 weeks after the programme finishes. You will be given the choice to take part in the interview on Zoom or in-person at the University of Canterbury. The interview will take approximately one hour, and will involve answering questions about your experiences of the mindfulness parenting programme. The interviews will be recorded (in-person audio recording; Zoom audio-video recording). The recordings will help us to summarise the discussion, and analyse the information from all participants. You will be offered the opportunity to review a transcription of your interview before this is included in the data analysis.

You will be offered koha of a $25 Prezzy card on each of three occasions through the study – upon completion of two online surveys and after taking part in the end of study interview. You can request a summary of the findings from this study.

Your participation in the study is voluntary. You have the right to withdraw from the study and the parenting group at any stage. You do not need to provide a reason for withdrawing. We can also remove any information collected about you and your questionnaire responses if you would like. After data analysis has begun, then it will not be possible to remove your data.

It is possible that you may know another parent who is taking part in the mindful parenting group. This might pose a social risk to you. For this reason, each parent taking part in the group will sign a confidentiality agreement to say that they will not share personal information from the group discussion with anyone outside of the study.

Taking part in this study will involve thinking about and talking about your own wellbeing, your experience of parenting and about your child on the autism spectrum. These aspects of the study could cause some emotional stress. If you do experience emotional stress while taking part in the study, then please let the group facilitator or researcher know. They will talk to you about the stress, and give you some information about seeking support.

If you would like advice about local and national support available to Autistic people, and their families, in Aotearoa New Zealand, then we recommend contacting one of the national autism organisations below:

Autism New Zealand - https://www.autismnz.org.nz/

Altogether Autism - https://www.altogetherautism.org.nz/

Data and security

All the information we collect from the study will be confidential. The data and any personal information about you (for example, your name, email address) will be stored in separate password protected files, on the University of Canterbury secure server. The Masters student (Madeline Groom) and Principal Investigator (Lisa Marie Emerson) will manage these files. Only members of the research team will be able to see these files. Any paper copies of information or data (e.g. consent forms) will be stored in a locked filing cabinet at the University of Canterbury. We will not keep the data, or recordings, with your name or contact information. We will securely destroy your contact details after 10 years.

We will make the data anonymous by taking out all information that can identify you. There is no limit on how long we will store this anonymised data for. This anonymised data may be made available to other researchers for their own future research, either by request or via a data repository.

We will publish the anonymised data from this study. The public will be able to read these publications. Quotations about your experience of the mindful parenting group may be used in the publications. We will not report personal information about individual participants. We will not edit, rearrange, or use any quotations out of context. To ensure your anonymity and confidentiality, we will use pseudonyms (made-up names) in the publication of any quotations. We will not report any information that may identify you. You can choose your own pseudonym.

We are making a list of parents and caregivers of children on the autism spectrum who are interested in taking part in future research studies with our research group at the University of Canterbury. We will use this list to send information about upcoming studies. This information will be stored securely, and only people in our research team will have access to this information. If you would like your information to be included on this list, then please let us know. This is optional, and not a requirement of taking part in this study.

For more information

If you have any questions about the study at any stage, you can contact the Principal Investigator:

Lisa Marie Emerson
Phone: 03 369 4398
Email: lisa.emerson@canterbury.ac.nz

If you would like to make a complaint about the study, you can contact the Chair of the University of Canterbury Human Ethics Committee that approved this study:

Email: human-ethics@canterbury.ac.nz

This study has been given ethical approval by the University of Canterbury Human Ethics Committee at the University of Canterbury. This means that the committee may check at any time that the study is keeping to ethical procedures.

If you would like to take part

If you would like to take part in this study and mindful parenting group, then please use the link below to complete the consent form and screening questions:

[link]

Alternatively, if you would like to receive this information and consent form by post, or email, or complete this with a researcher over the phone, then please contact [Masters student information].

If more people express an interest in taking part in this study than we have capacity for, then we will let new volunteers know that this is the case and share information about where they can get more information about mindfulness for parents, or parenting support.

Thank you for taking the time to read this information sheet.

Appendix C

Consent and Screening Survey

Te Rāngai Ako me to Hauora | College of Education, Health and Human Development
Te Kura Mātai Hauora | School of Health Sciences
University of Canterbury
Private Bag 4800
Christchurch
New Zealand

CONSENT FORM (online)

Please tick, or place an X next to the statement, to indicate you agree to the following:

☐ I have been given a full explanation of this study.

☐ I have had the opportunity to ask questions.

☐ I understand what I will be asked to do if I take part in the study.

☐ I understand that it is voluntary (my choice) to take part in this study.

☐ I understand I can leave the study at any time without penalty.

☐ I understand that leaving the study will also include deleting the information I gave, if possible.

☐ I understand that the end of study interview will be audio or audio-video recorded.

☐ I understand that only the research team can see the information or opinions I give.

☐ I understand that any published or reported results will not identify me.

☐ I understand that all data from the study will stay in locked and secure facilities. Electronic data will also be password protected.

☐ I understand that the researchers will keep my personal information for 10 years.

☐ I understand that the researchers will keep anonymized data indefinitely (no time limit).

☐ I understand that the researchers may make the anonymized data from this study available for future research.

☐ I understand the risks associated with taking part in the study, and how they will be managed.

☐ I know who to contact for more information about the study.

☐ I know who to contact if I have a complaint about the study.

☐ I will not share personal information or opinions that we talk about in the parenting group with people outside of the parenting group.

☐ I agree to take part in this study.

I would like a summary of the findings from this research study: YES/NO

I would like to be contacted by this research team about future research studies about autism: YES/NO

Name:____

Date:________________________

Email address: ____

Screening questions.

1) This research is open to parents and caregivers of an adolescent on the autism spectrum, aged 12 – 18 years. Please confirm that you are a parent or caregiver of an adolescent on the autism spectrum:

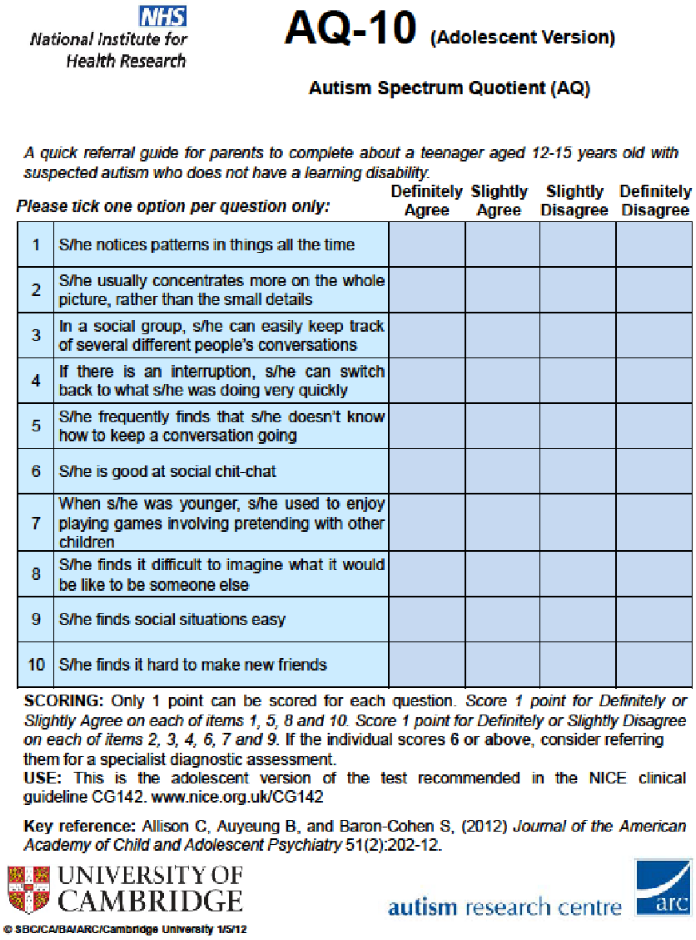
- Yes [next question]
- No [screen out to thank you page]

2) Age of your child on the autism spectrum: (years)

3) You are not able to take part in this study if you are currently enrolled in another parenting programme. Are you currently enrolled in another parenting programme?

- No [next question]
- Yes [screen out to thank you page]

Parents will also complete the Autism Spectrum Quotient – 10 in relation to their child, at screening via an online survey hosted on Qualtrics (see copy below), and be asked to email a copy of their child's diagnosis report to the Masters student researcher.



NHS
National Institute for
Health Research

AQ-10 (Adolescent Version)

Autism Spectrum Quotient (AQ)

A quick referral guide for parents to complete about a teenager aged 12-15 years old with suspected autism who does not have a learning disability.

Please tick one option per question only:

		Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
1	S/he notices patterns in things all the time				
2	S/he usually concentrates more on the whole picture, rather than the small details				
3	In a social group, s/he can easily keep track of several different people's conversations				
4	If there is an interruption, s/he can switch back to what s/he was doing very quickly				
5	S/he frequently finds that s/he doesn't know how to keep a conversation going				
6	S/he is good at social chit-chat				
7	When s/he was younger, s/he used to enjoy playing games involving pretending with other children				
8	S/he finds it difficult to imagine what it would be like to be someone else				
9	S/he finds social situations easy				
10	S/he finds it hard to make new friends				

SCORING: Only 1 point can be scored for each question. *Score 1 point for Definitely or Slightly Agree on each of items 1, 5, 8 and 10. Score 1 point for Definitely or Slightly Disagree on each of items 2, 3, 4, 6, 7 and 9.* If the individual scores **6 or above**, consider referring them for a specialist diagnostic assessment.

USE: This is the adolescent version of the test recommended in the NICE clinical guideline CG142. www.nice.org.uk/CG142

Key reference: Allison C, Auyeung B, and Baron-Cohen S, (2012) *Journal of the American Academy of Child and Adolescent Psychiatry* 51(2):202-12.

UNIVERSITY OF CAMBRIDGE

autism research centre arc

Appendix D

programme Evaluation

Parents will complete the programme evaluation questionnaire upon completion of the MP programme.

Please take a moment to tell us what you think about the Two Hearts programme and personal changes that you have experienced. There are no right or wrong answers. Please indicate what is right for you for each question.

1. Do you feel you got something of lasting value or of importance by participating in the Two Hearts programme?

   Yes: ☐ No: ☐ Prefer not to answer: ☐

2. Have you made any changes in your lifestyle, in relating with your child or family, or in your parenting practices as a result of participating in the programme?

   Yes: ☐ No: ☐ Prefer not to answer: ☐

3. Did you become more aware of your parenting as a result of participating in the programme?

   Yes: ☐ No: ☐ Prefer not to answer: ☐

4. Did your thoughts, or your feelings, about your parenting change through the programme?

   Yes: ☐ No: ☐ Prefer not to answer: ☐

5. Is it your intention to keep on practicing the mindfulness practices that you have learned (i.e., the body scan, sitting meditation, 3-min breathing space, walking meditation, standing and lying yoga)?

Yes: ☐ No: ☐ Prefer not to answer: ☐

6. Is it your intention to keep on practicing mindfulness in your daily life as a parent?

Yes: ☐ No: ☐ Prefer not to answer: ☐

7. During the programme, how many times a week, on average, did you practice the mindfulness practices?

Never: ☐ 1-2 times: ☐ 3-4 times: ☐ 5-7 times: ☐

8. How often do you pay attention to your child in moments when you are together now, compared to before the programme?

Less than before: ☐ As much as before: ☐ More than before: ☐ Much more than before: ☐

Please use the scale below to indicate how useful you found each part of the Two Hearts programme:

1 = not at all useful

5 = moderately useful

10 = extremely useful

	Not at all useful				Moderately useful					Extremely useful	Prefer not to answer

Sitting meditation in the group	1	2	3	4	5	6	7	8	9	10	
Sitting meditation at home	1	2	3	4	5	6	7	8	9	10	
Walking meditation in the group	1	2	3	4	5	6	7	8	9	10	
Walking meditation at home	1	2	3	4	5	6	7	8	9	10	
Body scan in the group	1	2	3	4	5	6	7	8	9	10	
Body scan at home	1	2	3	4	5	6	7	8	9	10	
Yoga in the group	1	2	3	4	5	6	7	8	9	10	
Yoga at home	1	2	3	4	5	6	7	8	9	10	
3-min breathing space	1	2	3	4	5	6	7	8	9	10	

Mindful awareness in daily parenting	1	2	3	4	5	6	7	8	9	10	
Mindful awareness of parenting patterns and schemas	1	2	3	4	5	6	7	8	9	10	
Self-compassion and loving-kindness	1	2	3	4	5	6	7	8	9	10	
Group discussions	1	2	3	4	5	6	7	8	9	10	
The homework logs / diaries	1	2	3	4	5	6	7	8	9	10	
The information in the workbook	1	2	3	4	5	6	7	8	9	10	

Please indicate if you experienced change in any of the following aspects of your life by participating in the Two Hearts programme.

1	Knowing to take care of myself	Negative change	No change	Some positive change	Positive change	Prefer not to answer
2	Actually taking care of myself	Negative change	No change	Some positive change	Positive change	Prefer not to answer
3	How often I experience parenting stress or frustration	Negative change	No change	Some positive change	Positive change	Prefer not to answer
4	The intensity of parenting stress or frustration	Negative change	No change	Some positive change	Positive change	Prefer not to answer
5	Believing that I can improve the relationship with my child and family	Negative change	No change	Some positive change	Positive change	Prefer not to answer
6	Feeling self-confident as a parent	Negative change	No change	Some positive change	Positive change	Prefer not to answer
7	Feeling hopeful as a parent	Negative change	No change	Some positive change	Positive change	Prefer not to answer
8	Dealing with emotions (anger, sadness, fear) in parenting	Negative change	No change	Some positive change	Positive change	Prefer not to answer
9	Awareness of what is stressful in my life	Negative change	No change	Some positive change	Positive change	Prefer not to answer

10	Awareness of stressful parenting situations in my life	Negative change	No change	Some positive change	Positive change	Prefer not to answer
11	Awareness of stressful parenting situations at the time they are happening	Negative change	No change	Some positive change	Positive change	Prefer not to answer

Appendix E

Semi-Structured Interview

The one-to-one interview will follow this broad structure, with additional follow-up and prompt questions asked where appropriate.

We are interested in hearing about your experiences of the mindfulness-based parenting group.

Tell us about your experience about taking part in the MP programme.

(a) What components of the MP programme did you find useful? (content, structure, facilitation, online content and Zoom sessions, etc)

(b) What components of the MP programme were not useful to you?

(c) How did you find the mindfulness practices? (recordings, home practice, application to daily life and parenting)

(d) Is there anything from the programme that you will take forward in your life as a parent?

Tell us about any changes you've noticed since taking part in the MP programme.

Have you noticed any changes in your

a) parenting?
b) own stress or emotional wellbeing?

c) child's behaviour?

d) your relationship to your child/ren?

Any other changes?

Any further thoughts

Thank you once again for taking part in this study. Is there anything else related to your experience or opinion about the mindful parenting group that you would like to tell us?

Appendix F

MP programme Outline

Module Format	Module Title	Themes	Mindfulness Practice	Specific Mindful Parenting Exercise	Home Practice
Module 1 (Weeks 1 and 2) Series of four short videos, audio file, programme workbook, home practices (approx. 3 hours)	Mindful Awareness in Parenting	Introduction to Mindful Parenting and orientation to programme; The evolution of parenting stress; Body awareness and the stress response; Finding a Breathing Space	3-min Breathing Space	Imagination: parenting stress exercise	Parent Workbook readings; 15 min guided Body Scan practice (1 pd, 5 times pw); Breathing Space (2 pd, 5 times pw); use of optional mindfulness home practice record
Module 2 (Weeks 3 and 4) Series of four short videos, home practices (approx. 3 hours)	Mindful Parenting in Action	Automatic pilot parenting; Body awareness and Mindful Movement; Rupture and Repair	Mindful Movement	Imagination: Rupture and Repair exercise	Parent Workbook readings; 15 min guided Body Scan practice (1 pd, 5 times pw); Breathing Space (2 pd, 5 times pw, and use during stressful interaction); Parenting Stress Diary (1-3 entries pw); Rupture and Repair process at home; use of optional mindfulness home practice record
Module 3 (Weeks 5 and 6) Series of two short videos, audio file, *Useful Resources* PDF, home practices (approx. 2 hours)	Compassion in Parenting	Compassion, Stress and the Body; Growing Self-Compassion	Soothing Rhythm Breathing (Gilbert, 2009); Self-Compassion Break (Neff & Germer, 2013)	Imagination: compassion for self during parenting stress exercise	Parent Workbook readings; '*What Do I need?*' reflective exercise (Bögels & Restifo, 2014; Germer, 2012); Individualised commitment practice based on practices learned to date; inclusion of Module 3 Self-Compassion practices; use of optional mindfulness home practice record
Group Support Sessions Zoom video-conferencing (up to 90 minutes, once before the programme, and three times during the programme at the end of weeks 2, 4, and 6)	N/A	Review of individual mindfulness practice and mindful parenting scenarios; Positive reinforcement of parent efforts; Collaborative problem-solving of barriers and challenges in mindfulness practices	N/A	N/A	N/A

Appendix G

PBS-A Cronbach’s Alpha and Standard Deviations

Stimulating Development	Cronbach’s alpha = 0.81 SD (G) = 0.49 SD (B) = 0.46
Adapting the Environment	Cronbach’s alpha = 0.69 SD (G) = 0.52 SD (B) = 0.52
Positive Parenting	Cronbach’s alpha = 0.87 SD (G) = 0.50 SD (B) = 0.47
Discipline	Cronbach’s alpha = 0.79 SD (G) = 0.74 SD (B) = 0.75
Harsh Punishment	Cronbach’s alpha = 0.81 SD (G) = 0.44 SD (B) = 0.44
Rules	Cronbach’s alpha = 0.85 SD (G) = 0.50 SD (B) = 0.45
Material Rewarding	Cronbach’s alpha = 0.69 SD (G) = 0.56 SD (B) = 0.60

Note: SD = Standard deviation, G = girls, B = boys.

Appendix H

CBCL Cronbach’s Alpha and Standard Deviations

Internalising Subscale	Cronbach’s alpha = 0.90 SD (G) = 10.5 SD (B) = 9.1
Externalising Subscale	Cronbach’s alpha = 0.94 SD (G) = 13.3 SD (B) = 13.0
Total	Cronbach’s alpha = 0.97 SD (G) = 32.7 SD (B) = 30.9

Note: SD = Standard deviation, G = girls, B = boys.