University of Reading

How can we best support mothers of children with sensory processing differences that impact participation in daily occupations from a coaching perspective?

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Declaration

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Susan Allen

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Preface

This research journey started with a box of tissues and a cup of coffee. Chatting with the occupational therapy team over a coffee break we realized that mothers were frequently tearful and distressed when attending children's initial occupational therapy assessment and feedback sessions. Mothers often reported relief at identification of underlying difficulties alongside frustration at the length of time it often took to access any acknowledgement or support. This led to a research study aimed at exploring levels of maternal stress and its possible correlates (Allen & Knott, 2016). Two factors were evident one was social support, and the other was sensory differences. At a similar time, the Dingley child development occupational therapy team undertook an audit of a recently introduced parent and teacher training session (Simmonds et al., 2016). Parents and teachers reported that the sessions were useful and descriptively that it was informative, and supportive. However, no evidence was available to identify if this was the best way to support these families or if the information received in the groups was then applied to everyday life. This thesis is an attempt to begin to unravel the next step in supporting families.

Thesis Abstract

Many children experience sensory differences that are associated with disruption to child and family daily occupations and increased maternal stress. Emerging evidence suggests that a one-to-one coaching approach with parents is helpful, but there are numerous gaps in both. The current studies aim to identify gaps in current evidence, to ascertain what mothers find helpful, then to pilot a brief online group coaching intervention based on occupational performance coaching for mothers of children with sensory differences.

Study 1: A scoping review identified current knowledge and gaps in the literature, showing that there is some limited evidence for individual or family coaching, but evaluation of group coaching was missing.

Study 2 and 3: As the scoping review highlighted that mothers' voices were rarely heard in studies, qualitative semi-structured interviews with six mothers and then a large-scale survey with 132 participants explored mothers' everyday experiences. Using both thematic and descriptive analysis, the significant impact of sensory differences on both mothers and children's everyday life and relationships was clear. Mothers are empowered by relationships based on listening, gaining knowledge, and understanding as well as adapting activities and the environment to accommodate for child's sensory needs. Supportive social and professional relationships, media, social media, and direct intervention to mothers were reported by mothers as helpful. The survey sample was split by mothers of autistic versus non-autistic children. The mothers of autistic children with sensory differences reported greater levels of challenge in everyday activities and relationships, particularly in the school and community. Supportive relationships, media and parent intervention was equally helpful to both subsamples of mothers of children with sensory differences.

Study 4: A pilot study of a brief online group coaching with eleven mothers of children with sensory differences explored the acceptability of the intervention to mothers and demonstrated coaching was perceived to build social networks and reduce maternal stress as well as improve child occupational performance.

A wide range of approaches to intervention are helpful to mothers of children with sensory differences including supportive relationships, media, and parent intervention. Brief online group coaching is supported by emerging evidence but requires further study.

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1 Chapter 1: Introduction

How can we best support mothers of children with sensory differences that impact participation in daily occupations, from a coaching perspective?

Occupational therapy promotes participation in the everyday activities or occupations that we need or want to do. These occupations should be meaningful to the individual. In doing so occupational therapists consider the person, their occupations and the context or environment in which this takes place (World Federation of Occupational Therapists, 2023). Fundamental to occupational therapy practice, is that therapists should work inclusively without discrimination (Royal College of Occupational Therapists, 2021a).

The approach to this thesis topic has been shaped by ecocultural theory as opposed to a biomedical framework (Curtin et al., 2017; Llewellyn, 2012). In a biomedical framework there is a binary distinction that there is health or there is ill health/ disability. The aim of intervention is to remove ill health or disability to achieve a state of health. This assumes direct cause and effect in treating the problem of illness or disability. However, the biomedical approach does not consider the interrelationship between the individual and the environment.

The more socially based ecocultural framework sees functioning as an interaction between the individual and their cultural environment including social, physical and political attributes. A social model of health perceives the social context as the barrier or facilitator of health. For example, if a child struggles to participate in going to the toilet in a shopping centre because of the sound of the hand dryers, the environment is the barrier. The environment creates the disability. The action required would be to turn off the hand dryer or replace the hand dryer with soft paper towels and so enable participation in the occupation. In so doing the fit between the person and the environment improves enabling the occupation (Law et al., 1996). However, the ecocultural perspective differs from the social model by considering the characteristics of the individual as interactive with the quality of the environment (Dwyer, 2022).

The ecocultural perspective aligns more readily with a neurodiverse affirming approach that does not assign causation to the person or the environment but does advocate for the choice of action to be sat with the individual facing the challenge. For example, where a child / family are experiencing challenges in participation in daily mealtimes. The choice of the child/ family maybe for the child to work on extending their range of preferred food through direct therapeutic intervention or through adjusting the sensory qualities of the food/ environment. Placing the child and family at the centre of decision making in intervention supports a neurodiversity affirming approach (Dundon, 2024; Fulton et al., 2020).

The term neurodiversity was coined in the 90's within the autistic community to promote acceptance and inclusion (Kapp, 2020). While there is no fully agreed definition of neurodiversity there is consensus that neurodiverse conditions have underlying traits of processing and experiencing information differently from neurotypical peers (Dallman et al., 2022). Neurodiversity as a concept asserts that those with neurocognitive differences should be afforded the same respect as would be given to those of differing sexual orientation or race (Greenburg & Des Roches Rosa, 2020). Healthcare professionals are on a pathway of learning into how to integrate this into practice.

Current children's occupational therapy services in the United Kingdom are experiencing increasing demand. Children and young people are presenting with more complex needs and there are not enough staff to help them (Payne, 2022). This is an unsustainable equation. Occupational therapists are encouraged to advocate for children, young people, and families, and, to ensure that resources are used wisely. Wise use of resources requires a robust evidence base, for the outcome of the interventions that we have available to serve families. If we are to commit to occupational and social justice, families need support (Barrios-Fernandez, 2022).

The Royal College of Occupational Therapist in partnership with healthcare professionals, carers, and those who access services, identified the top ten research priorities for the profession. The third of these priorities focuses on how we can work more effectively with the families, and carers of people who access services, both to address the carers health and well-being, as well as the care and well-being of those they support (Micklewright & Farquhar, 2022). Mothers are both a key component of a child's environment but also a person in themselves. How we support mothers who are facing additional caring demands of a child with sensory differences needs further research.

This thesis aims to provide a clearer understanding of what mothers of children with sensory differences find helpful to everyday life and how a coaching intervention may increase support to these mothers. This introduction will identify our understanding of the impact of child sensory differences on children and their mothers. The next step will be to discuss what we know about mothering a child with additional needs and specifically sensory differences. The rationale, for further exploration of the impact of child sensory differences on the daily lives of mothers and these children, will be identified. It will then explore the evidence around current occupational therapy intervention. Then finally what coaching might offer in terms of improvement to everyday life for mother and child.

1.1 Sensory differences

Sensory differences in the typical population are thought to be between 3 and 15% (Ahn et al., 2004; Galiana et al., 2022; Gouze et al., 2009). However, higher rates are noted in neurodiverse individuals. In a United Kingdom study of autistic children, a prevalence of sensory modulation difficulties of over 70% was recorded (Adamson et al., 2006). In the United States rates of sensory differences reactivity in autism have reported to be as high as 95% (Tomchek & Dunn, 2007) as measured by the Short Sensory Profile (Dunn, 1997). Also in a US cohort 46% of children diagnosed with Attention Deficit and Hyperactivity Disorder (ADHD) were reported to have sensory differences (Lane et al., 2010), as measured by the Sensory Over-responsivity Scale (Schoen et al., 2008). In a United Kingdom cohort of children with Developmental Co-ordination Disorders 88% experienced reported sensory differences (Allen & Casey, 2017), as measured by Sensory Processing Measure (Parham et al., 2007). Criticisms of prevalence studies include inconsistent use of terminology, small participant numbers, reliance on parent reporting, variable use of measurement tools and thresholds of diagnosis of a difficulty, as well as insufficient reporting of methodology (Ben-Sasson et al., 2009). However, it is apparent that children with neurodevelopmental diagnoses are more likely to experience sensory differences. It is also important to note the sensory differences occur not only alongside neurodevelopmental disorders but also where no developmental diagnosis is observed (Dean et al., 2022; Owen et al., 2013). Therefore, while sensory differences are more prevalent alongside neurodiversity they can be observed independently of any diagnosis. Not all children with neurodiversity have sensory differences and not all children with sensory differences are neurodivergent.

The Current Diagnostic and Statistical Manual of Mental Disorder (DSM-5) (American Psychiatric Association, 2013) identifies 'hyper or hypo reactivity to sensory input or unusual interest in the sensory aspect of the environment' as a diagnostic criterion for Autism. DSM-5 does not at present formally recognize sensory differences in any other developmental or behavioural disorder or as a stand-alone diagnosis (Zimmer et al., 2012) despite the evidence on high rates across neurodiverse conditions.

1.1.1 What is sensory processing and sensory integration

All of us process and integrate sensory information. This helps us to regulate our nervous systems and act on that information appropriately e.g. identifying when we are thirsty and then using that to drive the motor action of seeking out a drink. Processing and integrating sensory information subserve our development of life skills by impacting self-regulation, behavior, social interaction, and development of refined and sequenced motor skills (Bundy & Lane, 2019). Sensory processing has been defined very broadly as the mechanism connecting humans and their environment (Williams, 2017). Sensory integration is described as the perception and synthesis of sensory data that enable a person to interact effectively with their environment. Both sensory processing and sensory integration have previously been identified as types of dysfunction (Ayres, 2005).

‘Sensory processing’ and ‘sensory integration’ disorders are not recognized as diagnostic terms. However the diagnostic criteria for autism (American Psychiatric Association, 2013) include hyper-reactivity as an adverse response to sensory stimuli, hypo-reactivity as an indifference to sensory stimuli and, sensory craving as an excessive desire for sensory input. Extensive research (DeBoth & Reynolds, 2017) and first-person accounts, for example Kirby, Dickie, et al. (2015), have described sensory differences experienced by autistic people. Recognizing neurodiversity affirming language, the current preferred term, in line with the Royal College of Occupational Therapists (2021b), is sensory differences. Confusingly the terminology will be varied within this thesis to accommodate the preferences of journals that the work has been or will be submitted to. However, where possible the term sensory differences are preferentially used.

The term ‘sensory integration’ was first used by Ayres in 1963, an academic psychologist and occupational therapist who explored the association between sensory integration and behavior, emotional responses, and learning (Ayres, 1963). There are four frameworks that have been used to explain or classify sensory differences that are associated with challenges in everyday life, each directly or indirectly acknowledging Ayres (Ayres, 1973) original contribution to the topic. The first has been most recently described in the work of Bundy and Lane (2019) who defined the Complex Schematic representation of sensory integration dysfunction, linking neurological structures and the sensory systems to classifications of sensory modulation and discrimination/ praxis. This model provides a representation of our neurological understanding of the subject, whilst acknowledging that the current evidence base reflects an evolving understanding. This framework is supported by the work of Lane, Mailloux, et al. (2019) who explicitly link the function of the vestibular, proprioceptive and tactile system and their relationship to ocular, postural, bilateral integration, praxis and sensory modulation.

For the second framework Lucy Miller (Miller et al., 2007) developed the work in a slightly different way with a proposed nosology for the identification of sensory processing. Miller et al. (2007) described differences in modulation (sensory over responsivity, sensory under responsivity and sensory seeking/ craving), sensory movement-based disorders (including postural control and praxis or motor planning) and sensory based discrimination disorders (qualitative interpretation of sensory information). This structure provides an accessible method to aid understanding of this complex topic.

The third framework, describes another structure for classification of sensory differences, comes from the work of Dunn (1997). Dunn described a conceptual model featuring four basic patterns of sensory processing emerging from the interaction between neurological thresholds and behavioral responses. Neurological thresholds are the threshold at which a person notices or responds to a sensory stimulus. If a threshold is low, a response would be easily activated. The risk would be an over-response to a sensory cue, for example when a child walking down a busy corridor is brushed against by someone, they may perceive the touch as threatening and respond aggressively by lashing out. If a threshold is high a stronger stimulus would be required for a person to notice or respond to the sensory cue, with a risk that the stimulus and therefore learning opportunity would be missed. In terms of behavioral responses, the range is from passive to active. In a passive response, the individual would not engage with a stimulus, whereas an active response would be reflected in utilization of active strategies to adapt to or avoid the stimulus. The resulting four patterns are sensation seeking (high threshold and active self-regulation strategy), sensory avoiding (low thresholds and active self-regulation strategy), sensory sensitivity (low threshold and passive self-regulation strategy), and low registration (high threshold and passive self-regulation strategy). Dunn's approach emphasizes that everyone is on the continuum somewhere rather than seeing differences in sensory processing as a disorder. Metz et al. (2019) explored the neurological threshold and behavioural responses in typical adults and, confirmed the ordinal scale nature of threshold but not behavioural responses. Furthermore, they suggest that behavioural responses are likely to be a product of the interaction between the individual and the environment, favouring a top-down approach to intervention. In contrast, the threshold axis is suggested to be a personal, endogenous characteristic that may lend itself to a bottom-up approach to intervention.

These first three frameworks offer us an insight into the link between how we hypothesize that sensory information is processed, and how that affects observable behavior and physiological responses. However, there remains a lack of empirical evidence to support the direct links between neurological sensory systems and function (Lane, 2020).

The fourth framework is a recently developed working taxonomy of sensory differences in autistic individuals (He et al., 2023). The taxonomy proposes five levels of analysis that are organized approximately hierarchically. The first level is of sensory related ‘*neural activity’* or how sensory related central and peripheral neural structures activate in response to sensory stimuli. The second level is defined as ‘*perceptual sensitivity’* and describes how an individual detects and discriminated the characteristics of low-level sensory information. The third level is ‘*physiological reactivity*’ to sensory input and refers to how much an individual displays changes in relevant bodily processes in reaction to sensory input, for example galvanic skin response or cortisol levels. The fourth level is ‘*affective reactivity’* to sensory input and describes how a person appraises and reacts to sensory input. The final level is “*Behavioural responsivity’* to sensory inputs, reflecting how an individual responds or not to sensory input they may find discomforting or pleasurable. From a clinical perspective this taxonomy helpfully links a variety of assessment to each of these levels. However, this model is so recent that it was not used in the development of the research in this thesis.

Defining sensory issues is one step in an intervention process but definition of sensory differences alone may not elicit change for the individual and their family. In line with Royal College of Occupational Therapists (2021b) sensory differences are only of concern when they impact participation in daily occupations. As such sensory differences should be considered in the context of the person's occupational engagement and performance within their relevant environment. Understanding the interaction between the child, their daily occupations and their social and physical environment is key to effective intervention.

1.1.2 Impact of sensory differences on the child

Sensory differences are observed from early development and are associated with fussy behaviour, difficulty engaging in co-occupations with caregivers such as dressing and bathing (Purvis et al., 2013), feeding, and sleeping disorders (Tauman et al., 2017). Sensory differences are also identified as risk factors in psychopathology (Gouze et al., 2009), social emotional problems, adaptive social behaviour, motor behaviour and anxiety (Lane et al., 2010; Mattard-Labreque et al., 2013). Sensory differences have also been noted to be predictive of later developmental challenges. Chen et al. (2023) explored the trajectory of infants with sensory differences through to school age and found links to developmental challenges, such as social responsiveness, adaptive behaviour, motor, and daily living skills, by school age.

Through childhood, difficulties in sensory differences are demonstrated to interfere with participation across environments including home, educational and leisure activities (Bar-Shalita et al., 2008; Chien et al., 2015). As an example, and although limited to autistic children with sensory differences, two authors have demonstrated the negative impact of sensory differences on classroom, learning (Jones et al., 2020) and behaviour (Alateyat et al., 2022). Both studies explore observational data from the teacher’s perspective only, without the child’s voice. However, sensory differences act as a barrier to participation in the occupations of everyday life for children and their families at home, at school and in their community leisure activities. Sensory differences have an impact on the child participation in occupation, but what about the family?

1.1.3 Impact on family

In a large birth cohort-based study, sensory over-responsiveness alone conferred a unique risk for family impairment leading to restrictions on the family social and personal lives. For example: avoiding taking the child to visit friends or parents reporting feeling exhausted all the time (Carter et al., 2011). Similarly, a small qualitative study explored family routines when living with autistic children with sensory related behaviours (Schaaf et al., 2011). Sensory behaviours limited family participation in work, family, and leisure activities.

Caregivers can develop strategies to manage individual and family routines despite these challenges. Primary caregivers describe the need for flexibility, and vigilance and, the need to avoid, anticipate and plan ahead (Bagby et al., 2012; Jones et al., 2020). Parent and child adaptation, and the ability to establish routines evolves over time (Daly et al., 2022; Fletcher et al., 2019). In summary sensory differences impact everyday family life and parents adapt their routines and occupations to accommodate the child's sensory needs.

1.1.4 Impact on primary caregivers

When looking more specifically at the impact on primary caregivers we see that adaptation over time may come at some cost to the primary caregiver. In a large cross-sectional survey of mothers of autistic children, maternal psychological distress was associated with poorer child auditory processing and higher tactile sensitivity (Suzuki et al., 2019). Similarly, the association between caregiver strain and child sensory differences has been identified in number of studies. Kirby, White, et al. (2015) found support for the correlation between sensory features (hyperresponsivity, sensory interests, repetitions and seeking behaviours) and caregiver strain in children with developmental disabilities. Caregiver strain was defined as 'the demands, responsibilities, and negative psychic consequences of caring for a relative with special needs' (p.32). Hand et al. (2018) found in contrast that strain was positively associated with more general sensory reactivity and multisensory integration.

Parent stress is associated with sensory differences in young children with developmental issues, behavioral issues (Gourley et al., 2013), and autism (Chiang et al., 2019). When exploring the subscales of the Parent Stress Index – Short Form (Abidin, 2012) increased sensory differences were associated with both total parent stress and the 'difficult child' subsection (Gourley et al., 2013). The total parent stress is calculated by the sum of the scores of child characteristics, parent characteristics and situational variables. The 'difficult child' subsection quantifies the extent to which the characteristics of the child make them difficult to manage. When looking in more detail at sensory features, stress was raised with more extreme child sensory responses, sensory interests, repetitions and seeking behaviours (Ausderau et al., 2016). Focusing more specifically on mothers of children with

Asperger's syndrome (Epstein et al., 2008) and autism (Nieto et al., 2017), a correlation between total parent stress and sensory differences were also demonstrated. The studies were mostly cross sectional, with only the Ausderau et al. (2016) collecting longitudinal data. This means that there is a gap in our understanding of the longer-term impacts of sensory differences and parent stress. Most studies were specific to parents and carers of autistic children apart from Gourley et al. (2013) who focused on parents and carers of children attending an out-patient clinic with social-emotional, behavioural, and developmental problems. Finally, although all studies used the Parent Stress Index-Short Form (Abidin, 2012), a variety of tools were used to assess sensory differences. Direct comparison of the data is therefore not possible. However, the link between maternal stress and child sensory differences is established in mothers of pre-school and school age children with a range of behavioural and developmental concerns.

1.2 Mothering as an occupation

Occupations refer to what we do, through work, play and activities of daily living. Our occupations are characterized by our roles, habits and routines and shaped by the context of our temporal, physical and socio-cultural environment (Taylor & Keilhofner, 2017). When our daily occupations reflect a balance between meaningful work and leisure roles we attain the concept of occupational balance. However, when the demands or allocation of time required for one occupation preclude another, we experience occupation imbalance compromising health and quality of life (Backman, 2004; Christiansen & Townsend, 2004).

Mothering is a lifetime occupation (Francis-Connolly, 2004), also described as a complex occupation with layered roles and responsibilities (Esdaile et al., 2004). Societal expectations and personal capacity lead to a unique experience for each mother. Common themes of experience are observed however caring and nurturing are identified as prevalent roles across child age ranges (Francis-Connolly, 2000; Shrestha et al., 2019). Enfolded activity occurs when 'multiple tasks require attention simultaneously' (Francis-Connolly, 2000)(p.282). For example, preparing meals while acting as a play partner. Enfolded occupations are observed in the occupation of mothering.

A lack of predictability is particularly associated with mothering a preschool child (Francis-Connolly, 2002), and as such it disrupt habits and routines. A disruption of habits can create a sense of disorientation and imbalance (Taylor et al., 2023) reflecting a period of occupational imbalance The developing role of motherhood is balanced against loss or adjustment of income, sleep, control, sense of self and potentially relationships with other (Shrestha et al., 2019).

Bar and Jarus (2015) also noted a sense of role overload experienced by mothers and identified the buffering effect of social support. This link between the challenges that mothers experience and the positive effect of social support is seen across several studies with mothers of typically developing children (Fang et al., 2022; Machado et al., 2020). A sense of organization and support aids mothers' sense of their own role management efficacy, reflecting a shift back to occupational balance. Mothers are aided in their roles by connection with people and culture and specifically peer to peer support (Machado et al., 2020; Odgers et al., 2023). Mothering a typical child is intensive and demanding but social support helps.

Before moving on it is important to acknowledge the impact of parental stress on both the child and the mother. For the child, raised parent stress is extensively associated with poorer physical and mental health outcomes (Fields et al., 2021; Larkin & Otis, 2019; Stone et al., 2016) and increased risk of abuse (Martins et al., 2023). For the mother raised stress is associated with increased mental health concerns and less capacity to be responsive to the child (Martins et al., 2023).

1.2.1 Mothering a child with additional needs

Mothering a child with additional needs creates additional care demands on mothers (Bamber et al., 2023; Cheng & Lai, 2023; Papadopoulos, 2021; Smith et al., 2013). An example of this is seen in mothers of children with feeding concerns. Mothers identified stressors in dealing with the child's needs and in dealing with health and education professionals that were unresponsive to them (Winston et al., 2010). When parents are not listened to, understood, or validated, they experience a sense of isolation. This sense of isolation can be further impacted through loss of opportunity to engage in work roles or social events outside the house (Olson & Esdaile, 2000). Therefore, mothers of children face barriers to social support from professional and social networks. They also face missed opportunities to extend their own social networks associated with the caring demands of a child with additional needs. Mothers juggle the complex occupation of mothering within social environments that are not always supportive.

Mothers of children with disabilities devote more time to caregiving and household chores leaving less time for their own occupations (McGuire et al., 2004). Mothers bolster their own well-being through a positive mindset and a perception of control (Larson, 2000). A perception of control links back to the exploration of mothering by Francis-Connolly (2002) who identified the relationship between development of habits and routines with a sense of predictability and control. Establishing habits and routines helps mothers perceive a sense of control but children's additional needs may disrupt traditional mechanisms of developing those habits and routines. For example, multitasking or enfolding (doing more than one occupation at a time) is used by mothers of typically developing children but may not be as successful with atypically developing children. Segal (2000) found that mothers of children with Attention Deficit and Hyperactivity Disorder (ADHD) used enfolding of occupation. However, they found greater success with child participation in occupations when they focused on specific tasks or chunks of those tasks to support engagement with the child. This was described as unfolding occupations and was identified as 'advantageous' showing that flexibility of habits and routines are required of mothers of children with attention and behavioural challenges.

When comparing mothers of adolescents with typical development and those of adolescents with disabilities there are many commonalities. In a qualitative interviews study (Crowe et al., 2016) mothers of children with disabilities engaged in preparing the adolescent for independence, a role not highlighted in mothers of typically developing adolescents. This anticipatory driver of a child's future needs was also reported in a two-month naturalistic observational study of mothers of young children with disabilities

(Kellegrew, 2000). Kellegrew (2000) described the mother's occupation as 'an orchestration of daily routines' (p258), that appeared to be a blended process between accommodation of everyday events and anticipation of future needs. This reflects the temporal element of occupations, anchored in the present but very much planning for the child's future needs and independence. By helping mothers to have clarity on current experience the possibility of working towards future aims is opened. An example of this would be a mother's identification of dressing as a goal. In doing so the mother is reflecting on current performance but also what the child needs to do to develop skills to support future independence.

An important issue for this thesis is the notion of seen and unseen disability. Some differences are easily observable while others are not. Sensory differences lack an established diagnostic label (He et al., 2023) and are often not observable. To investigate hidden impairments Cronin (2004) explored the experiences of mothers of children with Cystic Fibrosis, and ADHD. In this study these were described respectively as a physical and a behavioural disorder. The mothers of children with Cystic Fibrosis reported family and professional support and the ability to establish 'normal' routines in everyday life. In contrast the mothers of children with ADHD, a more hidden and less well accepted impairment, reported little family and professional support and difficulty establishing daily routines, linked to the unpredictable nature of their child's behaviour. Mothers reported feeling overwhelmed and simultaneously isolated from social support. Therefore, it can be argued that the occupational and social barriers created in mothering a child with ADHD, a more hidden impairment, have a greater impact on the social support network available to mothers.

The impact of hidden disability is further illustrated in mothers of autistic children who described feeling ignored, abandoned and like a 'burdened supermom' (Sutherland, 2002) (p.48). Raised parent stress is linked to having an autistic or developmentally disabled child (Valicenti-McDermott et al., 2015; Woodman et al., 2015). Parent stress is greater in parents of autistic children, compared to neurotypical children or children with other disabilities (Hayes & Watson, 2013). There are factors that can mitigate this stress. In a study of mothers of autistic children, risk of stress is reduced in higher income families, families of 3 or more children, through emotional social support and neighbourhood social support to the mothers (Zablotsky et al., 2013). This reflects the value of social support to mothers, though importantly, the perception of support is more strongly related to a sense of wellbeing rather than the amount of support received (Haber et al., 2007). Furthermore, parents of autistic children articulated the limitation of social and professional networks who did not understand the lived experience but reflected the importance of connecting with other parents with the same lived experience (Jones, 2018).

1.2.2 Mothering a child with sensory differences

Pragmatically, this thesis will focus on the mother rather than explore the experience of carers or fathers. While fathers and other primary caregivers are important, it is acknowledged that the mothers typically take a more intensive primary parenting role and are more engaged with the providers of education, support, and services (Gray, 2006; May et al., 2017). Therefore, rather than attempting to explore a wide approach at this stage the focus of the thesis is on the experience of mothers only. It is acknowledged that a broader perspective on fathers and carers is preferable longer-term. To date few studies have even explored the experience of mothers of children with sensory differences. The occupations in which mothers of children with sensory differences are engaged are specifically impacted by sensory differences. Mothers go to great lengths to adapt activities and the environment to support successful participation of the child e.g. recruiting additional adult support (Schaaf et al., 2011) adapting mealtimes, morning and evening routines at home (Bagby et al., 2012; Whitney & Theeke, 2019) and adjusting or avoiding social gatherings (Bagby et al., 2012; Schaaf et al., 2011).

Stress levels are excessively raised in mothers of children with sensory differences. The additional demand on mothers comes at some cost. Multiple authors have identified the association between child sensory differences and mothers stress and strain levels, in both mothers of children with and without a developmental diagnosis (Allen & Knott, 2016; Kirby et al., 2019; Nieto et al., 2017). Whilst maternal stress and strain are associated with autism, there is evidence that child sensory differences confer increased maternal stress in a degree to which family life routines are disrupted (Ben-Sasson et al., 2013; Chiang et al., 2019). Maternal stress and strain are greater than would be expected in those with autism alone. The risks to the physical and mental well-being and safety of both mother and child (Abidin, 2012) present a strong case for further exploration of mother's stress and, strategies that may ameliorate it.

Mothering is a complex and demanding occupation. Having a child with disability increases demands on mother's time and need for flexibility. When that disability is 'hidden' the support is less accessible. Mothers of children with sensory differences face increased demands in the everyday routines of family life, and this is reflected in raised maternal stress levels. However, our understanding of mother's experiences and more importantly what can help them is limited.

1.3 Intervention

Occupational therapist, support children and families to participate in the occupations that they need and want to do (Royal College of Occupational Therapists, 2019b). Services can be delivered to children and families through a range of settings, these might for example include Child and Adolescent Mental Health (CAMHs), school based or community paediatrics.

Whatever the setting there are many approaches to intervention that occupational therapists may use. A recent scoping review of school based occupational therapy identified that occupational therapists provide intervention to address individuals' occupations and activities through considering the demands of the activity and person factors, provision of assistive technology and environmental adaptions and address individual self-regulation. This is achieved through direct intervention, education and training of clients and carers and advocacy. Intervention is delivered through individual, group or virtual formats (Salazar Rivera et al., 2024). However, the evidence base for specific interventions is variable. For example a systematic review on the effectiveness of occupational therapy interventions in CAMHs services found limited evidence for cognitive and play interventions for children with Aspergers and Attention deficit and hyperactivity disorder (Brooks & Bannigan, 2021). A systematic review of intervention for children with Attention deficit hyperactivity demonstrated positive outcomes with mindfulness, weighted vets and executive function training with outcome measures on social interaction, process and cognitive skills. For children with Autism social skills interventions were supported (Watroba et al., 2024). Salazar Rivera et al. (2024) points out that there are gaps between the evidence base and the delivery of services.

A widely used approach to address sensory differences is direct intervention based on 'Ayres Sensory Integration'. Whilst studies have demonstrated evidence of significant gains in individualised goals and positive qualitative parent feedback, the recent Sensory integration therapy for children with autism and sensory processing difficulties: the SenITA randomised control trial (SenITA) in the UK concluded that ASI intervention did not offer a cost-effective strategy for meeting the behavioural challenges of autistic children. Despite the non-significant outcomes in relation to behaviour, significant occupational gains in the intervention group were observed (Randell et al., 2022). Whilst acknowledging the need for further research the International Council for Education in Ayres Sensory Integration (ICE-ASI) identifies measurable improvements in individualised goals for autistic children through a number of randomised controlled trials of ASI (Schaaf & Auld-Wright, 2023). Adaption of the environment or occupation are alternative ways to approach intervention.

Another way to address sensory differences that impact daily occupations is described by the Royal College of Occupational Therapists (RCOT) as 'sensory based' approaches (Royal College of Occupational Therapists, 2021b). Sensory based approaches are broadly, adapting the task or environment or improving the persons capacity for self-regulation to facilitate occupational performance. To explore the concepts that underlie this RCOT Informed View (Royal College of Occupational Therapists, 2021b) the person - occupation - environment (PEO) framework can help us to understand differing approaches to intervention. When the 'person is treated', intervention will aim to improve skills or functioning in the individual. Occupation can be adapted to better meet the needs of the individual or the occupation can be a therapeutic activity in and of itself. Finally, intervention strategies can use adaptation of the physical or social environment. The concept of changing the ‘person’ is not favoured in a neurodiverse affirming practice (Dallman et al., 2022). Professional practice guidelines (Royal College of Occupational Therapists, 2021b) advocate for an occupation focus to intervention and go on to state that ‘sensory issues must be considered in the context of the person’s occupational engagement and performance within relevant environments’ (p.1).

The National Institute for Clinical Excellence (NICE) guidelines for support and management of autism spectrum disorder in under 19’s (National Institute for Health and Care Excellence, 2021) again reflect this consideration of the child’s occupation and the environment. For addressing occupations, the NICE guidelines identify that local autism teams should promote functional adaptive skills e.g. daily living skills, and access to leisure activities. In relation to the environment, the NICE guidelines propose adjustment to the social and physical environment considering the child’s sensory needs e.g. lighting and noise levels. Group-based family intervention focuses on the family to influence the child’s social environment, supporting reduction in behaviours that challenge, parent stress, quality of life and the child or young person’s adaptive functioning. At the heart of this is the professional responsibility (Royal College of Occupational Therapists, 2021a) of occupational therapists to ensure consideration of the complex interaction between the child, their occupations and the environment or context, set against the foundation of informed choice to the client and their family.

As stated at the beginning of this chapter there is increasing demand for services to families of children with sensory differences that challenge participation in daily life. The National Health Service Long Term plan (National Health Service, 2019) advocates for tiered models of care. One framework to support tiered models of care is universal, targeted and specialist delivery of care (Hutton et al., 2016). Universal services describe whole population interventions that may include adaption of environments, education to school staff, advice, support, or signposting resources to parents. Targeted interventions are aimed at children who may be at risk and may involve parent / teacher training or class based groupwork with children. Specialist intervention describes the more traditional face to face individual contact between a therapist and child.

The Royal College of Occupational Therapists (Royal College of Occupational Therapists, 2024) advocates for broadening the offer of universal and targeted support with every school having access to occupational therapy services. Occupational therapists consider the person, their environment and the occupations that they want and need to do. They take action to reduce barriers to participation in occupation and increase facilitators. This can mean working directly with children in a one to one or in small groups to develop or practice skills that support the occupation e.g. sensory processing or motor skills. It can also mean engaging in the occupation itself to practice and enhance participation e.g. dressing or feeding. As occupational therapists carefully consider the environmental context of occupation, intervention may focus on adapting the environment rather than the child. This could be education of carers or teachers which is considered a targeted strategy. Adaption to the environment that is accessible to all e.g. adjustments to sound, lighting or furniture, is a universal intervention strategy. A recent survey of current United Kingdom children and families occupational therapy services (Gimeno et al., 2024) identified that Autism (86%) and ADHD (76%) were the conditions most frequently addressed. The top 3 occupations addressed were self-care, education related (e.g. handwriting) and play. Most children's occupational therapists reported providing assessment of occupational needs, direct intervention with the child and advice/ consultation. Less than one third of children's occupational therapists reported providing direct intervention to parents. The data presented by Gimeno et al. (2024) gives a picture of primarily, ongoing specialist service delivery and does not evidence a shift towards increased targeted or universal intervention. This suggests that so far there is a lack of application of the Royal College of Occupational Therapists (2024) ambitions for widening access to occupational therapy services. Therefore, further effort needs to be made to explore how we can work with children and families to deliver targeted child and carer group-based interventions. Group carer coaching offers a 'targeted' solution to meet this need.

Another way to consider approaches to intervention is to look through the lens of the Ecological Systems Theory. This provides a framework for understanding child development in the context of the environment from the micro, child, and family context to the macro, or sociopolitical context (Bronfenbrenner & Morris, 2006). Intervention has primarily focused on a one-to-one approach with the therapist and child, aimed at changing the child's functioning rather than the environment around the child. In considering the population of children with sensory differences. Nieto et al. (2017) suggests that the interaction between sensory thresholds within the context of the environment at micro-level (family routines) and macro-level (cultural environment) should be considered. This requires a shift away from a focus on the child to a wider eco-cultural perspective. Primary carers, or in the context of this thesis, mothers, often are the closest circle around the child, reflecting the importance and impact of the mother-child relationship. Parent intervention aligns with this framework, by recognizing the importance of a supportive and nurturing environment in child development. When professionals work with a caregiver, they are seeking to influence the social environment around the child as the conduit for enhancing function in the child.

In the face of increasing client complexity and challenges in meeting staffing requirements (Royal College of Occupational Therapists, 2022) it is sensible to consider other ways of working. Two groups have put forward frameworks for working with children with sensory differences and their caregivers (Ashburner et al., 2014; Reynolds et al., 2017). Ashburner et al. (2014) divided their framework into strategies for individual children or families, or a support for multiple children in a shared environment. Examples of multiple children in a shared environment are captured by universal design such as adjusting acoustics or lighting for optimum sensory comfort. Within their consideration of individual families, Ashburner et al. (2014) identified the need to share information and coaching to support families in problem-solving, citing the work of Dunn et al. (2012) who used a coaching approach to support families in generating their own solutions. Dunn's study was noted to be quite expensive, requiring 10 x one-hour sessions but was family-centered and being based in the family's chosen environment, demonstrated ecological relevance.

The framework of Reynolds et al. (2017) split intervention into three strategies, environment focused, caregiver focused and child focused. Their framework further referenced the work of Dunn et al. (2012) as a support for coaching with families of children with autism and sensory differences. Reynolds et al. (2017) advocated the use of a coaching approach citing the work of Graham et al. (2013) in recommending parent coaching to support the family system. Each framework explicitly articulated the need for parent intervention, with a specific identification of the potential value of coaching. These proposed frameworks advocate for a variety of means to address a child’s sensory needs considering both the child themselves (person) their activities (occupation) and the context (environment). Working with caregivers reflects adaption of the environment around the child which can impact the child and family occupations (Llewellyn, 2012). Child or person focused intervention can be impairment based or strengths based. An impairment-based focus would seek to improve skills or performance of the child. However, this approach assumes that it is the individual that is deficient in some way and needs fixing. A strengths-based approach would seek to expand areas of strength and requires a perspective that is wider than a traditional biomedical approach. This can shift the focus to promote engagement in a child’s preferred activity with a secondary consequence of skills building through the process of participation (Rosenbaum & Gorter, 2012). A child centered approach may be valuable if the child ‘s goal is to improve performance in an aspect of function or to develop underlying skills. The development of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2007) reflected a shift in thinking away from the biomedical model and towards a wider understanding of the need to consider the interaction between the individual and their unique environmental context. Family-centered services acknowledge the family as the primary environmental context within which this interaction occurs. It acknowledges that families are experts in their own lives, that each family is unique and that families are constant in children’s lives. Providing services from a family centered perspective acknowledges and respects their individual perspective and seeks to build capacity within the family unit (Rosenbaum, 2021). Family centered coaching intervention for families of children with autism has been identified as an evidence-based approach to address caregiver sense of competence, empowerment or self-efficacy and the occupational performance for both mother and child (Watling et al., 2023).

Despite the recommendation of two esteemed teams of researchers and a systematic literature review advocating for coaching, current intervention with parents is often focused on parent education alone (Heyburn et al., 2023; Simmonds et al., 2016). These two small cohort studies described findings pre and post a single education session for parents and carers. Neither study had follow-up measures nor a comparison group, reducing the reliability and generalizability of findings. Heyburn et al. (2023) study allocated 20 mins in the single session intervention for caregivers to identify a goal and to then identify and discuss self-selected strategies. The use of goal setting begins to engage with self-determination theory (Ryan & Deci, 2018). Self-determination theory refers to the ability of individuals to make choices and determine their own action and the environmental conditions that support this action (autonomy, relatedness, and competence). Unfortunately, unlike coaching that allows for implementation and subsequent evaluation of strategies, these education sessions did not complete the circle of evaluation of goals.

In resource constrained environments, considering the balance between accessibility for a wide population of a universal approach versus the reducing level of access for targeted and then specialist service needs to be balanced. Balancing the cost effectiveness of services versus the perceived benefit, is a consideration in NHS service planning and influences service choices available. Working with groups of mothers rather than individual mothers offers a targeted approach to intervention and provides benefit beyond potential cost effectiveness through peer support (Nacif, 2021; National Institute for Health and Care Excellence, 2021).

Family-centred care is a theory that acknowledges the family as a primary source of support and caregiving for a child (Bamm & Rosenbaum, 2008), developed from the original concept of a partnering relationship in person-centred care (Rogers, 1959). Occupational therapy parent intervention embraces this perspective by actively involving parents in the therapy process, recognizing their expertise, values, and goals in supporting their child's development (Llewellyn, 2012). This is in line with priority 3 of the Royal College of Occupational Therapists top ten research priorities (Royal College of Occupational Therapists, 2019a), that is ‘How can occupational therapists work more effectively with the family and carers of people who access services?'. Mothers are a key component of the child's direct environment and therefore intervention with the mother offers a strategy for influencing the child's functioning. An online coaching approach fits well with the advocated family-centred approach, where parents are seen as experts in their own family's life and service engagements are through a collaborative relationship (Bamm & Rosenbaum, 2008).

The current NHS Long-Term Plan advocates for a shift to online access options for out-patients supporting creating partnerships with clients and their carers (Price et al., 2023). This is further supported by the Royal College of Occupational Therapists survey that reported digital or telehealth approaches make it easier for families to access occupational therapy services (Royal College of Occupational Therapists, 2022). Online coaching enables increases accessibility to occupational therapy services and meets criteria laid down by the NHS long-term plan.

There is increasing demand for occupational therapy services for children and their families (Royal College of Occupational Therapists, 2022). In equating the balance between increasing demand and resource limited services, clinicians are faced with drivers to change practice. In line with the National Health Service Long Term Plan (National Health Service, 2019), new ways of thinking and service transformations are required, as defined by the Royal College of Occupational Therapists (RCOT) to meet the needs of children and their carers (Royal College of Occupational Therapists, 2019a). Coaching addresses RCOT's defined research priority of identifying ways to impact everyday lives, effectively supporting the families, and support self-management. Comparisons of parent coaching with community interventions for parents of autistic children suggest that coaching may be a cost-effective way to move forward (Tsiplova et al., 2022). Coaching therefore offers a potential opportunity to raise both effectiveness and efficiency in service delivery to children with sensory differences and their families.

1.3.1 What is coaching?

Originally coaching developed within the sporting context, but the scope has now widened. The coaching process was described by John Whitmore, a business coach. He identified a 4-step process called the GROW model, i.e. Goals, Reality, Opportunities and Way forward. The process started with setting goals and identifying the current **r**eality, then exploring **o**ptions and finally establishing the will or way forward (Whitmore, 2017). The International Coaching Federation (2024) outlined coaching as a partnership with clients that facilitates a thought provoking and creative process, to enable people to maximise their potential. Starr (2016) describes it as a conversation between a coach and a coachee (the person being coached) influencing the coachees' understanding, learning, behaviour, and progress, with a specific focus but broad impact. This definition reflects the reciprocal nature of the interaction between coach and coachee in facilitating change. It also reflects that whilst that change may have a specific focus on a pre-set goal the process itself can have a broader impact on the coachee's independent ability to enable change.

The important locus of control is with the coachee, aligning with the theory of self-determination (Ryan & Deci, 2018). Self-determination theory identifies autonomy, relatedness, and competence as drivers of self-motivation influencing our choices and actions, that can lead to sustainable changes in behaviour. Autonomy is our ability to make our own choices without environmental constraint. Relatedness reflects our need for positive human relationships. Competence describes our need to feel effective in our actions. We are more likely to engage in a process of growth or change when that change is meaningful to our current life experience, and we have a high degree of control over the process. The process of setting goals and being supported in the problem-solving approach to meet those goals can be described as autonomy-supportive strategies. As the coachees' views and aspirations are acknowledged and placed as a central focus there is alignment with their internal values and external action creating validation (Zivianni, 2015). Kahlon et al. (2023) suggest that competence is supported through the reframing process in coaching by supporting parents to reflect on their understanding of both their child and themselves. Zivianni (2015) identifies the parent as the agent of change therefore engaged in a competence building process in coaching. The importance of setting up an environment that provides emotional warmth and safety is a key part of the therapeutic relationship (Taylor, 2020) and identified as a crucial factor in occupational therapy coaching approaches (Graham et al., 2009; King et al., 2023). Coaching offers the opportunity to the coachee through the meeting of the need for autonomy, relatedness and competence therefore empowering promoting self-directed behaviour.

Shifting to think about coaching in a child and a family centred healthcare context requires reflection on the philosophical perspective and emerging approaches. Rush and Shelden (2011) identify early intervention coaching as an adult learning strategy where the coach promotes the coachee's ability to reflect on an action to determine its effectiveness, then to develop a plan for refinement of the action to enact it. They further identify key elements consistent with the principles of adult learning: capacity building, non-directive, goal oriented, solution focused, performance based, reflective, collaborative, context driven and as hands on as it needs to be.

More recently a comparison of three coaching approaches (King et al., 2023) identified common elements of coaching in paediatric rehabilitation illustrated in Table 1-a.These approaches were Solution-focused coaching in Pediatric Rehabilitation (SFC-peds), Coping with and Caring for Infants with Special Needs (COPCA) and Occupational Performance Coaching. All three are designed for use with parents or families. SFC-peds takes a strengths-based approach to coaching children and families supporting goal setting and implementation of plans. In a systematic review of intervention for children with cerebral palsy SFC-peds is identified as a partially effective intervention for parent outcomes (Novak & Honan, 2019).

COPCA is a family-centred early intervention approach that provides an educational and coaching intervention to parents. COPCA has been tested in 3 small, randomized control trials and demonstrated significant gains in motor repertoire for the infants with special needs versus standard care (Akhbari Ziegler, von Rhein, Meichtry, Wirz, Hielkema, Hadders-Algra, et al., 2021).

Occupational Performance Coaching is a strengths-based goal-oriented approach in which client agency takes precedent in selection, analysis, and application of their own goals. The healthcare professionals' role is to amplify the client's expertise and agency, through the domains of Connect, Structure and Share. Connect refers to the process of listening, empathising, and developing a sense of partnership. Structure refers to the process of identifying goals, analysing performance, taking action, reviewing action, and generalising skills gained. Finally Share reflects the coach's approach of asking first, being curious, prompting reflection, teaching principles only and expecting resourcefulness. Occupational Performance Coaching studies have identified significant improvements of parent identified occupational goals for both performance and satisfaction for children with cerebral palsy and children with occupational concerns (Ahmadi Kahjoogh et al., 2019; Graham et al., 2013)

Table 1-a

Table of coaching approaches

	MECHANISMS	OUTCOMES
Coaching philosophy • Client/ family centered coaching approach: transdisciplinary, tailored, strengths based, solution-focused **Target population** • Clients with a variety of health conditions. Disabilities, their parents, and families **Delivery setting** • Coachee‘s natural environment Target goals • Goal-orientation intervention • Participation and quality of life goals	**Practitioners change mechanisms** • Coach behaviors: non-directive, collaborative, reflective, use of positive language • Emphasis on active and engaged listening, • Emphasis of relational strategies • Open, curious, and client centered coaching mindset **Client change mechanisms** • Engagement • Self-efficacy	**Goal achievement** **Empowerment** **Capacity building**

These three paediatric rehabilitation coaching approaches (King et al., 2023) all advocate for a relationship of trust, open communication, and joint sharing of information with a focus on exploring solutions to coachee identified goals. The coachee (or in this thesis, mother) identifies and seeks solutions through reflection on everyday life situations. The coachee is deemed to be capable of making their own decisions and undertaking a desired course of action. Shifting away from a traditional medical model with the therapist as expert, to a collaborative approach that aims to promote participation in daily activities and build capacity for the future. Importantly coaching interventions have alignment with a neurodiversity affirming approach (Dallman et al., 2022) working with the parent to adapt the environment around the child rather than acting to change the child themselves, taking an individualized and strengths-based perspective.

Whilst coaching is received positively by mothers in general, there is little evidence to suggest that it explores what parents of children with sensory differences would value in terms of support. In a large study exploring parents hopes for outcomes of child focused occupational therapy services for parents of children awaiting intervention for sensory differences, parents hoped for better performance skills (e.g., self-regulation and motor skills) in support of improved occupational performance, for example developing friendships or handwriting (Cohn et al., 2014). Further exploration of what supports mothers of children with sensory differences value is indicated. A study (Graham et al., 2014) explored mothers' experience of Occupational Performance Coaching. Twenty-nine mothers of children with occupational concerns answered open and closed questions about their experience of Occupational Performance Coaching and the descriptions were largely positive. They reported gaining insights into themselves and their children and learning specific strategies to support their child’s occupational performance. Whilst these two studies have begun to share the parents' voices, they do not fully explore what mothers of children would find helpful for themselves and in support of their children.

In summary, all applications of coaching with parents and carers of children with identified occupational concerns have demonstrated positive changes in child functional goals. To date, there has been little exploration of coaching intervention for parents and carers of children with sensory differences. Further research into family coaching is advocated to identify the sustainability of outcomes, operating mechanisms, and fidelity of interventions (King et al., 2023). It is important to establish what evidence exists to support the use of a coaching approach with mothers of children with sensory differences. There is also little exploration of the mother’s perspective. So, whilst emerging evidence tells us that coaching is supported, we have little information on what mothers want or how to provide this type of intervention within current resources.

1.4 Research question:

How can we better support mothers of children with sensory differences from a coaching perspective?

The overarching aim of the thesis was explored through four separate research activities which are presented in the form of research papers, two of which are already published.

Objectives:

To identify current practice in coaching with parent of children with sensory differences to identify the gaps in evidence and the implications for practice.

To understand the experiences of mothers of children with sensory differences and to explore what they find helpful. To pilot a mothers group coaching intervention.

Thesis structure:

Chapter 2: Coaching Parents of Children with Sensory Integration Difficulties: A Scoping Review. Published paper (Allen et al., 2021)

The introduction identified the potential for coaching to impact child occupational performance and reduce mother’s stress. This study therefore aims to synthesize, appraise, and identify gaps in the literature through a scoping review. A scoping review was selected as the methodology due to the emerging nature of this topic.

Research questions:

a. What is the current evidence on coaching intervention with parents of children with sensory differences?
b. What are the gaps in our knowledge of coaching intervention for parents of children with sensory differences to inform future research?

Chapter 3: Mothers' perspectives: daily life when your child has sensory differences. Published paper (Allen et al., 2024)

As highlighted in the introduction and the scoping review, mothers' perspectives have rarely been considered in understanding the impact of sensory differences or in developing interventions. This study therefore aimed to gain an understanding of daily life for mothers and their children with sensory differences. Qualitative interviews with thematic analysis were conducted to gain an in-depth understanding of mother's experience. The thematic analysis was inductive (allowing the data to drive the codes and themes rather than placing an external structure), experiential (grounded in the experience of mother's daily lives) and socially constructed (using language to interpret experiences).

Research questions:

a. What do mothers of children with sensory differences tell us about daily life?
b. What do mothers identify as being supportive regarding the impact of their child's sensory differences?

Chapter 4: What do mothers of children with sensory differences perceive as helpful? A survey. Paper in preparation.

In this study, the experiences of a large sample of mothers from the UK and Ireland were investigated using a survey tool which was developed using the findings from Chapter 3. A survey was the selected method to support the collection of data from many participants.

Research Questions:

a. What is the reported impact of child sensory differences on mother's experience of everyday activities and relationships?
b. What helps mothers and their children with sensory differences participate in daily life?

Chapter 5: Brief online group coaching for mothers of children with sensory differences (Allen et al, under submission)

The scoping review suggested that individual coaching has potential to support mothers of children with disabilities. Data from the interviews and survey suggested that mothers valued parent intervention, and that coaching was an underutilised intervention tool. The aim of this study is therefore to pilot a brief online coaching group for mothers of children with sensory differences that are impacting participation in daily occupations with the following question:

a. Is the study, recruitment, format, and intervention acceptable to participants?
b. Does child occupational performance, parent stress and parent sense of competence change with brief online group intervention?

Chapter 6: Discussion

2 Chapter 2: Coaching parents of children with sensory integration difficulties: A scoping review.

NB See Appendix 8.1 Table of ethical approval and factors considered, and 8.4 for published paper Allen et al. (2021)

Author contributions: Susan Allen (Conceptualization, Project Administration, Methodology, Investigation, Data Curation, Formal Analysis, Writing – original draft, Writing -review and editing), Fiona J. Knott (Conceptualization, Methodology, Data Curation, Supervision, Writing - review and editing), Amanda Branson (Conceptualization, Supervision, Formal analysis, Writing - review and editing), Shelly J. Lane (Data curation, Formal Analysis, Writing - review and editing).

2.1 Abstract

Aim: To review current evidence regarding the effectiveness of occupational therapy coaching interventions for parents of children with sensory integration difficulties, delivered to individuals or groups of parents.

Method: An historical scoping review was completed of empirical research records to summarize what is known and how this information can guide future research. The process was guided by PRISMA guidelines. Inclusion criteria were English language, peer reviewed empirical studies of parent coaching intervention for children with sensory processing or sensory integration difficulties. Five databases were searched. Papers were critically reviewed using McMasters' guidelines.

Results: Four studies met the search criteria. Three studies took a direct coaching approach with individual parents or families. The fourth study took a mixed educational/coaching approach with groups of parents and teachers.

Conclusion: There is some evidence to conclude that occupational therapists can deliver individual parent-focused coaching interventions which impact positively on individual child goals, parental stress, and sense of competence. Group intervention can lead to caregivers improved perceived and actual knowledge of sensory integration, as well as a sense of self-efficacy in dealing with sensory related child behaviours. Current evidence is limited. Suggestions for future research are offered.

2.2 Introduction

Sensory integration is the process by which we receive and respond to information through our senses, and the way we organize and use this information to participate in everyday activities. In typical development children gain skills to manage the sensory demands of their bodies and environment to make sense of themselves and their world to interact appropriately (Ayres, 1973). Difficulty integrating this information enacts a range of processes and responses affecting physiological, cognitive, motor, emotional and regulatory functions impacting on social relationships and participation in everyday life (Lane, Mailloux, et al., 2019). The term 'sensory processing disorder' is also used to describe difficulty in detecting, regulating, interpreting, and responding to sensory input where difficulties impair daily routines or roles (Miller et al., 2007). For the purpose of clarity and in line with the work of Lane et al. (Lane, Bundy, et al., 2019) the term 'sensory integration difficulties' will be used to describe the barriers experienced by individuals with challenges in sensory processing or sensory integration. Occupational therapists' primary concern is how these difficulties impact on the successful participation of children and families in their daily lives (Ismael et al., 2018; Watling et al., 2018).

At a policy level in the United Kingdom, the College of Occupational Therapy briefing paper (College of Occupational Therapists, 2015) considers intervention for sensory integration difficulties from two perspectives. The first approach is defined as impairment orientated and includes Ayres Sensory Integration, a specialised assessment and direct intervention carried out mainly by occupational therapists with specific postgraduate training using procedural and structural criteria as defined by Parham et al. (2011). Impairment oriented approaches also include sensory based interventions, a wide range of sensory stimuli, and sensory experiences using 'sensory' equipment in specialized settings. The second approach is defined as performance orientated. This approach emphasises managing, rather than changing, the sensory needs of the individual through adapting the environment, modifying the task, or developing strategies for the individual to self-manage the task. A variety of interventions have been developed for children and their families with varying effectiveness (Novak & Honan, 2019; Schoen et al., 2019). This paper explores parent focused coaching intervention, an under used approach with parents of children with sensory integration difficulties.

Parent engagement in therapy sessions is seen as desirable (Bundy & Szklut, 2019) and at least one child-centred approach explicitly identifies the importance collaboration and problem solving with parents (Miller et al., 2020). However, impairment-orientated, and performance-orientated approaches primary focus is on the child rather than the parent's needs. The impact of sensory integration difficulties on parents has been investigated in several papers demonstrating high levels of parent stress as well as challenges to daily occupations. Parents at times use negative coping strategies that can exacerbate the impact of stress for both the parent and the child (Allen & Knott, 2016; Ben-Sasson et al., 2013). Despite research recognising the impact on parents, there is little evidence about the best way to support parents. Ecological theory (Bronfenbrenner & Morris, 2006) reflects the interactive nature of the child with their social and physical environment. Parents experience higher stress and may use negative coping strategies but can nonetheless be positive agents of change for themselves and their children. There is therefore a need to move beyond child focussed work and to explore the value and effectiveness of parent-based interventions. Such interventions include those which increase parental knowledge and understanding to enable parents to gain confidence and competence in developing strategies to better manage their family and children's participation in daily activities.

Two papers have proposed frameworks of intervention for children with sensory integration difficulties and their families. Both frameworks (Ashburner et al., 2014; Reynolds et al., 2017) advocate direct interaction with parents using a coaching-based approach, either with parents alone or in addition to intervention with the child or environmental adaptation. It is acknowledged that one approach to intervention cannot meet the whole needs of clients across the variety of settings that we practice in. Multicomponent approaches, have the flexibility to allow the needs of children and families to be met in a way which is both cost effective and acceptable to the family. Some parents, for instance, may benefit from support to identify and manage environmental challenges, while for other families, direct intervention with the child may be the most appropriate starting point. We therefore need to consider, develop, and evaluate a variety of intervention approaches in our practice and coaching is one of these.

Coaching has roots in fields outside occupational therapy e.g. sports and business. It has been simply described as unlocking people's potential to maximize their own performance (Whitmore, 2017) and is founded upon the relationship between coach and coachee (Downey, 2003). Coaching implies a highly collaborative approach that can standalone or be delivered in combination with other approaches to intervention (Seruya et al., 2022).

Coaching is a well-accepted ingredient in many early intervention programmes but key ingredients that lead to positive change are poorly understood. The heterogeneity of literature covers a spectrum from parent training to parent coaching (Akhbari Ziegler, von Rhein, Meichtry, Wirz, Hielkema, & Hadders-Algra, 2021; Seruya et al., 2022; Ward et al., 2020). Training aligns with an instructor – learner interaction style. Coaching aligns with interaction as equal partners supports families to make informed decisions and actions with the goal of optimal participation of the child and family (Akhbari Ziegler, von Rhein, Meichtry, Wirz, Hielkema, & Hadders-Algra, 2021). Ward et al. (2020) undertook a systematic review of coaching practices in early intervention for a range of developmental disabilities. The articles reviewed were compared to the criteria laid down by Rush and Shelden (2011). These are joint planning, observation, action/ practice, reflection and finally feedback. Manualised interventions demonstrated a higher rate of adherence to Rush and Sheldon's five criteria, although very few studies reported meeting all the 5 criteria. Interestingly noting that feedback and reflection were the least utilised strategies (Ward et al., 2020). However, the domains of occupational therapy practice in considering daily occupations across naturalistic environments support the goal of promoting carer's ability to extend the capacity for change beyond the context of direct intervention, in a way that is meaningful to families and places them at the centre of prioritizing goals (Seruya et al., 2022). Health coaching provides a more focused definition as a goal-oriented, client centred partnership that is health-focused and occurs through the process of client enlightenment and empowerment. It promotes parent self-management and empowerment in the presence of their child's emerging chronic condition (Ogourtsova et al., 2019). Training for healthcare professionals is described as essential with a need for professional education and ongoing support. However, training it is often poorly described and few studies have manualized interventions or fidelity checks (Akhbari Ziegler, von Rhein, Meichtry, Wirz, Hielkema, & Hadders-Algra, 2021; Ward et al., 2020). This limitation means that it is difficult to replicate studies directly.

Parent coaching interventions were found to be well accepted and recommended as a capacity building strategy and considered and active ingredient in many early intervention protocols (Akhbari Ziegler, von Rhein, Meichtry, Wirz, Hielkema, & Hadders-Algra, 2021; Seruya et al., 2022).Retention rates were 85% or higher for most studies (Ogourtsova et al., 2019). Coaching is observed to be acceptable and engaging to parents.

Goals of intervention vary but are generally focused around developing strategies within the caregiver to promote their own and their child’s health and well-being aligning with the core components of the occupational therapy scope of practice (Seruya et al., 2022). The most frequently used outcome measures focused on child outcomes with fewer studies using psychometrically sound measures of parent behaviour, parent stress, parent sense of competence and self-efficacy (Ward et al., 2020). There is moderate to high evidence that coaching improves child outcomes for educational attainment in at risk children and in autism and, communication skills in children with developmental delay. There is lower evidence suggesting improvements in individualised goals and life skills in children with disabilities and developmental skills in children with developmental disabilities (Novak, 2014). A more recent systematic review identified coaching as effective versus comparison or no treatment in improving parent related outcomes. Interestingly when parent related measures changed, child related measures changed in the same direction. For example, if parent measures improved, so did the child’s measures. However, the evidence base is limited, and further research is recommended (Ogourtsova et al., 2019).

Coaching can be delivered across a wide range of settings (Ward et al., 2020). In recent studies telehealth services are increasing being used a means to enable access to services and demonstrate high levels of acceptability to parent (Hippman et al., 2023; Qu et al., 2022). When compared to self-guided learning parents are more than twice as likely to engage with telehealth coaching intervention. With significant positive outcomes for child behaviour and child anxiety. Parent outcomes showed enhanced parenting skills but inconsistent findings of parent distress (Hippman et al., 2023). Telehealth parent coaching has the capacity to increase access to services.

Returning to occupational therapy research Reynolds et al. (2017) describe coaching as a structured process including emotional support and information exchange. Caregiver interventions are recognized to build on family strengths, occur in natural contexts and are embedded in daily occupations which support goal acquisition Reynolds et al. (2017). Caregiver interventions offer the opportunity to empower families in generating strategies compatible with their own routines as well as to be generalized to other situations (Ashburner et al., 2014). Miller-Kuhaneck and Watling (2018) systematically reviewed the outcomes of both parent education (didactic teaching) and parent coaching studies for parents of children with autism and sensory integration difficulties and found that although limited, there is some evidence to support parent training. They recommend that occupational therapy is well suited to providing parent training. These papers have opened an exploratory door on parent interventions. Notably they included only one paper on parent coaching. The remaining studies were concerned with teaching parents an activity to apply to the child (e.g., massage or applied sensory stimuli) or addressing sensory integration difficulties as part of a broader intervention for parents of children with autism. The interventions described either did not specifically address the wider population of parents of children with sensory integration difficulties or did not explore coaching as proposed by the recommended frameworks (Ashburner et al., 2014).

This study's overall aim is to review the literature available to support future development of a parent coaching intervention for parents of children with sensory integration difficulties. Specific aims are to synthesize and appraise what we know about parent coaching interventions for parents of children with sensory processing and integration difficulties and to define gaps in the literature to inform future research.

2.3 Methods

To map the literature, identify gaps in our knowledge and understanding of the field and make recommendations, a scoping review was conducted. PRISMA guidelines for scoping reviews were followed (Tricco et al., 2018).

Eligibility criteria were designed to be inclusive. Selected settings included: all years to 1st January 2020, peer-reviewed English speaking, empirical papers. To explore a wide and occupational therapy-focused range of literature, five databases were selected. These were: Web of Science, CINHAL, PsychInfo, OTDatabase, OTSeeker. In addition, reference lists and citations of the identified key papers were hand-searched. A search strategy was developed by the research team and supported by a specialist librarian. Search terms were sensory processing OR sensory integration AND parent# OR famil# OR child# AND intervention OR treatment OR therapy OR coaching. Inclusion criteria were parents of children with sensory processing or sensory integration difficulties, and parent-focused coaching intervention. Papers were excluded if programs taught the parents an intervention to be applied to the child e.g., Qi Gong Massage (Silva et al., 2011) as the focus of this review is coaching. Screening and eligibility were undertaken by authors 1 and 4. Level of evidence was identified using Oxford Centre for Evidence Based Medicine Levels of Evidence (Oxford Center for Evidence Based Medicine Levels of Evidence Working Group, 2011). Data was charted by two authors using McMasters University's Critical Review Form for Quantitative Studies (Law et al., 1998). This form has eight sections (study purpose, literature, design, sample, outcomes, intervention, results, and conclusions or clinical implications), including questions that prompt the evaluation of the study's quality.

2.4 Results

As indicated in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram, see Figure 2i (Moher et al., 2009), 1196 articles were identified from the databases and a further 18 from hand searches. Following the removal of duplicates, 1152 articles were screened by title and abstract. Seventy-one papers were read in full, to determine relevance to the research questions; of these, four studies met all inclusion criteria, cross checked by the second author. Table 2a provides a summary of the final four papers.

Figure 2-i

PRISMA flow diagram of coaching interventions for parents of children with sensory differences

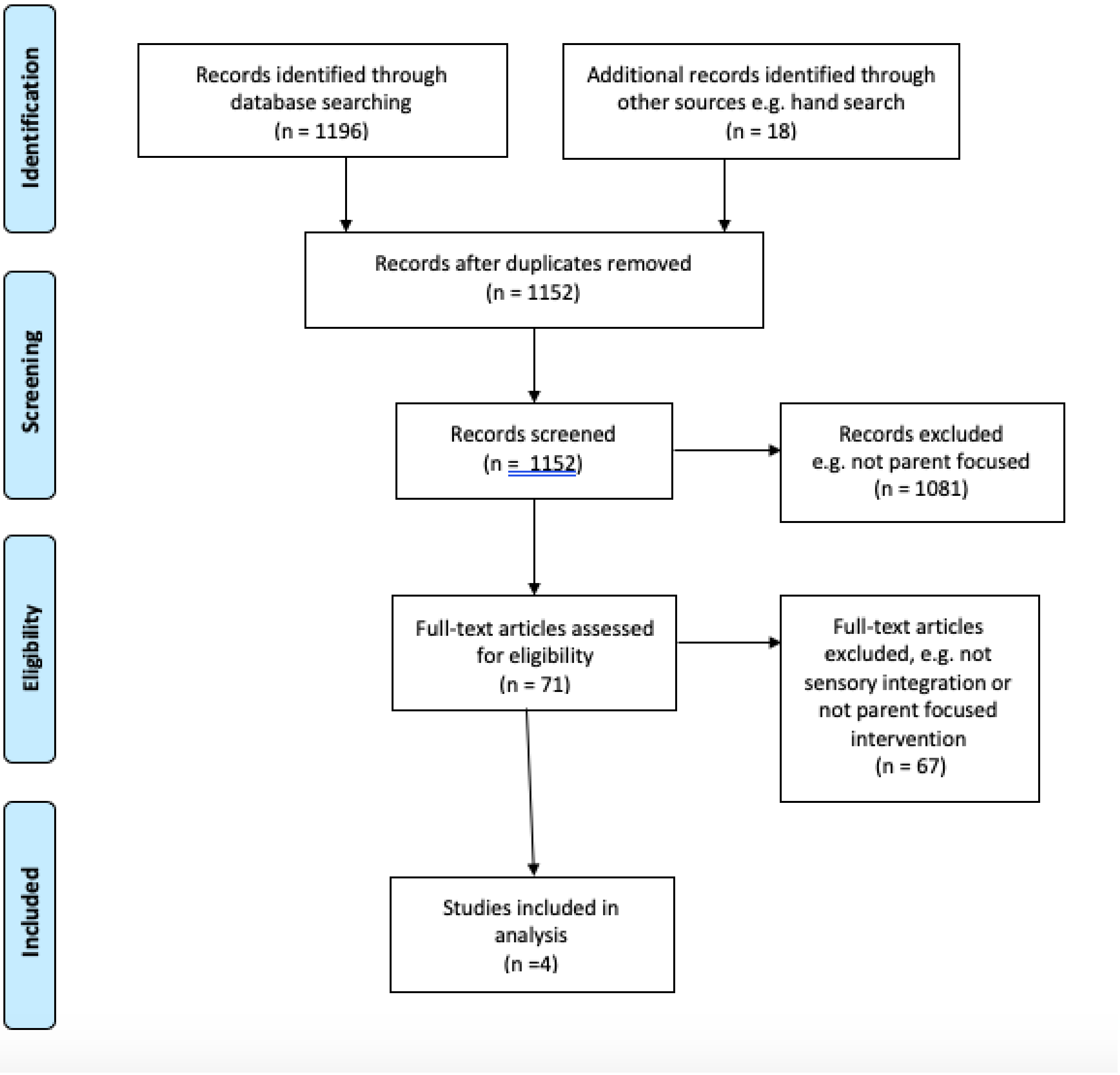

Table 2-a

Summary of papers

	Design	LoE*	Sample	Format and environment	Frequency, intensity, duration	Approach	Outcome measures
Bulkeley et al. (2016)	Single case experiment design using an ABA protocol	4	n=3 mothers of children with autism; age range 3-5y Child sensory issues identified through the Infant/Toddler Sensory Profile (Dunn, 2002)	Individual family-centered coaching based in principles of sensory integration theory as their initial intervention Environment: Home	4 x 1 hour per intervention, 1 week or more apart	Brief family-centered coaching using a sensory-based framework	Visual Analogue Scale for target individual behaviors 1. Tolerance of the sound of a hairdryer 2. Reduced rigid eating behavior 3. Reduced reckless and dangerous behavior
Dunn et al. (2012)	Repeated measure pre-test/post-test. 1. Baseline 2. Pre-intervention 3. Post-intervention 4. 4-week follow-up.	3	Individual family intervention; n=20 (19 mothers, and one father) of children with autism; age range 3- 10y Child sensory issues reported through Sensory Profile (Dunn, 1999).	Individual family centered coaching. The intervention reflected principles of context therapy Environment: a location of their choosing, in person or via telehealth	10 x 1-hour weekly sessions with some flexibility to meet scheduling needs	Coaching in family context within daily routines informed by the child's sensory patterns	1. Individual goals: Canadian Occupational Performance Measure (COPM); Goal Attainment Scaling (GAS); e.g. dressing, eating, having injections, riding in car, transitioning for bus to home 2. Parent Stress Index-Short Form (PSI-SF) 3. Parent Sense of Competence Scale (PSOC)

	Design	LoE*	Sample	Format and environment	Frequency, intensity, duration	Approach	Outcome measures
Gee and Peterson (2015)	Pre-test-post-test 1. Week 1 2. Week 6	3	n= 7 parents, n=3 teachers of children with autism; age range 5 to 10 years Child sensory issues reported by parent or through child Short Sensory Profile(McIntosh et al., 1999)	Group intervention. Environment: conference room in a college campus	6 x 1 hour per week 6 weeks	Education Week 1 – 5 promoting parent's knowledge Week 6 _ promoting problem solving (A SECRET (Miller & Fuller, 2014))	Adapted parent completed questionnaires on 1. Self-perceived knowledge of sensory processing concepts 2. Actual knowledge of sensory processing concepts 3. Self-rated competency for dealing with children exhibiting behaviors related to sensory processing disturbances and/or disorders.
(Pashazadeh Azari et al., 2019))	Randomized Control Trial	2	Parents of children with Autistic Spectrum Disorder with at least one sensory pattern outside the typical range as measured by Short Sensory Profile II (Dunn, 2014). n=15 intervention group, n=16 wait list control group	Group sessions plus Individual coaching sessions Environment: Rehabilitation Centre	2 sessions group training sessions Plus 10x45 minute weekly individual session	Three treatment characteristics 1.Sensory Processing Knowledge 2.Coaching 3.Social Support	1. COPM 2. GAS 3. Parent Sense of Efficacy Measure

LoE* - Levels of Evidence

What do these four studies tell us?

The four studies each used, at least in part, a coaching or problem-solving approach to support parents in developing skills to better manage their children, all of whom had autistic spectrum disorders and sensory integration challenges that caused disruption to daily activities. Three of the four studies were based at home, school or an environment selected by parents supporting a naturalistic setting. All four studies reported improvements in child behavior or parent knowledge and self-efficacy. Three of the four studies supported parents in their own goal setting. Once the studies started, three studies identified that no dropouts were reported in any of the interventions. Study design was highly variable with evidence between levels 4 and 2 (Oxford Center for Evidence Based Medicine Levels of Evidence Working Group, 2011). Participants, when reported, were of a generally higher level of education than the general population. Sample sizes were small, increasing the risk of low generalizability and Type II error (failure to reject a false null hypothesis). Follow-up was limited or missing. Demonstration of fidelity to a manualized intervention is present in at least three of the four studies. In the following section, each study is briefly described and appraised in turn, after which the findings and application to practice are discussed to identify gaps and key areas for future research.

Study 1

Bulkeley et al. (2016) aimed to explore the hypothesis that mothers will better manage their child's behavior challenges in the context of daily routines following intervention. Participants were recruited through two child development centers and screened for eligibility for a larger study, then randomly allocated to this intervention. The intervention used a family-centered approach to coaching; based on the principles of sensory integration theory, involving five components adapted from Anzalone and Williamson (2000). These components were: observing and reframing sensory processing challenges in context; modifying the environment; modifying the activity; managing the activity and promoting agency in the child in response to a sensory challenge. Participants were mothers of three children aged three to five, with autism and atypical sensory processing that impacted on behavior and daily routines. Using experimental single-case studies with an A-B-A design, the study examined changes in child behavior based on individualized goals selected by the mothers. During the baseline phase (A), mothers rated their perception of the child's target behavior each day using a visual analogue scale (VAS) modified specifically for this study. Following the baseline phase, each mother worked with an occupational therapist for four, hour-long sessions a week apart (B). Mothers completed VAS daily to report their rated perception of the child's targeted behavior. Following the intervention, the baseline phase (A) was repeated without the support of an occupational therapist. Data were graphed and inspected visually, supported by descriptive visual analysis using the median and range of VAS. Improved maternal ratings of child's behavior were observed between the baseline and the end of the intervention phase for all three children, however improvements were only maintained for one child during the final return to the baseline phase. Strengths of this study include the use of the Infant/Toddler Sensory Profile (Dunn, 2002) a standardized tool to identify sensory challenges, supporting the definition of the population being studied. Strategies to support adherence to the intervention protocol or fidelity were described including the use of a checklist against audio recordings of intervention sessions. Finally, the structured use of A-B-A design enabled the isolation of one behavior for measurement demonstrating changes in this small cohort. The primary limitation was the variability in child behavior before the start of the intervention phase.

Study 2

The goal of Dunn et al. (2012) study was to explore the hypothesis that a contextual occupational therapy intervention delivered individually to families would increase child participation and parent sense of competence to support positive child and family outcomes. Context therapy is an intervention approach that focuses on changing the characteristics of the task and/or environment, rather than the child's impairment, as described by Darrah et al. (2011). The intervention contained three elements: activity settings, daily life routines and sensory processing patterns. Participants were parents of children with autism, atypical sensory patterns, and self-reported unmet needs in their family life. Working with twenty parents (mother n=19, father, n=1), using a pre-test/post-test follow-up design, the study examined changes in child behavior (based on individualized goals) and parent competence (based on standardized parent reports of sense of competence and stress). Data were gathered at four time points: four weeks prior to the intervention, at the start of the intervention, at the completion of the ten one-hour sessions of contextual intervention, and, finally, at four weeks follow-up. Significant improvements in individual self-care, productivity, leisure, and desired behavior goals were reported from pre- to post-intervention which were sustained at follow-up. Post-hoc analysis revealed significant differences, with large effect sizes between pre intervention and post intervention as well as pre intervention to follow-up for individualized child participation goals. In addition, parental defensive (under reporting of difficulties) responding, and sense of competence improved significantly from pre-baseline to follow-up. Total parental distress demonstrated clinically significant improvement between baseline and follow-up. Strengths included the use of a standardized measure of sensory difficulties i.e. the Sensory Profile (Dunn, 1999), staff training and a similar manualized procedure reported in a subsequent publication (Dunn et al., 2018).

Study 3

The goal of Gee and Peterson (2015) study was to explore the effectiveness of caregiver psycho-education groups in increasing the caregiver's perceived and actual knowledge of sensory processing difficulties and their perceived competency in managing the sensory-related behaviors of children with autism. The sample was primarily parents but also included some school staff. The intervention was based on the work of and consisted of five sessions of instructional content with one final session focused on a reasoning approach for addressing challenging behaviors related to sensory processing as outlined by Bailer and Miller (2011). No written manual or measurement of fidelity was reported. Outcome measures of parent perceived knowledge, actual knowledge and self-perceived competence were adapted from a previously designed parent survey questionnaires and which demonstrated face validity. A pre-test/post-test design was used to measure change between the first and last sessions of intervention. Actual and perceived knowledge of caregivers improved significantly, as did confidence, satisfaction, and feelings of being in control of sensory-related behaviors. However, parents' perception that they possessed the necessary skills to positively manage their child's behavior did not change significantly. Limitations included there being no measure of the child's sensory challenges, limited evidence of the reliability or validity of the study's measurement tools, lack of detail to support replication and no follow-up.

Study 4

Pashazadeh Azari et al. (2019) aimed to identify if Contextual Intervention Adapted for Autism spectrum disorder (CI-ASD) promotes child participation in family activities and routines, promotes parenting sense of efficacy. In addition, Pashazadeh Azari et al. (2019) intervention acceptability and participation were explored. The sample was recruited from two rehabilitation centers in Tehran. Parents were randomly allocated to an intervention or wait list control group. Intervention was reported to be based on a wide range of coaching approaches (Foster et al., 2013; Graham et al., 2013; Rush & Shelden, 2011). Key characteristics of the intervention are described as 1. Sensory processing knowledge, 2. Coaching and 3. Social support. No measure of fidelity was reported but future publication of theoretical underpinnings of the intervention how the contextual intervention was adapted for this population was reported to be in print. The authors kindly shared the intervention protocol. Data were gathered at three time points: prior to the intervention, at completion of two group and ten one-hour sessions of contextual intervention, and, finally, at four weeks follow-up. Both the intervention and control group demonstrated positive changes in individualized participation and functional goals, with statistically significant greater gains in the intervention group between pre and post intervention and in post intervention to follow-up. Parent self-efficacy was significantly higher in the intervention versus control group both at post intervention and follow-up. Attrition was low with 89% of parents completing the intervention protocol. A treatment acceptability questionnaire demonstrated that most participating parents rated the intervention acceptability as high. Limitations were that the assessment was not blinded and follow up was short.

2.5 Discussion

This scoping review has identified preliminary but positive findings on the impact of coaching parents of children with sensory integration difficulties. Improved outcomes were observed in child functional skills and behaviour as well as parent sense of competence and reduced parent stress. Where measured, the acceptability of one-to-one coaching intervention was reported to be high. However, there are several threats to the validity of these findings. Each study took different approaches to the intervention with variety in approach and dosage, as observed in wider systematic reviews of coaching parents of children with additional needs (Seruya et al., 2022; Ward et al., 2020). It is not therefore possible at this stage to pool data for analysis or to compare the effectiveness of approaches. Only one study used a control group, while the other studies used single-case or single cohort designs. Without comparison or further controlled trials we cannot be confident that the changes did not occur by other mechanisms. Follow up was either not present or of short duration. Parent and child changes occurred but we do not have demonstrable evidence that the impact is maintained over more than 4 weeks post intervention.

The studies used in this scoping review were face to face. There is increasing evidence that telehealth interventions can offer equivalent benefit with greater accessibility to parent. A more recent study on coaching delivered by parents to parents of children with self-regulatory difficulties were found to have consistent fidelity whether the intervention was in person or online (Caron et al., 2022). Online healthcare coaching warrants further research.

Transferability of the findings is limited by small underpowered samples, volunteer participants across limited social economic status groups and educational levels. Additionally, all children were reported to have a comorbid diagnosis of autistic spectrum disorder. While a high proportion of children with autistic spectrum disorders experience sensory integration difficulties, not all children with sensory integration difficulties have autistic spectrum disorders Adamson et al. (2006). Therefore, we have no evidence yet that this approach could be applied to a wider cohort of parents of children with sensory integration difficulties that impact participation and function in everyday life.

2.5.1 Points for practice

Given the preliminary nature of the use of coaching approaches with parents of children with sensory integration difficulties it is unsurprising that the content of the intervention and ways of working differed. All studies identified the need for shared problem solving. Information sharing was a component of each of the studies either as a taught component or as a tool for activity analysis and reframing behaviour. It is not possible to identify the active ingredients from this review. However, Dunn et al. (2018) identified four guiding principles as follows: to situate coaching in everyday life, to seek understanding by working collaboratively with the client, foster clients deep thinking about their own life and to explore resources with clients. (Dunn et al., 2018). They then go on to specify what does and does not constitute Occupational

Performance Coaching (OPC). If we consider wider evidence within occupational therapy on Occupational Performance Coaching the work of Graham et al. (Graham et al., 2009) provides an alternative detailed description of Occupational Performance Coaching (OPC). They identified three enabling domains of OPC (emotional support, information exchange and a structured process) and applied techniques of collaborative performance analysis, questioning, listening, observing, modeling, explaining, and in vivo coaching to assist mothers in identifying strategies that support their child's performance. Graham (Graham et al., 2017) demonstrated preliminary evidence supporting the effectiveness of OPC in improving child and mother occupational performance and mother parenting self-competence in families of children with occupational performance concerns. More recently Bundy and Bulkeley (2019) have expanded the original work of Rush and Shelden (2011) to identify the coaching process as joint planning, action, observation, reflection, and feedback with the addition of reframing (behaviour). Robust fidelity to a manualised intervention is key to replicability and evaluating future research.

The goal of occupational therapy is to support participation in daily occupations, and indeed recent frameworks (Ashburner et al., 2014) suggest that the best starting point for an intervention might be goals that focus on participation in a family routine or occupation rather than on behavior. In Bulkeley et al. (2016) study, all child behavioral goals improved, but these improvements were not sustained in two of the three cases following the intervention. While this might stem from the brevity of the intervention with only 4 sessions, the authors suggested that sensory strategies may become embedded more easily in family routines if the goal is focused on increased participation rather than on behavior.

The utility of family participation-based goal setting was demonstrated by Dunn et al. (2012) who reported increased participation both at home (e.g. dressing and play) and within the community (e.g. grocery shopping) according to family set goals. Goal setting appears to be an important part of the coaching process. In terms of problem-solving strategy's goal setting helps parents to perceive that they have control and supports change (Kolehmainen et al., 2010; Webb & Sheeran, 2006). This empowers parents to be agents of change within their own families (Graham et al., 2014). However, goals alone may not be enough, as habits and the environment can act as a barrier to change (Ajzen, 2002).

There is a need to consider the wider social context or how the social network around the family acts as a barrier or facilitator to potential change. Interestingly Gee and Peterson (2015) involved teachers widening the scope of engagement in intervention for the child and family. There is no evidence from these papers, but other papers consider parent training support engagement with a wider social network (Forehand & Kotchick, 2002). While we can change knowledge and/or intention, this needs to be supported by the empowerment of the individuals and their environment for that knowledge or intention to be applied to everyday life.

The high attendance rate reported in all studies reviewed is notable (89 to 100%), in comparison with behavioral parent training studies which report attendance ranging from 37% to 98% (mean attendance of 73%) (Chacko et al., 2016). This may reflect the selective nature of the research samples or a significant level of motivation among parents of children with sensory integration difficulties to engage with intervention opportunities. The Pashazadeh Azari et al. (2019) study explored engagement by identifying the acceptability of the intervention to participants. High acceptability further supports the value of this coaching approach to parents.

The papers reviewed considered both group and individual approaches. It is difficult to compare the impact of group versus individual intervention in this context due to the lack of detail of content and variety in dosage of interventions. While individual intervention allows focus on family-centered goals, there are advantages of a group intervention in access to peers and social support networks. Group parent intervention may be more readily available in resource restricted contexts but lacks robust research from a telehealth perspective (Hippman et al., 2023). Wymbs et al. (2017) surveyed parents of children with ADHD and found that 85% choose group intervention over paper information. A further study that considered group and follow-up individual parent intervention for parents of children with autistic spectrum conditions supported the social validity of the group-based approach (Rivard et al., 2017). However, the message from both papers was that the group intervention did not substitute the need for direct one to one intervention for the parent or child.

Three studies explored intervention in home, school or parent selected setting away and one study was based in a clinic environment. The move towards intervention in a more naturalistic environment reduces the demands for time, travel and finance on families who are already experiencing additional demands and is advocated in the wider occupational therapy literature (Darrah et al., 2011). Interventions varied in length from four to ten hours for individual coaching, and six hours for group parent/teacher training. Bulkeley et al. (2016) suggest that a longer period of intervention may be required to sustain changes post-intervention than the 4 hours of intervention in their study. Indeed, Vismara et al. (2009), found parents acquired strategies by the fifth to sixth hour of a 12-hour group-based education program for parents of autistic children. This would suggest that four hours of intervention may be too little to support sustained changes, while six hours plus may be more effective in facilitating longer term strategies, but this assertion has not been tested with parents of children with sensory integration difficulties.

2.5.2 Limitations

From the perspective of the studies reviewed, there are several limitations. Most of the studies rely on volunteers which may limit the generalizability of findings. Sample size for the combined studies remains small. Data collection was either parent led, or therapist led and non-blinded. Findings are limited by the lack of control in three of the four studies. Methods of data collection varied, although three of the four studies considered goals that were individualized to the child or family. From the perspective of the scoping review there are also limitations. Due to the variety of intervention approaches, it is not possible to compare or combine data from these articles. As a scoping review, this paper gives an initial mapping of the information available.

2.5.3 Gaps in the literature and areas for further research

All studies reviewed identified the need for further research in this area. Three of the four studies incorporated an element of parent goal setting enabling parents to identify and address parents' own agenda. However, parents were not invited to indicate their own preferences in terms of support delivery. Identification of what support parents do or do not value provide the foundation for meeting parent identified needs. Do parents want support and if so, what is their preferred format to receive it?

The design of interventions was based on coaching literature and sensory integration knowledge and understanding. It is difficult to identify from the current studies which aspects promote change in child or parent outcomes. To identify the contribution of each intervention component, it may be pertinent to consider the impact of sharing information on sensory integration versus only coaching parents without framing within the context of sensory integration concerns. A manual of the intervention is important to demonstrate replicability. Evaluation of consistency between manual of intervention and actual intervention scored by an independent assessor can assure implementation fidelity. Evidence of group parent intervention is scant with only informal measurement of parent knowledge and competence. There is a need to consider the impact of group versus individual intervention. Given the differences in staff costs and the additional benefits of peer support further investigation of group-based parent coaching might be considered as an area for further exploration. In measuring outcomes there is inconsistency. Group-based intervention may impact parent stress and coping alongside child functioning and the wider health outcome of family participation, but this has not yet been explored.

Parent coaching needs to be considered in the context of the range of services available to families (Ashburner et al., 2014; Reynolds et al., 2017). Reynolds et al. (2017) see coaching as one piece of multifaceted intervention This assertion is supported by the findings of Rivard et al. (2017) who suggests that parent coaching while children were on a waiting list provide benefits to the child, but may be detrimental to parent stress if child focused early intervention services are not concurrently available (Rivard et al., 2017). In contrast Ashburner et al. (2014) suggest coaching as an appropriate starting point alongside universal design approaches. In addition to the evidence base, health economic drivers and context of delivery will influence approaches to service delivery. That is, coaching provides one approach to intervention that may also include, for example, direct intervention with the child or adaptation to the environment. At present we do not have sufficient evidence to comment on whether concurrently using multiple interventions, sequencing a series of interventions, or utilizing a single intervention in isolation best meet the needs of children and their families as no direct comparison studies have been undertaken. At this stage it is not about one approach to intervention replacing another but understanding what each approach contributes.

Finally, there is little long term follow up and application to wider social economic status, a wider range of participants would increase our understanding of the relative merits of a parent coaching intervention.

2.6 Conclusions

These studies demonstrate that it is possible in families of children with sensory integration difficulties to increase a parent's knowledge and understanding through education; but that approaches benefit from a coaching perspective so that the knowledge gained can be applied to everyday life. It is also possible to improve child behaviour, reduce parental stress and increase a parent's sense of competence through parental coaching. Evidence for one-to-one intervention with parents of children with SID is limited but promising. There is scant evidence to support group parent intervention in parents of children with sensory integration difficulties.

3 Chapter 3: Mothers' perspectives: daily life when your child has sensory differences.

NB See Appendix 8.5 Published paper Allen et al. (2024)

Preface

Chapter 2 (Allen et al., 2021) identified that parents were not asked in any of the reviewed studies to indicate their own preference for support or identify what they do or do not value. This led to the objective for the chapter with a focus on understanding mothers life experience, what they found helpful or not and what further support they would like. To gain an in-depth account of mother's experiences and perspectives interviews were undertaken.

Author contributions: Susan Allen (Conceptualization, Methodology, Project administration, Investigation, Data curation, Formal analysis, Writing - original draft, Writing - review and editing). Fiona J. Knott (Conceptualization, Supervision, Formal Analysis, Writing – review and editing), Amanda Branson (Conceptualization, Methodology, Supervision, Formal Analysis, Writing – review and editing), Shelly J. Lane (Formal Analysis, Writing- review and editing).

3.1 Abstract

Background: A child's sensory processing and sensory integration (SP-SI) differences can be a barrier to participation in daily life for both child and mother. Supporting mothers is advocated for, but little is known about the everyday experiences of these mothers.

Objectives: To gain an understanding of daily life for mothers and their children with SP-SI differences.

Methodology: Qualitative semi-structured interviews with six mothers were analysed through Thematic Analysis.

Results: Theme one described the impact of child SP-SI on daily life, including challenges in occupations across environments; adaptions required, and the lack of knowledge and understanding from social and professional networks. Theme two identified what helps: empowering mothers through relationships based on listening, gaining knowledge, and understanding; adapting the activity and the environment.

Conclusions: Mothers report that their child's SP-SI differences impact daily occupations and social relationships. In addition, supportive relationships, adapting activities and adapting the environment, support participation.

Plain Language Summary

What is daily life like when you have a child with sensory processing and sensory integration differences?

To develop a better understanding of everyday life with a child with sensory processing and sensory integration (SP-SI) differences, mothers were asked about their experiences. Six mothers were individually interviewed. They reported challenges to everyday life at home, at school and in their local communities e.g. sleep, mealtimes and leisure choices were impacted for both themselves and their child. They faced a lack of understanding from family, friends and professionals and had to adjust their activities and routines to accommodate for their child's needs. It helped mothers to be listened to and to interact with other people who had

knowledge and understanding of SP-SI differences. It also helped to be able to adjust activities, routines, and their environment to better suit their child’s sensory needs.

Research ethics: University of Reading Research Ethics Committee 2018-083-FK. Further details in Appendix 8.1

3.2 Introduction

Sensory Processing and Sensory Integration (SP-SI) differences (Watling et al., 2018), also referred to as sensory differences (Royal College of Occupational Therapists, 2021b) impact many aspects of children's participation in everyday activities. Areas affected include play, social participation, activities of daily living, sleep, engagement in learning (Parham & Cosbey, 2019) and shared family occupations (Schaaf et al., 2011). Much of the existing literature focuses on addressing the specific needs of the child, with limited attention paid to the perspective of parents. The focus of this study is the daily life experiences of mothers of children with reported SP-SI differences. Understanding mothers' experiences will help to inform future strategies for supporting mothers in their daily occupation of parenting.

As occupational therapists, our goal is to enable participation in daily occupations in a way that supports the health and well-being of children and their families (Law, 2002). SP-SI differences are one factor impacting participation in daily occupations, such as mealtimes and homework (Ben-Sasson et al., 2013). The complex interaction between the child and family, and their social and cultural context has not been unpacked in the literature. What we do know is that where child SP-SI differences are reported, investigators often view findings through a deficit lens, identifying elevated levels of parent stress and caregiver strain (Kirby et al., 2019), along with altered family and social relationships e.g. juggling the needs of siblings (Schaaf et al., 2011). Mothers are frequently blamed for their child's behaviour within family and school settings (Chiu, 2013). To shift the narrative and promote participation in daily occupation for children and families following a socioecological perspective (Curtin et al., 2017), a broader understanding of both daily life and the factors that might support mother and child participation is needed.

A number of approaches to working with children with SP-SI differences and their families are available, including environmental adaption, working directly with the child or working with parents (Reynolds et al., 2017). Individual parent coaching interventions can improve child participation in daily occupations, reduce parental stress, and reinforce a parent's sense of competence (Miller-Kuhaneck & Watling, 2018). Parents report strategies they have developed themselves to help with everyday life, such as controlling their child's sensory environment or maintaining a proactive attitude (Schaaf et al., 2011). Mothers also report the importance of continuing an employment role outside the family home (Dunstan & Griffiths, 2008). However, while we know that mothers of children with SP-SI differences face additional demands to those experienced by other mothers, there are few in-depth explorations of their experiences and the strategies they employ.

Thus, the purpose of this study was to examine the experience of daily life for mothers of children with SP-SI differences. Secondarily, we explored what mothers identify as supportive regarding the impact of their child's SP-SI differences.

3.3 Method

Design

It is acknowledged that a wide range of terminology is used in this field. Considering this, and in keeping with person-centered practice, we have chosen to use the phrase 'SP-SI differences' in this paper. Mothers are experts in their perception of the impact of their child's SP-SI differences to daily family life. This study uses an inductive approach and qualitative design to understand mothers' perspectives through one-to-one interviews. Participant involvement was guided in line with CONSORT, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Booth et al., 2014) and the National Institute for Health briefing (INVOLVE, 2012). Ethical approval was granted through the University Research Ethics Committee.

Participants

A purposive community sample (Bowling, 2014) was recruited by convenience through specialist online parent forums in the United Kingdom. Sampling maybe theoretical (sampling and analysis of data until no new codes are identified and conceptualisation is well-developed) and /or purposeful (sampling based on specific criteria to gain an in-depth account of a defined group of participants) (Palinkas et al., 2015). This study utilised a theoretical sampling to gain an understanding of the main themes. Mothers were invited to participate if they were resident in the United Kingdom and had one or more child with identified SP-SI differences that were impacting everyday life.

In reflexive thematic analysis meaning is generated through the interpretation of data. (Braun & Clarke, 2022). Therefore, the number of participants cannot be wholly determined in advance of data collection (Braun & Clarke, 2022). The term 'saturation' has been more meaningfully replaced by the conceptually descriptive term 'information power' that reflects the depth of meaning of the data (Malterud et al., 2016). Whilst generating new meaning from increased participants is always possible the goal is not to provide an exhaustive understanding of the topic but to gain general conceptual understanding of these mother's experiences and what helps them and their child. Acknowledging that meaning making is a dynamic process between the reported experience of the subjects and the situated interpretative judgement of the research team. No contact between researchers and mothers occurred prior to invitation to participate. Inclusion criteria were mothers who reported SP-SI differences in their children (aged under 19) and resident in the United Kingdom. Exclusion criteria: non-English speakers and, in this exploratory phase, primary carers other than mothers. As an initial exploratory study, the aim is to offer new insights to contribute substantially to our understanding (Malterud et al., 2016). Based on the aims of the research, sufficiency and pragmatic constraints, a proposed sample size of 6 or more participants was identified as sufficient (Braun & Clarke, 2022; Malterud et al., 2016).

The research team brought a range of backgrounds to this study, and all contributed to the study's research design and data collection. The first author is a female occupational therapist with over 30 years of clinical experience and a postgraduate research student with an interest in parent stress, family support and sensory differences. The second author is an occupational therapy academic and researcher with over 40 years of experience and a special interest in sensory integration and neuroscience. The third author is an occupational psychology academic and researcher with an interest in learning, motivation, and performance. The fourth author has over 30 years of experience as a clinical psychologist. She is also an academic with a special interest in autism, anxiety, and families.

Fifteen mothers expressed initial interest. Seven completed consent forms but one withdrew from interview due to child illness. Table 3a describes demographics. Pseudonyms are used for confidentiality. All mothers (N=6) described themselves as white with graduate or postgraduate levels of education. Five were married and one a single parent. Five were employed outside the home. All mothers were resident in the United Kingdom. Mothers were all in their own homes at the time of interview and either alone or with their direct family. Children (N=10) had been identified as having SP-SI differences by a parent, nurse, or occupational therapist. Child diagnosis is reported in Table 3-a. Nine of the ten children had a learning or developmental disorder. Mean lifetime access in the United Kingdom (Royal College of Occupational Therapists, 2022) to occupational therapy was eight hours.

Table 3-a

Participant and child demographic characteristics

Characteristics	N or M(SD)
Mother	6
Mothers age	45.5 (7.4) years
Highest educational level -	
Highschool or college	-
Bachelor’s Degree	1
Master’s degree or Doctorate	5
Ethnicity - White	6
Employment	
Employed	4
Self employed	1
Unemployed	1
Child with reported SP-SI differences	10
Age	12.2(3.6) years
Child Gender	
Female	6
Male	4
Child diagnoses*	
Autistic spectrum condition or awaiting assessment	6
Developmental Coordination Disorder or Dyspraxia	3
Dyslexia	2
Irlen Syndrome	2
Specific language Impairment	2
Selective Mutism	1
Slow processing speed	1
Anxiety	1
Learning disability	1
School setting	
Specialist	3
Mainstream	7

Procedure

Following written informed consent, online or telephone interviews were arranged according to each mother's preference. Interviews were conducted prior to the COVID-19 pandemic and guided by the evidence base on qualitative interviewing (Howitt, 2010).

The interview guide of semi-structured questions was developed by the authorship team. The guide was reviewed by two community partner mothers: no changes were suggested. Primary guide questions are given in Table 3b below. It is acknowledged that it can be difficult to identify whether sensory or primary diagnosis factors drive functional difficulties. Mothers were asked to focus on their child's sensory processing difficulties, rather than difficulties primarily associated with other conditions such as autism.

Table 3-b

Primary guide questions

Primary guide questions
a. What is life like for you for you with a child with sensory integration difficulties? b. How does this impact daily life? That is to say, are there things that you or your child are not able to do in everyday life because of their sensory processing and integration difficulties? c. What has been useful to you? What has not been useful? What support would you like to have had?

Interviews were completed in a single session and their duration varied from 30 minutes to 75 minutes. The first author completed audio recorded interviews. Field notes were taken to support understanding. Probe questions were used as needed to allow mothers to develop their responses more fully, and interviewees were encouraged to add areas of importance to them if these were not already covered in the interview. Recordings were transcribed blindly by a medical secretary and then checked for accuracy by the first author. One participant requested a copy or her transcript. All documentation was anonymised for confidentiality. The first author carried out all interviews. Participants were aware of the interviewer's occupation and research background, in particular her interest in mothers' experiences of family life when a child has SP-SI differences driven by the goal of service improvement.

Data Analysis

Transcriptions were uploaded by the first author into NVivo12 and analysed using the six-phase framework of thematic analysis (Braun & Clarke, 2022) process. These phases involve familiarising yourself with the dataset; data coding; initial theme generation; theme defining refining; theme naming and write up. To support reflexivity (acknowledging the researcher's role) all four researchers considered codes and themes. During interviews researcher 1 kept a diary to begin to reflect on key points raised by participants. Researcher 1 and 4 familiarised themselves with the data set and undertook coding. Coding was then reviewed with researchers 1 and 4. Coding was latent, with meaning being sought within content. Coding, theme generation and defining was generated by researcher 1,3,4. The themes and codes were further developed by Researcher 1 and 2 to refine themes. The theme definition process was repeated with research 1,3,4 and then Researcher 1,2. Naming and write up was initiated by author 1,3 and 4 then again developed by researcher 1 and 2. Themes and subthemes were repeatedly reviewed and refined by all four authors to ensure the thematic structure provided a systematic interpretation of the data (data available on request from first author). The content of the data related closely to the researchers' questions and supported the sample size. Themes were consistent across interviews, although it is acknowledged that in interpreting the meaning of data, it is never possible to reach an absolute endpoint (Braun & Clarke, 2022). A journal was collated by the first author, to record reflections on key points of interviews and to document the progression of code and theme development. Two volunteer participants reviewed and provided feedback on a written summary of results.

Quality can be affected by credibility, transferability, dependability, and confirmability. Each of these quality factors was considered as follow (Hannes, 2011). Credibility reflects whether the data represents the views of the participants and was assured by repeated analysis across time and person and by participants checking findings. Transferability evaluates whether findings are transferable to other settings. This was explored by understanding the demographics and context of participants. Dependability evaluates whether the research is logical, traceable, and clearly documented. In this study, it was supported through an audit trail of code and theme development supported by participants' quotes. Finally, confirmability (or the extent to which the findings are grounded in the data) was supported by the description of the theoretical basis and methodological process, along with identification of the researcher's backgrounds.

3.4 Results

Initial thematic analysis led to 56 codes which were grouped into four themes. Two further iterations led to the identification of two overarching themes with five subthemes. Please see Appendix 7.1 Development of Thematic Analysis for further details. Final findings are described in Table 3-c below. Italicised words are direct quotations from the mother. All names have been changed for confidentiality.

Table 3-c

Daily Life when your child has SP-SI differences: Themes, sub-themes, and descriptions.

Themes and subthemes	Description	Example quotes
1. The impact on everyday life		
a. Challenges in daily occupations	The child's SP-SI differences have an impact on mother's ability to participate in daily occupations	*It can be like walking on eggshells* (Eve). *She has really extreme reactions to self-care. Teeth…wash…hair…. nails it's a fight even having breakfast* (Ceri). *Family days out I just wouldn't do with all three of them. It wouldn't be worth the risk* (Anne).
b. The things we have to do	Choices or actions that mothers have made as a direct consequence of their child or children's SP-SI differences.	*Both of the grandmas got concerned and they would try to put a spoonful of food into her mouth, but she never swallowed this food. She would retch, and I decided that I had to put a stop to this because it obviously wasn't helping anything – I just hated it... (*Deb). *When we were choosing a house to move to, the criteria really was about how much noise she would be exposed to and things like that ……. Anything to get a good night's sleep* (Anne).
c. A lack of knowledge and understanding	A lack of knowledge or understanding by others about everyday life for a mother of a child with SP-SI differences.	*It's the lack of understanding from other parents which is hard* (Bonnie). *I was made to believe that it was all behavioral because I was doing the wrong things as a parent…. again, and again* (Ceri). *I would have liked a much greater awareness in the professionals including teachers and doctors* (Deb)

Themes and subthemes	Description	Example quotes
2.What helps?		
a. Empowering mothers: An attitude of understanding	Mothers are empowered when they and those who can support them and their child gain knowledge and understanding.	*Once you understand a bit of why children are behaving the way that they are, it is much easier to manage.* (Fiona) *Thankfully school is very supportive.* *My Mom, she kept backing me…she is a kind of lifeline* (Ceri) *I think the only thing about SPD is that it should be education, education, education for everybody… Because you need it* (Bonnie) *I found my voice, oh my...I didn't stop* (Fiona)
b. Adaption	Strategies and adaptions to daily life that support their participation in everyday life.	*Finding the right toothpaste, that's a game changer* (Fiona) *Soundproofing…wooden shutters… white noise maker improves it (sleep). ... In the school holidays we go out every single day* (Anne). *We aim to have one of us here when our daughter comes in… It sounds crazy, she forgets to drink... I make sure the first thing I do is give her a drink* (Eve).

3.4.1 Theme 1. The impact on everyday life

This theme describes the experience of daily life for mothers of children with sensory processing differences.

1a. Challenges in daily occupation

In the home, sleep, self-care, mealtimes, play, and chores were all identified as areas of challenge, with impacts on both child and mother. Deb shared her experience of both 'meltdowns' at mealtimes – both from her and her child – *'when (my) anger would come from nowhere'.* Anne further reflected: '*If there's the slightest noise, she's awake and then doesn't go back to sleep. It... affects the whole family's mood.'* Unaddressed sensory needs place additional practical and emotional demands on mothers.

Mothers described the impact of sensory processing differences on their child's role as a student including self-care. Fiona gave the example of her child's difficulty in dealing with the sensory environment of the school toilets, which resulted in him avoiding the facilities all day, then rushing out and urinating outside school. She said: '*They didn't see it as a school issue... totally as a parenting problem.*' Bullying was also identified as a problem in the school environment, resulting in a negative impact on social engagement.

Mothers also talked about restrictions to their own social, leisure and work opportunities. Difficulty coping with their child's behaviour led to avoidance of participation in community activities. Child safety concerns were highlighted, with several children running away from unanticipated or overwhelming sensory stimuli, for example an ice-cream van (Bonnie) or a busy toy shop: *'He put himself in so much danger'* (Fiona). Safety was a factor in mothers' decisions to participate or otherwise in shared leisure activities.

1b. The things we have to do

Mothers reflected on the challenges they faced in finding the right environment and/or support for their child. Support struggles ranged from minor (e.g. persuading school to allow a pencil topper) to extreme. One mother said: *'We'd have meltdowns nearly every day and I feel like I* *can't live like this. We need to really make some changes, and I didn't know how. So, I gave up my job. I sold my house, and we moved to the coast.'* (Fiona)

Thus, not only are mothers making significant changes to their child's environment and daily occupations but also to their own.

Additional resources needs were associated with raising a child with SP-SI differences. Parents *'spend a fortune'* (Eve) as well as time and emotional energy on '*letters, reports and phone calls'* (Deb). Where a child's SP-SI differences have led to additional care or supervision requirements, mothers reported applying for government financial assistance e.g., Disability Living Allowance (DLA) (Bonnie). Unfortunately, despite meeting the criteria, it can be a challenge to access financial support.

'It took a lot of effort and tears and formal complaint… It would have been much better if that kind of support had been more easily available.' (Anne)

Mothers report that the impact of increased costs associated with meeting the needs of a child with SP-SI differences are exacerbated by difficulties in sustaining employment outside the home.

1c. A lack of knowledge and understanding

Mothers described their initial struggles to understand why their child was behaving in an atypical manner, before SP-SI differences were identified. Not understanding the reasons for their child's 'unusual' behaviour left mothers frustrated:

'She'd launch herself onto the sofa with a massive bounce and then her legs would be flying in front of you... it's hard to refrain from shouting at the child for being in the way, when you just want a bit of down-time yourself.' (Deb)

A lack of knowledge and understanding within family, social and professional networks impact how both mother and child are perceived. Reflecting on her efforts to explain her child's needs at school, Bonnie said: *'It's the lack of understanding… that's hard.'* Deb described both grandmothers' concerns over her child avoiding food, which led to criticism and a breakdown in these relationships. At times, the pattern of broken relationships extends beyond the family. Bonnie shared the experience of a community barbeque organiser who said: '*I think it's just*

naughty boy syndrome'. Bonnie's response was to go elsewhere. Explaining, she said: *'I just don't want my son to be around 'cos they need education themselves.'*
Inconsistent levels of knowledge, understanding and empathy from trained professionals were also reported by mothers. Moreover, pathways to identifying SP-SI differences were complex. Frequently, mothers were told their child's behaviours were due to '*bad parenting'* (Ceri), with both healthcare and education staff showing a lack of awareness. Deb said: '*It's horrible not being believed'* and said she reached the point where she felt *'so angry at not being listened to ...that there would be even more delays in getting my child what she needed*.' The emotional impact on mothers was clearly expressed by Fiona when she said: *'I didn't know how to deal with it. I took it personally. I had lots of experts around me that laughed at me when I suggested that there was something not quite right.'* Both Deb and Eve expressed fears that reports or observations filed by third parties about their child's sensory-related behaviour would elicit child-protection concerns. Many mothers indicated that, because of poor understanding of their child's behaviours, they felt isolated and alone.

3.4.2 Theme 2. What helps?

This theme explores factors that mothers said they found helpful in everyday life.

2a. Empowering mothers: An attitude of understanding and support

An understanding and supportive attitude from family, school and the community empower mothers. Describing the value of being listened to and understood, Deb said: *'It was helpful to have any intelligent adult…our OT… listen to us about our child, take in what we were saying... not blanking us'.*
Ann explained that a sensory profile completed by a nurse practitioner was *'the most useful report we had ever read on her'* and that it *'explained… behaviours ... it was transformative for the family.*' Being heard and understood, and gaining understanding, empower action and choice for mothers.

Mothers advocated for their own *'social networks'* (Anne) and *'teachers'* (Deb and Eve) having wider knowledge and understanding of the impact of SP-SI differences. Mothers identified both fathers ('*Dads often get overlooked... he's very good'* (Ann)) and grandmothers as key players in providing practical and emotional support to them. *'If it wasn't for my mum, I probably would have thought, uh, hang on, uh, I'm a really bad parent…she's really supportive.'* (Ceri)

An attitude of understanding, when it exists, supports valued participation by children with SP-SI differences. Bonnie describes how such an attitude helped her child in his leisure activity: '*Thankfully we have an amazing… instructor – she gets him completely…. she will be understanding in terms of what he needs to get into the zone.*'

When the mother's or child's voice is heard, positive learning is gained. Ceri struggled with her daughter's sensory related after school meltdowns. School staff dismissed her concerns until a member of staff saw one such meltdown on the way home from school. After this, Ceri's concerns were validated, and her daughter was given a voice.

'They actually said, when she left the school, that they'd learned a lot from her… to develop their understanding of sensory.' (Ceri)

Several mothers took direct action when they did not feel heard. Describing the steps she took, Fiona said: '*Complain! … Nothing changes unless you make those in the right places aware of what's going wrong.'*

Others actively searched for support and validation for themselves and their children. Bonnie said she felt very alone until she '*met up with other parents*. Additional resources were cited as helpful, including books, social media groups, online resources, and support groups for parents, children, or teenagers.

When mothers and children are listened to, those around them gain knowledge and understanding. Helping family, friends, community leaders, education and healthcare professionals be aware of their own value in supporting the child and the mother can lead to increased participation in everyday life for both.

2b. Adapt

Adaption of everyday occupations was described as an important way to support participation in daily life. In an unexpected example, mothers adjusted their infants' breastfeeding habits to soothe a dysregulated child. *'He was constantly (breast)feeding,'* (Fiona). Often, this increased participation in breastfeeding also served the mother well, providing her with a period of calm.

‘Breastfeeding…gave me a kind of sensory reward…I cannot imagine how I would have survived parenting without (it).’(Deb).

Mothers also recognised the importance of adapting their environments, for example by providing a safe but challenging play space where, ‘*you can move and crash about*’ or by establishing a ‘*sound and light proofing bedroom’*(Anne). Some families were able to adapt and tailor their routines to support the child e.g., by seeking out alternatives to homework (Eve). Physical activity was often seen as a key strategy, Anne reported that: ‘*We are...an active family...we have to be to keep her regulated…*’

Mothers can sensitively identify the impact of SP-SI differences, but it can remain challenging to adapt the activity or environment sufficiently. Potentially problematic situations are made easier when the parent understands their child’s preferences and responds accordingly, for instance, by knowing ‘*what clothes to buy’* (Anne). However, the best laid plans can be thwarted by factors that remain difficult, or even impossible, to control, such as the weather. ‘*Because of the heat, he could not tolerate clothes, we were housebound’* (Fiona). Even in these situations, however, small adaptations can renew the possibility of participation, as one mother discovered when her child’s school showed some flexibility towards his sartorial needs. ‘*He's not tolerating school trousers – they’re quite lenient and he's allowed to wear towelling shorts.’* (Fiona)

Access to intense outdoor physical activity was cited as important through either mainstream activity, such as gymnastics or through a specialist provision. Whether active or more relaxation-focused, leisure activities are appreciated by mothers for the value they bring their children with SI-SP differences. However, even when participation is possible and successful, accessing these opportunities brings additional implications to mothers in terms of time, energy, and financial resources.

Over time, some mothers have been able to identify their child’s cues and to adapt an activity through preparation. An example of an area of adaptation was highlighted by Anne, Bonnie and Fiona who all raised strategies to ensure ‘*safet*y’ in the community. Strategies included control of the sensory qualities of the environment, additional adult support and being able to attend activities at a quieter time.

A successful application for government financial support (e.g. DLA) supports participation. Mothers not only use this funding for safety-related choices but also make decisions about how to spend the money based on what is meaningful to the family. Typical examples of how funds are spent include: additional childcare so the mother can work; fleece bedsheets; adapting toys; additional driving/swimming lessons, and multidisciplinary team meetings. Bonnie said: '*I know we get DLA for both of them, and people feel guilty about claiming it, but I don't for one minute because what I do spend the money on (is) these sort of things.'*

Activity/environmental adaption and additional resources, both financial and emotional, provide valuable tools for mothers to support participation in everyday occupations for both them and their children.

3.5 Discussion

In mothers' own voices, this study highlights the pervasive impact on everyday life of a child's SP-SI differences on both the child and their mother. Mothers described their child's SP-SI differences as presenting significant challenges for participation across all areas of occupation, including activities of daily living, work roles, and leisure activities at home, at school and in the community. However, they also described the creative solutions they had found, including seeking out strong social networks and adapting everyday routines, even when these were at the expense of the mothers' own work and leisure time. These findings reflect an ecocultural perspective (Bronfenbrenner & Morris, 2006; Llewellyn, 2012) and how the mother and child interact with an environment that can act as a facilitator or a barrier to participation. At a microsystem level, mothers are helped by a supportive family network and the capacity to adapt both their environment and occupation. At an ecosystems level, friends, school staff, healthcare staff and community leaders with knowledge, understanding and empathy support participation for both mother and child. At a wider mesosystems level, health, education, and social care policy influences accessibility to care, support and financial opportunities. Occupational therapists have a role to play in direct intervention with the child but also in providing education to the communities and organisations around the child and family unit.

3.5.1 Everyday life

A child's SP-SI differences create a barrier to participation in everyday life and increase caregiver strain with a changing pattern over time (Kirby et al., 2019). Our study further identifies the extensive practical and emotional experiences of everyday family life and illustrates how mothers adapt their own occupations from the child's infancy onwards. For example, at home, parents accommodate and adjust activities of daily living such as dressing, sleep and feeding. Outside the home, mothers negotiate the child's needs at school. They also appear to face additional demands in the identification of, and access to, family leisure activities and in maintaining safety. Disruptions in daily occupations impact an activity and the secondary opportunities linked to it. For instance, shared mealtimes provide time for socialisation and communication (Ochs & Shohet, 2006), however, where this occupation causes distress, the opportunity for positive interaction and social development is lost. Identification of such disruptions in daily life gives an opportunity for early intervention.

3.5.2 Empowering mothers

The experience of mothers in our study highlights how a lack of knowledge and understanding of SP-SI differences by both education and primary healthcare professionals impacts families. This has two implications. The first reflects an ongoing need to share information and offer education to our health care and education colleagues to facilitate development of knowledge, understanding and empathy towards families. The second implication is that there are missed opportunities in reducing parental stress and enabling child/family participation in daily occupations. Mothers strongly identified the importance of being listened to and validated. Professionals who do not listen can hinder access to services and limit parents of disabled children in their decision-making capacity (Lundeby & Tossebro, 2008). In our study, mothers articulated the positive impact of an open and respectful dialogue with medical and educational professionals. The importance of listening has been raised at a policy level for autistic individuals in United Kingdom, with specific focus on sensory sensitivities or overload (Pelicano et al., 2013). Mothers also strongly identified the importance of positive relationships across family, professional and social networks in facilitating participation in daily activities. Showing respect and listening to individuals and families is at the heart of family-centred practice (Pozniak et al., 2024) and the importance of applying these principles to mothers of children with SP-SI differences is reinforced by the findings of our study.

Mothers in our study spoke of being judged and blamed, and this is reflected in other studies of mothers of children with SP-SI differences (Chiu, 2013) and more widely by parents of children with disability (Pozniak et al., 2024). The expectations placed on mother's act as a social barrier to participation. Conversely, social relationships can act as facilitators to participation. Our study uniquely reported the importance of fathers and grandmothers in providing both emotional and physical support, highlighting the value of developing positive relationships within social networks as an intervention strategy. Worth exploring is the potential of intervention practices that engage the wider family. Alternatively building a peer support networks, such as occupational performance coaching groups (Suja Angelin et al., 2021). Another potential avenue for exploration is text-based communication networks for fathers (Ismael et al., 2018).

The benefits, for both parents and society, of empowering parents are recognised in a study of parent's experiences of advocating for their autistic child (Boshoff et al., 2016). Adult-learning theory suggests that providing information alone does not elicit change. The value of education with coaching is supported in studies with both individual parents of children with autism (Foster et al., 2013) and teachers of children with self-regulation issues (Hui et al., 2016). Coaching is a promising route to supporting the empowerment of mothers of children with SP-SI differences when these differences are impacting both mother and child’s participation in daily occupations.

3.5.3 Adaptation

To support and improve participation, mothers highlighted the need to combine forward planning and adaption of the environment. Adaption of the environment has previously been identified to support participation in events such as a community-based programme to enhance access to museums (Silverman & Tyszka, 2017). As is central to occupational therapy practice (American Occupational Therapy Association, 2020), the need to adapt the environment is valued by mothers across home, school, and community.

A notable support identified by mothers in this study was breastfeeding as a facilitator of maternal wellbeing and child self- or co-regulation. In typically developing infants, mother-child touch can reduce a mother's anxiety and improve her child's behavioural and emotional outcomes (Pickles et al., 2016). In infants or mothers, themselves (Talcer et al., 2021) who struggle to tolerate touch, typical regulatory strategies such as hugs may not support co-regulation. The data presented suggest that breastfeeding provided a strategy to some dyads, as a means of both connection and co-regulation.

Mothers continuously adapt their own occupations to support the child, including by applying limitations to their own work roles. In particular, the challenge of supporting a child's education means mothers are forced to reduce their work hours or even resign from employment outside the home. The ramifications of restricted access to employment and earnings are lifelong. In research on the financial impact on mothers of having an autistic child, it was found that earnings were 56% lower than for mothers of typically developing children (Cidav & Mandall, 2012). In our study, mothers were clear about the value of additional government funding in supporting parent and child occupations that would otherwise be inaccessible.

3.5.4 Limitations

Recruitment via specialist online parent forums identified mothers who were actively seeking out support or further information on the topic, future clinic-based recruitment may lead to a wider sample. The study focused only on mothers. To represent a wider population of caregivers, it would be necessary to look at all those who carry primary carer or shared carer responsibilities. In this small-scale study, participants were self-selecting and displayed limited social and ethnic diversity. Research with a more diverse populations is indicated. Most of the participants reported that their children had a diagnosis of autistic spectrum disorder. While it is difficult to fully separate the impact of a neurodevelopmental diagnosis from the impact of SP-SI differences, all participants attributed increased burden of care specifically to their child's SP-SI differences.

3.6 Conclusion:

Mothers report that their child's SP-SI differences impact daily occupations and social relationships. Mothers face additional demands to their parenting role from birth onwards, and advocate for early intervention. They adapt daily activities and their environments to meet the needs of their child and family, with varying levels of success. Mothers report that it is helpful when they and their children are listened to; when there is a supportive social and professional network, and when the activity and environment can be adapted to accommodate the child's sensory needs. This study supports engaging with social and professional networks around the mother and child to promote knowledge and understanding of SP-SI differences and the impact these have across home, school, and community settings.

4 Chapter 4: Mothers’ perspectives: Child sensory differences, daily life, relationships, media resources, and parent intervention. A survey.

This chapter is in preparation for submission (Allen et al., In preparation).

Preface

In Chapter 3: Allen et al. (2024), mothers described the significant impact of child sensory differences on both themselves, and their child at home, at school and in the community. Mothers identified that being listened to and supportive social and professional networks were helpful to them. As a small qualitative study generalization of findings are limited. Therefore, the next step was to explore these findings with a wider population of mothers of children with sensory differences.

Author contributions: Susan Allen (Conceptualization, Methodology, Project Administration, Investigation, Data curation, Formal analysis, Visualization, Writing - original draft, Writing - review and editing), Fiona Knott (Conceptualization, Methodology, Supervision, Writing- review and editing), Amanda Branson (Conceptualization, Methodology, Supervision, Writing – review and editing), Shelly J. Lane (Methodology, Writing- review and editing).

4.1 Abstract

Importance: To meet the needs of mothers of children with sensory differences, we need a greater understanding of their experience and what they find helpful.

Objective: To explore the impact of child sensory differences on daily occupations and relationships, from the mother's perspective. To identify the relationships, media, and parent interventions mothers regard as helpful, and further support they would value. In addition to compare mothers of autistic and non-autistic children with sensory differences. Finally, to identify patterns of responses through factor analysis to guide further research.

Design: A single cohort descriptive observational survey study with data collected between January and March 2020.

Setting: Online survey.

Participants: Mothers (n=132) of children with reported sensory differences accessed the online survey with a 79% completion rate.

Outcome and Measures: Survey items were generated from previous in-depth interviews with mothers of children with sensory differences. The questions addressed the impact of sensory differences on daily activities, occupations, and relationships, for mother and child; helpfulness of resources, relationships, parent intervention and what further support mothers need/want.

Results: Mothers reported that child sensory differences had a pervasive impact on everyday activities and relationships for both mother and child. Supportive relationships, media, social media, and direct interventions to mothers, were helpful. Mothers wanted/needed more practical and emotional support for themselves, education of others and specialist support for their child. The reported experience of mothers of autistic children versus non-autistic children with sensory issues are compared.

Conclusions and Relevance: Social and professional relationships, media and parent intervention are identified as helpful by mothers of children with sensory differences, supporting the use of a variety of intervention strategies. Whilst mothers of autistic children report greater impact of sensory differences, all mothers reported similar responses to the helpfulness of relationships and media.

What this article adds: Child sensory differences impact daily occupations and relationships for both the child and the mother. The impact of these differences is greater in mothers with at least one autistic child with sensory differences versus mothers of no autistic child with sensory differences. Supportive relationships, media and parent intervention are helpful to mothers of children with sensory processing differences.

Keywords: Sensory Integration, Family-centered practice, Caregivers, Occupation

Ethics approval statement: University of Reading Research Ethics Committee 2019-191-FK. Further detail in Appendix 8.1

4.2 Introduction

A child’s sensory differences impact successful participation in everyday life for children and their families (Carter et al., 2011). While the occupational challenges faced are acknowledged (Patten Koenig & Rudney, 2010), there remains debate about how these issues are addressed. The American Occupational Therapy Association advocates for consideration of occupation in all environments (American Occupational Therapy Association, 2020), including the physical environment, and social relationships. Two research teams have explored approaches to working with autistic children with sensory differences and their families (Ashburner et al., 2014; Reynolds et al., 2017). Ashburner et al. (2014) described a clinical reasoning framework to support optimizing participation, dividing the model into support for the individual child or family, and support for multiple children in a shared environment. Reynolds et al. (2017) took a different approach to conceptualize interventions to support the functional goals of children with sensory differences. These are environmental supports and adaptations, caregiver-focused interventions, and child focused interventions. Common to both approaches are a recognition of the need to support families, not just the child. To support families, we must have a greater understanding of their experiences.

Sensory differences are uniquely identified as a component of the diagnostic criteria for Autism Spectrum Disorder (American Psychiatric Association, 2013). Despite a lack of independent diagnostic recognition, there is increasing evidence that sensory differences occur both in autism and other neurodevelopmental populations e.g. Attention Deficit Hyperactivity Disorder (Lane et al., 2010), Developmental Coordination Disorder (Allen & Casey, 2017), and in those with no diagnosis (Reynolds & Lane, 2008). Acknowledging the identification of sensory differences in the autism spectrum disorder diagnostic criteria, this study will compare the reported experience of impact and what helps between the cohort of mothers of autistic children and non-autistic children.

The long-term stressors experienced by mothers of children with sensory differences (Kirby et al., 2019) are reported to be additional to those associated with a primary neurodevelopmental diagnosis (Ben-Sasson et al., 2013). Mothers spent more time and energy in their parenting role (Walbam, 2023) and adapted family life to make it more manageable e.g. carefully selecting activities and adapting their environment (Schaaf et al., 2011). Expanding the wider concept of environment, Llewellyn (2012) reminds us that to consider the child as separate from their context is to be ineffective as a therapist. However, social support around parents of children with sensory differences has to date not seen research attention, even though the link between family social support and parent stress has been established in wider populations (Dunst, 2022). Understanding more about the relationships around the family will help to understand how mechanisms of relationship support are perceived by mothers of children with sensory differences.

In a systematic review of parent education and coaching in children with sensory differences, intervention led to reduced parent stress and improved child occupations. Findings were limited by a small number of studies with differing methods and outcome measures, focusing only on autistic children (Miller-Kuhaneck & Watling, 2018). However, research does not identify what mothers perceive to be helpful or the additional support they may want. In line with family-focused intervention (Ashburner et al., 2014), occupational therapists need to think creatively about how we can best support mothers, including understanding of perceived impact of intervention. To enable development of preferred services, six mothers of children with sensory differences were interviewed, as described in Chapter 3 (Allen et al., 2024). Using qualitative thematic analysis, mothers' experiences were grouped into two overarching themes. The first was the '*Impact on everyday life*' of the child's sensory differences and subsequent challenges created at home, at school and in the community. The second theme identified '*What helps;*' mothers felt empowered by gaining knowledge/understanding through others, media, supportive relationships and being able to adapt activity and the environment. The '*What helps*' theme supported participation in everyday life for both mothers and children, aligning with a multi-faceted approach to intervention that includes direct support to parents as described by Reynolds et al. (2017).

The current study primarily builds on existing research by investigating the impact of maternal-reported child sensory differences, on mothers' and child's everyday activities and relationships using a large community sample. The secondary aim is to identify the relationships, media support and parent interventions that mothers find helpful and to identify further areas in which they would value support. This data will be analyzed by subgroups. Finally factor analysis will be completed to guide future research. The aim is to test the following research questions:

1a. Do mothers of children with sensory differences report negative impact on child and family everyday activities or relationships?
1b. Is there a difference in the impact of sensory differences on child and family everyday activities and relationships as reported by mothers of autistic versus non-autistic children?

2a. Do mothers of children with sensory differences report that relationships, media support and parent intervention are helpful?
2b. Is there a difference in the helpfulness of relationship, media support or parent intervention identified by mothers of autistic versus non-autistic children?

3. Are there associations reported by mothers of children with sensory differences among the variables of everyday activities and relationships?

4. What additional support would mothers of children with sensory differences like to receive?

4.3 Method

Research design

This study examined an uncharted area using an exploratory and pragmatic approach of a single cohort descriptive observational study (Bowling, 2014). The ‘Strengthening Reporting of Observational Studies in Epidemiology’ (von Elm et al., 2007) statement guided the development of this manuscript. Quantitative methods were used to identify current experience, and qualitative strategies were used to gain additional information. Data was gathered through a secure online survey tool, to support ease of access across a wide population. Ethical approval was gained from the University of Reading Ethics Committee. Advertisements were shared through online parent and special interest sensory groups with an embedded link to the information sheet, consent form and then survey. Participants could withdraw from the survey up to final submission, when the anonymized data was tabulated for analysis.

Participants

The survey was conducted from January to March 2020. Completed surveys were analysed (n=132). Inclusion criteria required that participants be mothers of children with reported sensory differences; a formal diagnosis was not a requirement of the study. Carers other than mothers were excluded. The mean maternal age was 39.9 years (SD 9.2 years). Mothers of children with reported sensory differences (n=174) provided the following details: mean child aged 9.4 years (SD 4.3 years), 66% male/ 33% female/ 1% non-binary. Child diagnoses were reported as: Autism (45%), Anxiety (23%), Attention Deficit Hyperactivity Disorder (17%), Developmental Coordination Disorder (13%). Additionally, 20% reported awaiting assessment or other diagnosis. No formal medical diagnosis was reported in 28% of children. Reported sensory differences classification followed Bundy and Lane's (2019) model of sensory integration: sensory over responsiveness (61%), sensory seeking (58%), poor body awareness (39%), sensory under responsive (32%), poor tactile perception (30%), sensory based dyspraxia (27%), inadequate interoception (26%), poor visual perception (23%), and poor discrimination (11%).

Survey Design

The online survey was generated by the research team from previous in-depth parent interviews, in collaboration with all four authors (Allen et al., 2024). The survey is not designed to be a comprehensive tool but to gain further data in the areas identified by mothers in the in-depth interviews. The survey was piloted with 3 mothers of children with sensory differences and two expert clinicians, who were asked to comment on clarity of questions and layout, leading to modifications to the wording and layout. Questions were presented in a logical order, with expansion on key questions, and tabulated for ease of response. Likert scale questions were used to capture the perception of participants (Jebb et al., 2021) about the impact of child's sensory differences on everyday activities and relationships, the helpfulness of relationships and resources and, where relevant, parent intervention content. Recognizing that not all children and mothers participate in all activities, a non-applicable option was available. Open ended questions were used to identify additional resources or support that mothers would like. Please see Appendix 8.3 for full survey.

Data Analysis

Descriptive statistics were calculated for quantitative data. Results are reported as mean (standard deviation) for Likert scales with percentages (rounded to the nearest whole number) for group data (Bowling, 2014). Research questions 1b and 2b are comparing the groups of mothers of autistic versus no autistic children. The non-autistic group was comprised of all mothers of children with no autism diagnosis, but included children with Anxiety, Attention Deficit Hyperactivity Disorder, Developmental Coordination Disorder, as well as those with no identified diagnosis. The Linear-by-Linear test (Chi-square test) was used to test for a trend in responses. This analysis approach is known as the Mantel–Haenszel test, or as the Cochran–Mantel–Haenszel test (McDonald, 2014; Vierra et al., 2023). Two assumptions must be satisfied. The first being that the observations must be independent of one another and the second is that the data must be acquired in the same manner for each group (Vierra et al., 2023). It is commonly used to understand relationships in observational studies while adjusting for potential confounders (Moral & Valle, 2023). Significance was set cautiously at p<.01*. Effect size was calculated using Cramer's V. Effect size <0.2 is weak, <0.2 to <0.6 is moderate and > 0.6 is strong.

To explore research question 3 and identify patterns of impact of sensory differences in everyday life and relationships Exploratory Factor Analysis using principal axis factors with varimax rotation techniques (Field, 2009) were selected. The final research question (4) generated qualitative data. The qualitative data were categorized by two researchers and confirmed by a third, using basic content analysis (Drisko & Maschi, 2015).

4.4 Results

4.4.1 Impact on everyday life

Research Question 1a: Do mothers of children with reported sensory differences report negative impact on child and family everyday activities or relationship? Between 69% and 97% of mothers reported a negative impact of child sensory differences on daily life activities for themselves and their children across home, school and the community environment. At least 68% of respondents reported that their child's sensory differences negatively impacted their own and/or their child's relationships. See Table 4-a. and Table 4b. In summary mothers of children with sensory differences report negative impact on child and family everyday activities and relationships.

Research question 1b: Is there a difference in the impact of sensory differences on mother and child everyday activities and relationships as reported by mothers of autistic versus non-autistic children?

There were significant differences that varied across environments, in the severity of impact reported by mothers of autistic versus non-autistic children. At home mothers of autistic children reported higher impact in two areas, family mealtimes and family finances. There were no reported differences in the remaining areas: self-care routines, toileting, play, time spent on screen, chores. Parents sleep approached significance. At school wearing uniform, dressing/undressing, mealtimes and time spent by parent dealing with school matters demonstrated a significant difference between mothers of autistic versus non-autistic children. Only toileting at school did not demonstrate a significant difference between the subsamples. In the community setting being safe in the community, mealtimes, choosing and participating in after-school and family leisure activities demonstrated significant differences between the subsamples. All everyday activities that reached significance showed a moderate effect size.

Sensory differences were reported to have significantly greater impact in some activities in the community, at school and in the home by mothers of autistic children. Despite the significant differences across environments, reported by mothers of autistic children, both subsamples showed high rates of impact in all aspects of daily life that were reported on. Most mothers of children with sensory differences with or without autism report a negative impact of child sensory differences on daily activities across environments.

Table 4-a

Reported impact of child sensory differences on mother and child everyday activities

		Everyday activities					
		Total respondents reporting a negative impact n (% of respondents)[a.]	Mother of autistic children Mean (SD)[b]	Mother of non-autistic children mean (SD)[b]	P value[b.]	Chi Squared[b] (*df*=1)	Effect size Cramer's V[b]
At home	Family mealtimes	121 (92)	3.36 (0.92)	2.91 (1.01)	<.01*	6.94	.28
	Family AM or PM routines	127 (97)	3.26 (0.75)	3.12 (0.86)	.34	0.91	.21
	Child self-care routine	121 (92)	3.32 (1.01)	3.06 (0.99)	.14	2.17	.21
	Child toileting	97 (74)	2.68 (1.13)	2.32 (1.24)	.09	2.93	.26
	Child being able to play independently	94 (71)	2.52 (1.18)	2.21 (1.06)	.12	2.38	.24
	Child Time spent on screentime	99 (78)	2.83 (1.07)	2.36 (1.04)	.02	5.62	.22
	Child – allocation of chores	99 (82)	2.97 (1.12)	2.57 (1.25)	.07	3.33	.24
	Childs Sleep	112 (85)	3.21 (1.07)	2.91 (1.17)	.12	2.37	.17
	Parent Sleep	102 (77)	3.03 (1.12)	2.48 (1.26)	.01	6.62	.29
	Family finances	106 (82)	3.22 (1.12)	2.50 (1.10)	<.01*	12.24	.36
At school	Wearing school uniform	91 (78)	3.07 (0.98)	2.17 (1.04)	<.01*	19.38	.41
	Dressing or undressing at school	94 (80)	3.07 (1.16)	2.14 (0.91)	<.01*	19.57	.44
	Toileting at school	85 (69)	2.60 (1.22)	2.23 (1.21)	.09	2.85	.25
	Mealtimes at school	104 (83)	3.33 (1.12)	2.54 (1.15)	<.01*	13.82	.35
	Time spent by parents dealing with school matters[a]	117 (93)	3.41 (0.87)	2.73 (0.96)	<.01*	15.58	.37
In the community	Choosing after school or leisure activities	113 (81)	3.65 (1.08)	2.98 (1.15)	<.01*	10.28	.30

	Everyday activities					
	Total respondents reporting a negative impact n (% of respondents)$^{a.}$	Mother of autistic children Mean (SD)^{b}	Mother of non-autistic children mean (SD)^{b}	P value$^{b.}$	Chi Squared ^{b} (*df*=1)	Effect size Cramer's V^{b}
Participating in after school or leisure activities	111 (90)	3.60 (1.08)	2.95 (1.18)	<.01*	9.35	.30
Toileting in the community	94 (72)	2.83 (1.24)	2.34 (0.96)	.03	4.7	.28
Mealtimes in the community	121 (92)	3.42 (0.96)	2.93 (1.07)	<.01*	7.51	.26
Choosing family leisure activities	125 (95)	3.57 (0.92)	3.08 (0.95)	<.01*	8.61	.32
Being safe in community activities (e.g., not running away, not harming self or others)	108 (83)	3.29 (1.14)	2.55 (1.15)	<.01*	12.34	.32

a. Not all participants responded to all questions

b. rounded to nearest 2 decimal points

Legend: 1. No impact, 2. Minor negative impact, 3. Moderate negative impact, 4. Major negative impact

* p<.01

4.4.2 Relationships

In the full cohort most mothers reported a negative impact of child sensory differences on both mothers and child relationships. Greater negative impact of child sensory differences was reported by mother of autistic children in mothers' relationship with family, friends and within her community. Mothers' relationship with partner and other parents approached significance. The relationship that showed no significant difference between the two subsamples was relationship with school staff. This suggests that for mothers of children with sensory differences relationships with school staff are negatively impacted regardless of presence or absence of an autism spectrum disorder diagnosis.

Mothers of autistic children reported a significantly greater negative impact on the child's relationship with family, and peers, with a moderate effect size. The perceived relationship between child and mother, and child and school staff showed no significant difference between subsamples at the level of significance set

Table 4-b

Reported impact of child sensory difference on mother and child relationships

Relationship		Respondent reporting a negative response n (% of respondants) [a.]	Mother of autistic children Mean Responses (SD)[b]	Mother of non-autistic children Mean Responses (SD)[b]	P value[b]	Chi Squared[b] (*df*=1)	Effect size Cramer's V[b]
Mother	Mother with partner	107 (91)	2.97 (0.87)	2.54 (0.95)	.01	6.08	.30
	Mother with family and extended family	106 (89)	2.94 (0.95)	2.45 (0.92)	<.01*	8.49	.32
	Mother with her friends	105 (80)	2.73 (1.03)	2.12 (0.95)	<.01*	11.32	.30
	Mother with school staff	95 (75)	2.41 (1.03)	2.17 (0.98)	.20	1.67	.16
	Mother with other parents	103 (81)	2.61 (0.95)	2.20 (0.89)	.01	6.17	.24
	Mother within her community	85 (68)	2.53 (1.00)	1.73 (0.85)	<.01*	19.72	.42
Child	Child with Mother	99 (75)	2.48 (1.04)	2.18 (0.99)	.09	2.90	.16
	Child with family or extended family	115 (87)	2.79 (0.94)	2.35 (0.86)	<.01*	7.29	.25
	Child with school staff	103 (76)	2.54 (0.98)	2.19 (0.91)	.04	4.17	.25
	Child with peers	125 (96)	3.38 (0.76)	2.81 (0.89)	<.01*	13.76	.33

a. Not all participants responded to all questions

b. rounded to nearest two decimal points

Legend: 1. No impact, 2. Minor negative impact, 3. Moderate negative impact, 4. Major negative impact.

* p<.01

Research question 2a: Is there a difference in the helpfulness of relationship, media support or parent intervention identified by mothers of autistic children and mothers of non-autistic children?

Mothers were asked to identify the provision and helpfulness of practical or emotional support regarding their child's sensory differences. The full sample profile is illustrated in Figure 4-i. Mean ratings of helpfulness of relationships indicate that partners/family and occupational therapists were most often perceived to be '*very helpful';* friends, other parents, school staff, physiotherapists, speech and language therapists and psychologists were generally *'slightly helpful;'* and doctors were most often '*not helpful*'. More mothers reported access to social/educational networks (friends, partner/family, other parents, and school staff) than health professional networks (occupational therapist, doctor, speech and language therapist, psychologist, and physiotherapists). Mothers were asked if they accessed media resources (books, websites, social media) and to rate how helpful they found them. Websites (95%) and social media (94%) were most frequently accessed, followed by books (83%). Of those who accessed media resources more than 90% found them helpful.

Figure 4-i

Helpfulness of relationship in providing practical or emotional support to mothers of children with sensory differences

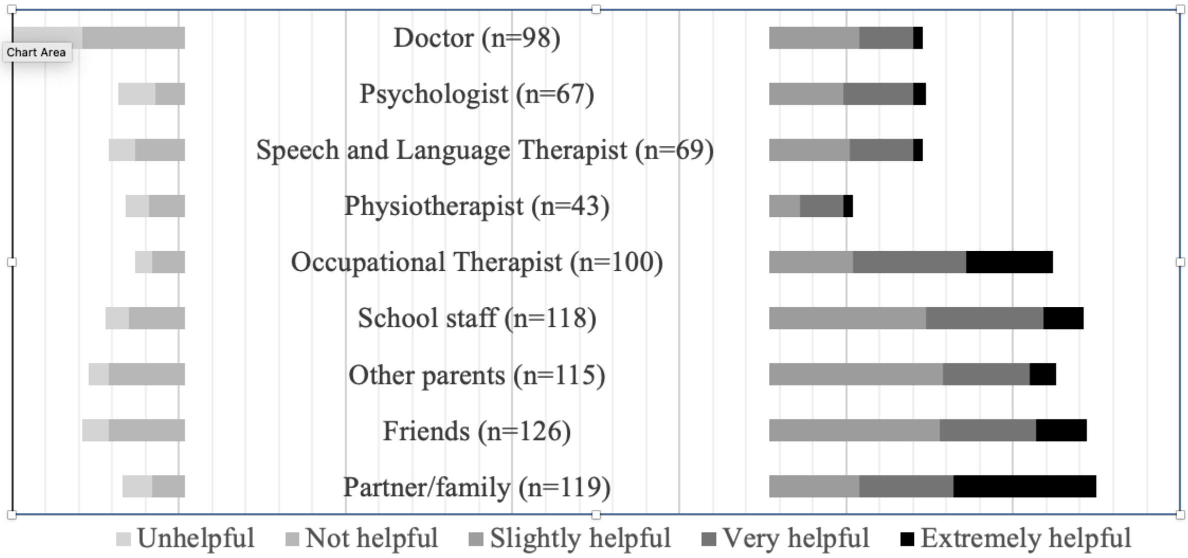

Figure 4-ii Helpfulness of relationship in providing practical or emotional support to mothers of children with sensory differences

When the sample was divided mothers of autistic verses non-autistic children, no significant differences in the helpfulness of relationships or resources were identified. See Table 4-c below

Table 4-c

Helpfulness of relationships and resources

	Helpful relationships and resources					
(n=mothers of autistic children / n=mothers with non-autistic children)[a]	Respondent reporting a positive response n (% of respondants)[a.]	Mother of autistic children Mean (SD)	Mother of non-autistic children Mean (SD)	P value[a]	Chi Squared (*df=1*)	Effect size Cramer's V
Relationships						
Partner and family (57/62)	100 (84)	3.67 (1.26)	3.84 (1.28)	.455	0.56	.12
Mum's friends (63/63)	95 (75)	3.14 (1.12)	3.17 (1.01)	.867	0.03	.10
Other parents (57/58)	86 (75)	33.11 (1.01)	3.02 (0.91)	.622	0.24	.15
Occupational Therapist (54/46)	85 (85)	3.56 (1.14)	3.78 (1.09)	.313	1.02	.19
Physiotherapist (26/17)	25 (58)	2.96 (1.28)	2.71 (1.16)	.504	0.45	.29
Speech and Language Therapist (43/26)	46 (66)	3.02 (1.03)	2.73 (1.12)	.270	1.22	.26
Psychologist (43/24)	47 (70)	3.00 (1.17)	2.92 (1.18)	.779	0.08	.20
School staff (59/59)	94 (80)	3.39 (1.05)	3.08 (0.97)	.104	2.65	.20
Doctor (53/45)	46 (47)	2.53 (1.15)	2.42 (1.03)	.633	0.23	.25
Resources/Media						
Books (56/53)	103 (94)	4.09 (1.00)	3.89 (0.89)	.265	1.24	.20
Websites (63/62)	120 (96)	4.21 (0.88)	4.23 (0.76)	.894	0.02	.11
Social media (63/61)	122 (98)	4.19 (0.82)	4.20 (0.83)	.265	1.24	.20
Parent support groups (53/32)	80 (94)	4.00 (1.00)	4.28 (1.02)	.215	1.54	.20

a missing data excluded,

b. rounded to nearest two decimal points

*p<.01

4.4.3 Parent intervention

A subset of the total sample of mothers (n=50) reported participation in intervention for parents of children with sensory differences. Of those who received intervention, mean parent intervention was 4 hours (Range 1-12). Most interventions were with groups of parents (73%) rather than individuals or family units (27%). Most were delivered by occupational therapists (84%) and the remainder by other healthcare professionals. Goal setting activities were reported by 36% of mothers. Of those goals reported, some were focused on performance (e.g., to stop his head banging) and others on participation (e.g., to be able to eat a meal together at home). The range of mothers' ratings of the usefulness of topics included in the interventions are shown in Table 4d. Within the sample of mothers receiving parent intervention 66% had an autistic child and 34% were mothers of non-autistic children. Mothers of autistic children were almost twice as likely to participate in parent intervention related to their child's sensory differences. Due to smaller sample sizes no other comparison was made between mothers of autistic children versus mother of non-autistic children regarding parent intervention.

Table 4-d

Usefulness of parent intervention topics

Area	**Number of participants reporting topics covered (n)**	**Mean (SD)**
Types of sensory differences	47	3.41 (0.67)
Muscle and movement system (proprioception)	41	3.27 (0.93)
Balance and Movement (vestibular)	44	3.29 (0.84)
Touch system	43	3.44 (0.62)
Hearing (auditory) system	40	3.15 (0.78)
Visual system	39	3.13 (0.93)
Smell and taste	41	3.25 (0.65)
Sensation from inside our body (Interoception)	37	3.32 (0.65)
How SPD can affect everyday life	43	3.28 (0.67)
Sharing your experiences with other parents	36	3.08 (0.91)
Practicing use of sensory strategies	36	3.11 (0.88)
Practicing problem solving	32	2.55 !1,4)

Key: 1 = Not useful, 2 = A little useful, 3 = Moderately useful, 4 = Very useful

In all areas covered except ‘practicing problem solving’ the mean average was moderately useful. The practical application of sensory strategies and problem solving were less frequently reported as covered in parent intervention.

4.4.4 Additional support or learning

Finally, a subset of mothers (n=64) described the additional support they would like regarding their child’s sensory differences. Mother’s responses were categorized into 3 themes (mothers’ words are italicized)

Practical and emotional support for mothers (n=42): Mothers wanted information and support for their child’s participation in ‘*daily routines’* (P28) across environments e.g., ‘*how to’ ‘calm his body for sleep’* (P1) or *‘prevent sensory overload at football club’* (P44). Mothers wanted advocacy to navigate through services e.g., Help ‘*to talk to... staff’* (P32). They were looking for acknowledgement of their ‘*resilience*’ (P28) and, to be ‘*understood*’ (P30).

Specialist support for their child (n=17): Mothers advocated for access to specialist healthcare services and child leisure opportunities with an understanding of sensory differences e.g., ‘*occupational therapy’ (*P42), ‘*SLT’* (P108), ‘*dieticians’* (P4), ‘*dental services’* (P77)*, ‘sensory friendly leisure’* (P97) and ‘*groups for children’* (P52)*’.* This access should be ‘*regular’* (P53).

Education of others (n=11). Training and support for school staff was identified as valuable ‘*so that they can help him more’* (P6); as well as education of other professionals e.g., '*doctors’* (P41) and ‘*community staff’* (P68). The need to raise the *‘media profile’* as ‘*the more people that have heard of it and have a general understanding the greater acceptance there will be for our children’* (P8).

4.4.5 Factor analysis

Full sample:

The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis KMO =.81. All items except participating in after school activities were above 0.70, well above the acceptable limit of 0.5 (Field, 2009). Bartletts test of sphericity c^2 (528) = 1874.51, p<.001, indicated that correlations were sufficiently large for analysis. Initial analysis was run to obtain eigenvalues for each component of the data. Eight factors had eigenvalues over 1 which in combination explained 72% of the data. The screen plot was slightly ambiguous and showed inflexions that would justify retaining 6 factors explaining 66.22 % of the variance. Therefore 6 factors were retained for final analysis. Table 4-e shows the factor loading after rotation. The items that cluster on the same components suggest that factor 1 represents mother and child relationships with family and friends (36.56% of variance); Factor 2 relationships and activities of daily living (ADL) in the school environment (8.98% of Variance) ; factor 3 loads with child participation in toileting across environments (6.68% of Variance); factor 4 loads with both parent and child sleep and safety in the community (5.06% of variance), factor 5 loads with child chores and leisure at home (4.72% of variance), factor 6 loaded with mealtimes across environments (4.26% of variance).

Table 4-e

Full sample factors identified from the Rotated Component Matrix

Item	Factor					
	1 Relationships	2 School matters	3 Toileting	4 Sleep and safety	5 Home chores and leisure	6 Meals
32.a.i.2. Your relationships with family and extended family (e.g. siblings, aunts, uncles, cousins and grandparents)	.777					
32.a.i.3. Your relationships with your friends	.753					
32.a.i.1. Your relationship with your partner	.738					
32.a.i.8. Your child's relationship with your family or extended family	.719					
32.a.i.8. Your child's relationship with your family or extended family	.719					
32.a.i.7. Your child's relationship with you	.677					
32.a.i.10. Your child's relationship with peers.	.627					
32.a.i.5. Your relationships with other parents	.520					
32.a.i.9. Your child's relationship with school staff		.772				
32.a.i.4. Your relationships with school staff		.713				
32.a.5. Time spent by parent dealing with school matters		.685				

Item	Factor					
	1 Relationships	2 School matters	3 Toileting	4 Sleep and safety	5 Home chores and leisure	6 Meals
(e.g. school meetings or homework time)						
32.a.1. Wearing school uniform		.544				
32.a.2. Dressing or undressing at school		.520				
32.a.i.5. Your relationships with other parents		.520				
32.a.3. Toileting at school			.880			
32.4. Toileting			.865			
32.a.9. Toileting in the community (e.g. when undertaking leisure activities or shopping)			.683			
32.5. Child/ children's sleep				.822		
32.6. Parents' sleep				.805		
32.a.13. Being safe in community activities (e.g. not running away, harming self or others)				.615		
32.8. Time spent on screen time					.694	
32.9. Allocation of chores					.679	
32.7. Being able to play independently					.611	
32.a.10. Mealtimes in the community						.743
32.1. Family mealtimes						.557

Factor Analysis based on subgroups

A factor analysis was completed on the subgroup od mothers of autistic children with sensory differences. The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis KMO = .55

All items except participating in after school activities were above 0.68, well above the acceptable limit of 0.5 (Field 2009). Bartletts test of sphericity c^2 (528) = 1097.81, p<.001, indicated that correlations were sufficiently large for analysis. See Table 4-f for the mothers of autistic children subgroup factors identified from the Rotated Component Matrix.

In the subgroup of mothers of autistic children, a 6-factor solution based on visual inspection of scree plot and eigenvalues above 1. Factor 1 loaded with mother and child relationships with family, friends, school and community (32.27% of variance), factor 2 loads with activities of daily living and mothers interaction with school (13.51% of variance), factor 3 loads with toileting across environments and mealtimes in the community (7.63 % of the variance), factor 4 loads with independent play, safety in the community and family finances 6.96% of the variance, factor 5 loads with child and parent sleep (5.82% of the variance) and factor 6 loads with school mealtimes and child relationship with school staff (5.21% of the variance).

Table 4-f

Mothers of autistic children factors identified from the Rotated Component Matrix

Item	Factors					
	1 Relationships	2 Home and School	3 Toileting	4 Finance, safety, independent play	5 Child and parent sleep	6 School
32.a.i.2. Your relationship with family and extended family	.850					
32.a.i.6. Your relationships within your community	.817					
32.a.i.3. Your relationships with your friends	.815					
32.a.i.8.Your child's relationship with your family or extended family	.801					
32.a.i.7.Your child's relationship with you	.636					
32.a.i.1 Your relationship with your partner	.599					
32.a.i.5. Your relationship with other parents	.596					

Item	Factors					
	1 Relationships	2 Home and School	3 Toileting	4 Finance, safety, independent play	5 Child and parent sleep	6 School
32.a.i.10 Your child's relationship with peers	.580					
32.2 Family morning or evening routines		.754				
32.a.2. Dressing or undressing at school		.754				
32.a.5 Time spent by parent dealing with school matters		.706				
32.3 Self-care routine		.674				
32.a.i. Wearing school uniform		.668				
32.a.i.4. Your relationship with school staff	.507	.651				
32.9 Allocation of chores		.542				
32.a.10. Toileting in the community			.827			
32.4 Toileting (at home)			.805			
32.a.3.Toileting at school			.789			
32.a.10 Mealtimes in the community (e.g. going to a restaurant)			.772			
32.10 Family Finances				.828		
32.a.13 Being safe in the community				.627		
32.7 Being able to play independently				.621		
32.5 Child / children's sleep					.820	
32.6 Parents' sleep					.758	
32.a.4.Mealtimes at school						.741
32.a.i.9 Your child's relationship with school staff						.647

Subgroup of mothers of non-autistic children

The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis KMO = 0.33, below the acceptable limit of 0.5 (Field, 2009) suggesting that this subsample of mothers of non-autistic children was not suitable for Factor Analysis.

4.5 Discussion

4.5.1 Impact on everyday life

In this cohort, mothers reported the pervasive negative impact of their child's sensory differences on everyday activities and relationships, for themselves and their children. This negative impact was observed across home, school and community environments. Consistent with the literature (Schaaf et al., 2011) child sensory differences impacted both child and parent activities of daily living and leisure activities. Almost all mothers report some level of impact on family mealtimes, morning and evening routines and participation in activities across the school and community. When mothers of autistic and non-autistic children were compared, mothers of autistic children reported greater impact in the school and community setting. The impact of child sensory differences on mother's health promoting occupations was recently explored in a study of mothers of children aged 3-8 with and without sensory differences (Doskalovich et al., 2025). Mothers with children with sensory differences (but not autism) reported reduced participation in health promoting occupations and reduced quality of life. Together the findings of the Doskalovich (2024) study and the current study, a pattern of occupational imbalance is reflected in the reported experience of mothers of children with sensory differences regardless of child autism spectrum disorder diagnosis or not.

4.5.2 Impact on relationships

Most mothers reported a negative impact of child sensory differences on their relationships with others, particularly with partner and family relationship. The impact on mother's relationships perhaps unsurprisingly, was greater for mothers of autistic children. Daly et al. (2022), in a qualitative evidence synthesis of family life with autistic children with sensory differences, it was reported that the ‘adaption and change required for successful engagement in occupation for the child, depended on parent’s intense engagement with vigilance and forensic sense making to understand the child’s sensory life’ (p.16). The extent of the child’s sensory needs creates additional demands on the parents’ role, it therefore makes sense that the impact is felt within social relationships. Partner and family relationship have been particularly identified as important to parental quality of life for parents of autistic children (Derguy et al., 2018). Parent quality of life appears to be determined by the quality of interactive processes used in the family: communication, listening, understanding, cooperation, support and problem-solving methods. Supportive family relationships make a difference to the wellbeing of mothers and their children with sensory differences. How to enhance familial relationships around the mother and child in this population warrants further exploration.

The greatest negative impact of sensory differences on child's relationships was with their peers. Reduced engagement with friends, by children with sensory differences versus matched typically developing peers has previously been reported (Cosbey et al., 2010). Parents identify important goals for their children relating to peer interaction (Cohn et al., 2014) and social participation (Schaaf et al., 2015). So, while the relationship between child sensory differences and peer relationships is observed, the impact on the child is less well explored.

Factor Analysis

Although not identical the factor analysis for the full group and autistic sub-group demonstrated similarity for factor 1 (relationships). It is perhaps not surprising that relationships were the strongest factor to be identified in the subgroup of mothers of autistic children. It is however more surprising that this pattern persisted for the full group where approximately half of participants did not have an autism diagnosis. Additionally similarities were present in both the full group and mothers of autistic children subgroup for factor 2 (relationships and Activities of Daily Living e.g. dressing), factor 3 (toileting). Factor 4 (Full sample) and factor 5 (mothers of autistic children sample) both highlighted a sleep cluster. The factors of relationships and everyday occupations appear to be broadly supported.

4.5.3 Relationships helpfulness

Mothers of children with sensory differences experience higher parenting stress (Ben-Sasson et al., 2013) so it is important to explore strategies to reduce that stress e.g. strengthening family support (Dunst, 2022) and direct parent support. Our study showed that every relationship has the potential to be helpful to mothers, with partner and family offering the greatest reported helpfulness. Although family centered practice has been explored with families of children with sensory differences (Gibbs & Toth-Cohen, 2011), our study is the first to examine the support relationships around mothers.

All health professionals except doctors were reported to be more helpful than not, a phenomenon observed elsewhere (Walbam, 2023). Doctors may need more tools to help them with this population or there may be a mismatch in the mothers' expectations of doctors as a resource (Taylor, 2020). Nonetheless, ways in which healthcare staff could be more helpful to mothers warrant further exploration.

Mothers reported accessing social/educational support more frequently than healthcare professionals support and generally rate its effectiveness more highly. The interventions reported above are family centered. However, the evidence presented here suggests it may be pertinent to consider a social network-centered care approach rather than family-centered care, to fully capitalize on the family/friend support potentially available to mothers.

4.5.4 Media resources

To our knowledge this is an area not previously explored among mothers of children with sensory differences. In this study, mothers report very high use and helpfulness of websites and social media. A review of medical information on the internet demonstrated the wide variety in the quality of information (Daraz et al., 2019). A large study of parents of autistic children highlighted the value of local access to information and peer group sharing, while the internet was seen as a less trustworthy source of information (Gibson, 2017). In contrast, in a more recent study of mothers with healthy infants, mothers reported valuing the accessibility and anonymity of information on the internet and that the content can be more trusted than social or professional contacts (Moon et al., 2019). The high accessibility of websites makes them a useful platform for sharing basic information, targeted at a wide audience, in line with universal service delivery (Hutton et al., 2016). However, quality evaluation of much health-related internet information remains uncharted, and it is suggested that from an ethical perspective as practitioners, we hold a level of responsibility in ensuring that our clients are guided to accurate information and, that inaccurate information is called out (Wu & McCormick, 2018).

Books offer an alternative solution for gaining information and developing strategies, usually with some level of peer review. There is evidence however that this does not fully replace direct intervention. For example, the study by Schechtman et al. (2019) directly contrasted coaching and self- help books for parents of children with ADHD. Schechtman et al. (2019) found similar increases in parent competence and some aspects of parent child interaction with both coaching and self-help books. This supports the concept that clinical approaches to supporting children and families require a variety of strategies.

Mothers frequently use social media (e.g., Facebook, WhatsApp) to both give and receive support (Duggan et al., 2015). Social media is not just about sharing information or resources but also has the potential to give mothers perceived support in real time (Frey et al., 2021). Healthcare providers need to be 'proactive in harnessing social media to encourage healthy decisions' (Moon, 2019, p.14), this is both a challenge and an opportunity for future service delivery with mothers of children with sensory differences.

4.5.5 Parent Intervention

Mothers who reported receiving direct intervention rated content highly, however two-thirds did not report receiving any intervention. Whether this was because services were not offered, or because mothers were not taking up services is unclear. In line with current evidence (Miller-Kuhaneck & Watling, 2018) mothers reported benefits of parent intervention, but the details of the specific characteristics that effected positive change remain unclear and require further investigation. The opportunity to work on problem-solving strategies in those attending intervention appeared to be less frequently included. Parent education provides information, but coaching enables a more active application, of knowledge gained, to everyday life (Graham, Kennedy-Behr, & Zivianni, 2021). Sharing information empowers choice, but active goal setting and problem solving helps individuals to shift from knowing to doing (Ryan & Deci, 2018). Goal setting was reported by about 36% of mothers who took part in parent intervention and suggests that this strategy can be further utilized.

When identifying further sources of support, mothers reported wanting *practical and emotional support*, *specialist support for their child* and the *education of others to promote understanding*. From a childhood disability perspective, the ecological framework (Bronfenbrenner & Morris, 2006) helps to identify a number of modifiable factors that support the child's participation through engagement with families, communities, and social systems (Kramer & Gorter, 2022). At the center of the ecological framework sits *'specialist support to the child'.* The efficacy of direct child occupational therapy intervention is debated (Novak & Honan, 2019; Schoen et al., 2019) in this population, but it is recognized that intervention leads to gains in individualized goals (Randell et al., 2022) and, continues to be identified as a need by mothers in this study. The shift to the next ecological stage of family focus is supported by mothers wanting '*practical and emotional support*'. Evidence to date suggests that occupational therapists share information through parent education and are beginning to take a more proactive approach in supporting families to problem solve for themselves through individual family coaching (Allen et al., 2021; Miller-Kuhaneck & Watling, 2018). Individual family coaching builds resources within the family but does not take the next ecological model step into a wider community engagement. Mothers identify the '*education of others'* as key, extending an understanding of the need to engage their own community but also create an influence at societal level e.g., '*through use of media.'*

4.5.6 Strengths, limitations, and future directions

The study has several strengths, such as the focus on the experience of mothers outside the United States. Ethnicity was limited and should be considered in future studies. Data were collected prior and into initial COVID-19 restrictions, and the shift from face to face to online services may impact longer term findings on parent intervention.

The psychometric properties of the survey were not formally evaluated. Parent and expert clinician feedback was gained and responded to. Use of a content validity index with content experts would strengthen the study. The subgroup of non-autistic children was a mixed diagnosis group. A larger sample size would enable examination of subgroups with greater specificity. Factor Analysis of the subgroups was limited by insufficient sample adequacy. Future studies should explore the impact on occupation and relationships in those with and without sensory differences and by comparing parent reports of child sensory differences to standardized testing. Furthermore, the links between child functional concerns, impact on relationships and type of support most helpful to mothers, warrants future study. Finally, these data focus on mothers only; recognizing that not all primary carers are mothers. Future research would benefit from expanding inclusion criteria to encompass the views and needs of all primary carers.

4.6 Implications for practice and conclusions

Mothers report a pervasive impact on both parent and child of reported child sensory differences, on daily activities and relationships. The reported impact on everyday activities and relationships is greater in mothers of autistic children. Most mothers, regardless of diagnosis find supportive social and professional networks, and the use of media helpful. Direct intervention is perceived as useful. Mothers advocate for further practical and emotional support for themselves, specialist support for their child, and education of others. Therefore, occupational therapists should consider:

- Building social and professional networks with an understanding of the impact of sensory differences on daily life.
- Providing direct intervention to mothers.
- Expanding the use of carefully curated online resources and social media to share information, providing a means to support advocacy for children with sensory differences and their mothers.

5 Chapter 5: Brief online group coaching for mothers of children with sensory differences

This chapter is in preparation for publication (Allen et al., Under submission)

Preface

To this point the thesis establishes that children with sensory differences and their mothers face additional demands on their daily occupations. Interviews with mothers in Chapter 3 (Allen et al., 2024) showed they perceive a lack of social support but value access to support in terms of knowledge and understanding and supportive social and professional relationships. The survey described in Chapter 4 showed that in the large cohort of mothers, only 38% had received direct intervention themselves either individually or in groups. Furthermore, the intervention that they had received was mainly based on didactic sharing of information rather than practical application of problem solving, as in coaching. Mothers reported wanting more support for themselves, their child and wider understanding of sensory differences. Parent coaching has the potential to provide more support for mothers and develop their capacity to support their child's occupational performance, to empower and support mothers in gaining insight (Allen et al., 2021). Despite the emerging evidence base, the survey (Chapter 4) showed that both goal setting and coaching appear to be under-utilised intervention strategies in practice.

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5.1 Abstract

Background: Many children experience sensory differences that are associated with disruption to both child and family daily occupations. Occupational therapists support participation in these daily occupations and have traditionally focused on intervention directly with the child. Emerging evidence suggests that a one-to-one coaching approach with parents is effective in increasing child performance and satisfaction in daily occupations, and in reducing maternal stress. The current study aims to pilot a brief online group coaching intervention for mothers of children with sensory differences.

Methods: Eleven mothers participated in a brief online group coaching intervention of 4 x 90-minute sessions. The sessions were based on Occupational Performance Coaching. Child occupational goals, parent stress and sense of competence and experience of the group were reported by mothers pre and post intervention.

Results: Child occupational performance and satisfaction, as rated by mothers, significantly improved. In addition, aspects of maternal stress were significantly reduced. Parent sense of competence improved but changes did not reach statistical significance. Suggestions were made by mothers on how future groups can be improved including, inclusion of other primary caregivers. They valued the sensory focus and found the group safe and supportive.

Conclusions: In this preliminary study a brief online coaching intervention, based on Occupational Performance Coaching, showed promising results in acceptability to mothers, child occupational performance and maternal stress. The findings require replication in a larger sample but underline the potential for brief online group coaching for mothers of children with differences in sensory processing and associated occupational concerns.

5.2 Introduction

Participation in daily life is harder when children have sensory differences, affecting play, sleep, daily living skills and social participation (Watling et al., 2018). When child sensory differences are identified, maternal stress is observed to be raised, regardless of the child's primary diagnosis (Ben-Sasson et al., 2013). Maternal stress has a wide range of negative outcomes for both parent and child (Abidin, 2012). Estimated general population rates of child sensory differences range from 5-15% and are much higher in children with developmental challenges (e.g. autism) (Adamson et al., 2006). Therefore, for a significant number of families, child sensory differences should be considered within family intervention.

Intervention with families of children with sensory differences is emerging and generating innovative approaches to extend occupational therapy to more families is advocated by the UK Royal College of Occupational Therapists (2022). Current research with families of children with sensory differences identifies the need to carefully analyze the child's sensory experiences to understand and adapt to family life (Daly et al., 2022). It further argues for the use of collaborative, problem solving and advocating strategies within family centered intervention (Daly et al., 2022; Popova et al., 2022). Explicitly, Ashburner et al. (2014) identify coaching as an appropriate tool to enable families of children with sensory differences, to develop their own solutions.

Coaching is a learning strategy that reflects a shift from a telling or guiding (psychoeducational) approach, to a focus on what can be visualized and achieved, in line with a strengths-based approach (Baldwin et al., 2013). Rather than the therapist being directive, caregivers are enabled to find the right answers for themselves and their child. Thus, the mother's expertise in her own family's experience is acknowledged. The process requires client-centered goal setting and working together to plan and actualize meeting those goals, with guided support from the coach. An additional aim is empowerment and building capacity for future goal achievement (King et al., 2023). Working individually with parents or mothers of children with additional needs has been shown to lead to gains in mother and child occupational goals, parent sense of competence and parent stress (Allen et al., 2021). Coaching parents or mothers can lead to positive outcomes for both child and parent.

Occupational Performance Coaching (OPC) is a person and family-centred approach that focuses on capacity building (Graham & Zivianni, 2021). Working with a population of parents of children with occupational performance challenges Graham et al. (2013) used OPC over 3 – 8 sessions. Mothers reported significant improvement in their child's individualized occupational participation goals as measured by the Canadian Occupational Performance Measure and Goal Attainment Scaling. These attainments were maintained at follow-up. For mothers' own goals, occupational performance, and satisfaction significant improvement was reported and maintained at follow up. Mothers sense of competence demonstrated significant improvement, but internal validity of the measure requires that caution be applied to findings. Graham et al. (2013) acknowledged the limitations of no blinding and a lack of control group. These findings suggest that OPC can have an impact on both parent and child occupational outcomes, but at this stage findings cannot be generalized. Findings of positive outcomes for the child and in many cases the mother have been replicated using OPC with mothers of children with occupational concerns (Graham et al., 2013), developmental disabilities (Chien et al., 2015) and autistic children (Suja Angelin et al., 2021). The clear descriptions of OPC as an intervention (Kennedy-Behr & Graham, 2021) and the width of reproducible evidence on both child and parent outcomes support the selection of OPC as the coaching tool for this study.

Two studies demonstrate that longer term and brief intervention can both generate similar statistically and clinically significant changes in child occupational performance (Bernie et al., 2022; Jamali et al., 2022). Significant positive clinical findings were reported in a 4 session (Bernie et al., 2022) and up to 16 sessions (Jamali et al., 2022) intervention of individual parent or family OPC. Furthermore, OPC has been reported to be effective within 1- 4 sessions when used with mothers of children with challenges in occupational performance (Bernie et al., 2022; F. Graham, 2021; Graham et al., 2013). Comparisons of parent coaching with community interventions for parents of children awaiting autism assessment, demonstrated that the families who had received coaching intervention used fewer services than usual care families (Tsiplova et al., 2022). Brief coaching based on OPC therefore offers a potential opportunity to raise both effectiveness and efficiency in service delivery.

The current United Kingdom National Health Service Long-Term Plan advocates for a shift to online access options for out-patients supporting creating partnerships with clients and their carers (Price et al., 2023). Online coaching fits with this advocated approach through increasing accessibility. In the scoping review of coaching for parents of children with sensory differences there was an identified gap in telehealth (Allen et al., 2021). The shifts in the landscape of healthcare delivery to children with developmental disabilities and their families following the onset of COVID-19, forced many rapid changes (Rosenbaum et al., 2020). The timing of this study design and delivery during periods of COVID-19 lockdown further supported the use of a telehealth approach. Camden and Silva (2021) advocate for telehealth based on accessibility, cost effectiveness and family centredness, but also acknowledging that it is not a one size fits all solution. They suggested factors that should be considered when assessing the balance between face-to-face intervention and telehealth include logistics, family and child-centred factors, and service capabilities. Telehealth has now been used as a medium for Occupation Based Coaching. For instance, one study demonstrated significant improvement in children's toileting behaviours over 5 sessions of telehealth intervention (Little, Wallisch, et al., 2018). The development of collaborative relationships and parent empowerment were identified as outcomes from qualitative interviews with mothers of autistic children following a 12-week Occupation Based Coaching telehealth Intervention (Wallisch et al., 2019). In a feasibility study using OPC, both video conferencing and face to face intervention were compared, leading to similar findings in child occupational goals (Bernie et al., 2022). Early evidence therefore suggests that telehealth coaching with a focus on occupation can lead to significant outcomes for both mother and child in a one-to-one context and can produce equitable results to face to face intervention.

The earlier scoping review (Allen et al., 2021) identified a lack of evidence in support of group coaching intervention. Graham and Ziviani (2021a) developed OPC for use with individuals or family groups. They do, however, suggest that OPC could conceptually be used with more than one client present (F. Graham (2021). They identified key features of facilitated reflection and self-discovery which lend themselves to group OPC delivery where there is commonality in goals, challenges, and needs. Nacif (2023) has explored groups for well-being and identified that groups require trust, collaboration and challenge. The dynamics of group coaching intervention increase the experience of positive emotion and belonging, particularly significant for those who feel lonely or isolated. A sense of isolation is reported by mothers of children with sensory differences and data from in-depth interviews (Chapter 3) (Allen et al., 2024) and the survey (Chapter 4) highlighted the positive impact of supportive social and professional relationships. Nacif (2023) describes how working as part of a group increases self-confidence and consequently self-belief. As self-belief grows, so the individual can contemplate a more ambitious vision for the future. This aligns with OPC, where the value of envisioning to support goal setting is highly specific to each individual and their own context (Graham & Ziviani, 2021b). The group structure also provides collective accountability (Nacif, 2023) where motivation to engage with one's own goal is supported by answerability to the group in feedback. Again, the concept of accountability is embedded in the description of OPC, (Graham & Ziviani, 2021b) and the group context has the potential to enhance this factor. Porter et al. (2023) undertook a scoping review of parents as adult learners in occupational therapy for child sensory differences and identified key valuable features when working with parents of children with sensory differences. These features were: active learning, small group reflection, peer support and contextual learning activities. OPC seeks to promote active learning and contextual application of learning (Graham & Zivianni, 2021). Setting OPC in a group context has the potential to enable small group reflection and peer support. Therefore the theoretical constructs of OPC (Graham & Zivianni, 2021) and of group coaching (Nacif, 2023) align in support of a small group approach to coaching mothers of children with sensory differences.

Exploring wider literature on parent group coaching intervention, Danino and Shechtman (2012) indicated that group coaching intervention for parents of children with learning disabilities was more effective than individual coaching in reducing parent stress. The most consistent predictor of reduced stress was therapeutic bonding with perceived social support. There is potential that the group context adds conferred benefits to the mother. Two prior studies used the principles of OPC to support coaching intervention over 10 or more sessions with groups of parents of children with additional needs and demonstrated positive changes in child occupation and parent sense of competence (Aragão et al., 2022; Suja Angelin et al., 2021). The studies did not elucidate if it is possible to observe changes in child and mother outcomes in a brief online group coaching intervention for mothers of children with sensory differences. The pressures of service delivery and the cost benefit of group versus individual intervention leads towards group rather than individual intervention. The potential economic benefit of a small group context may also enhance aspects of quality of care.

The benefits of brief group coaching based on OPC, using an online format have not yet been explored with mothers of children with sensory differences. Therefore, the aim of this study was to pilot a brief online coaching group for mothers of children with sensory differences that are impacting participation in daily occupations. It will aim to explore acceptability of the intervention and changes in occupational performance for the child as well as maternal stress and sense of competence.

5.3 Methods

This study used a pre-test/post-test design using online group coaching based on OPC, with mothers of children with sensory differences. Ethical approval was received from the University of Reading Research Ethics committee.

Participants

Mothers were recruited through social media from two special needs parent support groups in the United Kingdom between August 2021 and March 2022. Inclusion criteria were mothers of children aged 5-11 years with sensory differences that impacted participation in daily occupation. All participants provided informed written consent and initial demographics through a survey platform.

Intervention

OPC can be delivered in a group context with the suggestion that some tailoring may be required (Graham & Ziviani, 2021b). For this brief group online intervention study pragmatics guided the need for a pre intervention individual session to complete pre-assessment, to set goals and answer any question that mothers raised. In addition, participants received a Patient Information Sheet outlining the intervention and confidentiality parameters. This meant that at the start of the 4 sessions all participants had goals set and an understanding of the group parameters. A post intervention individual follow-up session was used to complete reassessment materials.

Eligible mothers were recruited consecutively to one of two groups: each group had 5 to 6 participants, total n=11. Participation required access to a mobile phone or computer with internet access. A zoom link was sent to parents for each of the four 90-minute, OPC informed, weekly coaching sessions. OPC encompasses three domains: Share, Connect and Structure. Each domain has key ingredients identified in **Error! Reference source not found.** 5a.

Table 5-a

Three enabling domains of Occupational Performance Coaching

Enabling domain	***Key ingredients***
1. *Connect*	*Listen*
	Empathise
	Partner
2. *Structure*	*Establish valued participatory goals*
	Collaboratively analyse performance
	Act
	Evaluate
	Generalise
3. *Share*	*Ask first*
	Be curious
	Prompt reflection
	Teach principles
	Expect resourcefulness

Following guidance on implementation (Graham & Ziviani, 2021a) the coach (First author) received face to face, videoconferencing training and mentoring during the period of intervention from an Advanced OPC practitioner. Details on implementation strategies are described in Graham and Ziviani (2021b) and a Template for Intervention Description and Replication is available (Hoffman et al., 2014) (adapted from Graham et al. 2021) (Supplementary material 1: Template for Intervention Description and Replication (TIDeR)).

Five threshold concepts support the implementation of OPC, and were used in this study:

1. *Establishing a high trust partnership, supported by strategies for physical and emotional safety*. Safety strategies included the use of a secure video platform and establishing clear confidentiality boundaries within the group. The first session started with a brief

slide show including confirmation of confidentiality and a reminder of mothers' right to withdraw at any time.

2. *Meaningful goals are where dreams come true rather than where problems are minimised.*
3. *Impairments rarely inform solutions, enabling strategies can arise from anywhere.* Aligning the second and third threshold concepts, coachee questions encouraged mothers to shift from a problem focus to a strength-based perspective. Mothers identified goals for their children in the initial assessment and these were individually explored. In line with OPC, reflective questioning was utilized to support analysis and identification of envisioned goals and alternative strategies for action.
4. *Clients, rather than coach, are the agents of change in coaching.*
5. *Expertise in coaching lies in how we engage with people rather than what we know about them.*

   To support the final two threshold concepts mothers were reminded that they are seen as expert in their own families lives and that the group is not about telling them what to do, but about enabling them to find their own answers. The coach only provides advice or strategies with explicit permission from the mother, seating the control of the narrative and selection of course of action with the mother. Differing from individual OPC, group mothers were able to share their experience related to the goal under discussion. Again, in line with OPC each mother articulated their own goal for the intervening week and gave feedback in the following session.

Screening Measures

Sensory Processing Measure Home Form (SPM-HF): A 75-item standardised measure identifying child sensory processing difficulties. The SPM home form is divided into eight sections. This first six cover the following sensory systems: Visual, Auditory, Tactile, Taste and Smell, Body Awareness and Balance and are summed to a Sensory Total. Each of the sensory sections. The final two sections are Planning and ideas and, Social Participation (Parham et al., 2007). The second edition was used in the study and is described as having good internal consistency, test-retest reliability, explanation of instrument design, construct, content and criterion validity. It is reported to be easy to use. Limitations are that there is no normative data outside the United States and that there is a lack of investigation into responsiveness. Despite the limitations it is described as a psychometrically sound tool providing a reliable and valid approach to measure aspects of sensory processing constructs. (Parham et al., 2007) (Brown et al., 2024). Higher scores reflect greater differences from typical sensory processing. Sensory differences are identified with one or more sensory area scored > 2 standard deviations (SD) above mean, or two or more areas > 1 SD above mean (Parham et al., 2007).

Outcome measures

Outcome measures were completed one-week pre, and up to two weeks post intervention.

Canadian Occupational Performance Measure (COPM): An individualized measure with adequate to good reliability and validity (Law, 2014). It is designed for use by occupational therapists to detect change in a client or carer's perception of occupational performance over time and is advocated as a suitable tool for measuring change in parent coaching interventions (Novak, 2014). The assessor supports the carer in problem identification and prioritization across child self-care, productivity, and leisure. Each mother identified three child occupational goals, rating child performance on a scale of 1 (unable to do) to 10 (able to do it extremely well). Then rating their satisfaction with child's current performance of the selected goals from 1 (not satisfied at all) to 10 (totally satisfied).

Parent Stress Index -Short form (PSI-SF): The 36 item standardized measure of parenting stress demonstrates good reliability and consistency with the full form (Abidin, 2012) was used. The Parent distress (distress in relation to parenting role), Parent-child dysfunctional interaction (parent's perception that the child does not meet the parent's expectation), Difficult child (basic behavioural characteristics of the child) subsections are summed to provide a Total Parent stress score. Higher scores reflect greater distress; with a score at 85th centile or above considered high, the 90th centile or above reflecting clinically significant levels of parenting stress.

Parent Sense of Competence (PSOC): The 17 item Parent Sense of Competence (Gibaud-Wallston & Wandersman, 1978) is a standardized measure of parents' sense of satisfaction and efficacy within parenting role. Higher scores reflect greater perceived sense of competence.

Maternal feedback*:* An informal mixed methods questionnaire invited feedback from mothers about their experience of the intervention. Open ended questions explored recruitment and assessment process, group format and content and suggestions for improvements. Mothers rated quantitative items on a scale of 1 to 10 indicating usefulness of the group for them and how useful they thought it would be for other parents.

Analysis strategy

For quantitative data, COPM, PSI-SF and PSOC, analyses were conducted using IBM SPSS Version 28.0. Normal distribution was checked using the small sample size method (Shapiro-Wilks). As the data were not normally distributed, nonparametric Wilcoxon Signed rank test was used to compare T1 to T2. For mothers feedback questionnaire, descriptive statistics were calculated for quantitative data. Qualitative data was explored and described by two researchers confirmed by the third author, using basic content analysis to summarize and illustrate mothers' experiences (Drisko & Maschi, 2015).

Participants

Child and mother characteristics are summarized in Table 5.

Table 5-b

Sample demographics

	Demographic	Mean (SD) or n (%)
Child	Child age	8.4 (18)
	Child gender	
	- Male	8 (73)
	- Female	3 (27)
	White British	11 (100)
	Co-morbid disorders, clinical diagnosis	
	- Autism Spectrum Disorder	8 (73)
	- Attention Deficit Disorder	4 (36)
	- Anxiety	6 (55)
	- Selective Mutism	1 (9)
	- No diagnosis	1 (9)
	Total Sensory Processing Measure: T-Score	73.45 (7.92)
Mother	Mothers age	38.10 (5.6)
	Highest level of education	
	- Completed A levels or equivalent qualifications	
	- Undergraduate degree/ Higher education	3 (27)
	qualifications	5 (45)
	- Postgraduate degree	3 (27)
	Parent living alone	3 (27)

[a] Parent report

Intervention

The mentoring process followed the OPC fidelity measure (Graham & Ziviani, 2021a) (Supplementary material 2: Retrospective Feedback and Reflections on Occupational Performance Coaching). Full scoring was applied to group 2, session 2 and 4 and fidelity was measured at 72 and 74% respectively.

Nine of the eleven mothers completed feedback forms. Attendance to sessions was 39/44 (89%). Reasons for non-attendance were reported as school/medical appointments, or variable access to wi-fi. All respondents confirmed that they received sufficient information prior to the group and that the online group format was agreeable. Eight respondents found the recruitment process and initial interview agreeable. One mother would have preferred a more strengths-based focus in the initial assessment.

All respondents rated the usefulness of the group to them as 10/10 and perceived that it would be useful to other parents rated 10/10. Qualitative feedback is summarized as follows. All mothers reported positively on the length of the sessions, topics of discussion, and valuing the shared experience/social support. Eight mothers gave positive feedback on the perceived safe space, seven commented on their growing self-confidence or validation of their own self-care. Four mothers gave positive feedback on the coaching process. Three mothers identified additional child gains observed following the group intervention. In terms of future recommendations, five mothers would like to have further sessions or a follow-up session and, one mother advocated for the involvement of other primary caregivers. Illustrative quotes are shown in Table 5 c.

Table 5-c

Post intervention feedback illustrative quotes

Topic	Illustrative quotes
Format	
Number of sessions	*'It was a good number.'* (3) *'Could have done with more* (sessions) *as they were fantastic*.' (8) *'It would be good to have a catch-up session in a few months to see how we are all getting on*.' (2)
Length of session	*'90 minutes was about right.'* (1) *'it felt too big to begin with but enabled everyone to have a meaningful amount of time*.' (4)
Group	
Coaching process	*'Having dedicated time to talk and then a timeframe of action points discussed, and feedback gave me the spur I needed.'* (4) *'Everyone had the chance to talk, no one talked over each other.' (5)* *'It was fascinating to learn and understand the reasons why children do certain things and then problem solve.'* (6)
Topic and sensory	*'I enjoyed all of the topics and could relate to all of them*.' (1) *'Important to me that this was a sensory group. I really related to everything and to the other parents because sensory is our biggest challenge. You don't need to tell me he's got ASD I need help with sensory. Shocked at how bad it was for other people. People make you feel like you are a pain, you are the problem, not that your child has an issue.'* (5)
Group	
A safe space	*'I found it a safe non-judgmental space where the other parents understood.'* (6) *'Everyone gave space for others to share ……. I don't think there was a better way.'* (3)

Topic	**Illustrative quotes**
Shared experience	*‘Even though a certain issue wasn’t my particular focus, I got a lot of ideas and suggestion from listening to people’s situations.’* (1) *‘I think it was easy to share because…. people could relate and understand better.’ (7)* *‘Now I’ve got like-minded friends who understand each other’s strengths and difficulties’ (5)*
Social support	*‘I really enjoyed the group, I found it helpful and look forward to carry-on talking to the mums I met in the group. (7)* *‘The best ever friendly supportive and absolutely amazing mums.’ (9)*
Reported changes	
Mother’s confidence and self-care	*‘I did not think I was doing enough… it made me feel a lot better about myself which then impacts on them* (children)…. *I feel more confident now in helping XX to try new things not just food., but in general life.’’ (2)* *‘Group put into perspective that wasn’t doing enough self-care and made me realize I had to take a step back.’ (3)*
Additional child changes	*Toileting is much better, and sleep is slowly improving. (9)*

(Respondent number)

Child and mother outcomes

COPM goals covered in order of frequency: participation in meals, washing, self-regulation, school skills, toileting, sleep, dressing, chores, travel, play with others and swimming.

For performance, 20/33 (61%) and satisfaction 26/33 (79%) of goals showed improvement, with clinically significant improvement at 56% and 70% of goals respectively. Table 5 d illustrates significant improvement in COPM performance and satisfaction, PSI-SF parent distress, parent child difficult interaction and difficult child. PSI-SF Total and PSOC showed improvement, but this did not meet statistical significance. Six mother reported reduced Total stress and four transitioned out of the clinically significant range (from above the 90th centile to below the 80th centile).

Table 5-d
Changes in child and mother scores [a]

	T1 Mean (SD)	**T2 Mean (SD)**	**Z score**	**p**	**Effect size**
COPM Performance	2.72 (0.93)	4.94 (2.04)	-2.80	<.01**	.85
COPM Satisfaction	2.18 (0.91)	5.12 (1.79)	-2.81	<.01**	.85
PSI-SF[c] Parent Distress	85.27 (16.74)	77.27 (18.31)	-2.24[b]	.03*	.68
PSI-SF[c] Parent Child Difficult Interaction[c]	86.09 (15.47)	79.00 (18.57)	-1.99[b]	<.05*	.61
PSI-SF[c] Difficult Child	95.73 (5.73)	90.18 (9.42)	-2.03[b]	.04*	.61
PSI-SF Total[c]	92.36 (11.00)	84.82 (15.21)	-1.95[b]	.05	.59
PSOC	69.73 (8.97)	72.64 (11.66)	-.67[B]	.51	.20

a Wilcoxon Signed Rank

b Based on negative ranks

c Percentile Score

*P<0.05, ** P<0.01

Abbreviations: COPM - Canadian Occupational Performance Measure, PSI-SF - Parent Stress index 4 - Short Form, PSOC - Parent Sense of Competence.

5.4 Discussion

This pilot study is the first to explore an online brief group coaching intervention to support mothers of children with sensory processing differences based on OPC. Findings indicate that the study recruitment, format, and intervention were acceptable to participants, and that outcomes were generally positive.

Qualitative findings suggested that Mothers felt safe, heard, and supported. The importance of trust and engagement in relationships are identified in threshold concepts in OPC (Graham, Kennedy-Behr, & Zivianni, 2021) and this aligns well with the key features of collaborating, problem solving and advocating modes that are associated with higher quality family centered practice (Popova et al., 2022). The sense of belonging and constructed community, reflected in comments (Table 3), made it clear that mothers valued the opportunity to connect with '*like-minded friends.'* Mothers also projected those relationships into the future, further developing a sense of community. This link between occupation and sense of self was initially articulated by Wilcock (1999) through: doing, being, becoming and on to belonging. Only by actively participating do we shape our own future. The process of group OPC may empower mothers to participate in shaping their own and their child's daily occupation, changing their sense of self and sense of community belonging.

Mothers feel a mismatch between their actual and expected achievement in care of their child and themselves (see illustrative quotes on mother's confidence and self-care). Following the group, mothers described a positive change of '*confidence', 'perspective',* and '*feeling better about myself.'* This change in mothers' self-perception is reflected in Graham et al. (2014) qualitative study of mother's experiences of OPC which identified 3 themes. These themes were doing better, gaining insight and different ways of being (Graham et al., 2014). The current study reflected doing better with improved child occupational outcomes (COPM), gaining insight through mother's changes in perception and different ways of being through confidence to try new approaches. However, the extent to which these themes are supported is not yet evidenced.

Mothers reported a positive response to the online format and that they felt listened to aligning with the guidelines for OPC. OPC identifies listening within its first enabling domain of support, putting it at the heart of the practice. All mothers actively chose to participate in the study groups. Both being listened to and being offered a choice of intervention were similarly identified as factors that support engagement in telehealth (Graham et al., 2022). In line with Bernie et al. (2022) the current study adds additional cautious support to the use of telehealth for the delivery of coaching to mothers.

Pre-group assessment was a time-consuming process for mothers and has the potential to act as a barrier to mother's engagement. However, most mothers reported that the time taken for assessment was acceptable. Most mothers identified a need for more sessions, and this may reflect the need for more sessions or further consideration of transition strategies. Clinicians' time equated to 3 hours per mother. A recent study that used video conferencing OPC for families awaiting assessment for autism where 6.5 hours of clinician time was reported for each family (Bernie et al., 2022). There is a reduced clinician time requirement when working in a group context.

Mean changes in COPM performance and satisfaction and were consistent with those observed in a one-to-one brief individual coaching intervention (Bernie et al., 2022). However, in contrast to Graham et al. (2013) study, it did not document significant changes in PSOC. This suggests that the study's nature, either brief or group or online, did not provide the right context to address mothers' sense of competence. Future studies may wish to further research the factors most important to address maternal sense of competence. None of the studies referenced here have yet been replicated therefore findings should be applied with caution.

Limitations and future directions

This is a small single cohort study. Assessment was not blind, and no follow-up assessment was undertaken. This study provides the foundation for a feasibility study with blinding, randomization and follow up assessment. Future studies would benefit from exploring costings. Recommendations include exploring fidelity with the recently outlined criteria (Graham & Ziviani, 2021a), comparing group OPC to waiting list control or individualized family OPC and considering what impact this has on future need for services. In this study intervention focused on mothers but wider consideration of parents and carers would be more inclusive.

5.5 Conclusion

In this study brief online group coaching based on OPC was an effective strategy to reduce maternal stress and increase perceived child occupational performance and mothers' satisfaction in that performance. Group intervention has the added advantage of widening the support bubble and in building community, so mothers feel that they are not alone. An OPC approach is cautiously supported with this population as an adjunct to the toolkit of interventions available to clinicians, particularly in resource constrained contexts. More work is needed to robustly and consistently apply this methodology online with groups of mothers.

Key messages

1. Brief online group OPC based intervention is reported to be acceptable and helpful by mothers of children with sensory differences.
2. Brief online group OPC based intervention led to positive and significant changes in mothers established COPM goals, for both performance and satisfaction.
3. Brief online group OPC based intervention led to reported reduced parent distress and perception of the child as difficult and parent/child difficult interaction.

5.6 Supplementary material 1: Template for Intervention Description and Replication (TIDeR)

To support replicability and build on research findings the TIDeR form was used (Hoffman et al., 2014). The TIDeR form was developed to improve the completeness of reporting and ultimately replicability of interventions. The form was developed by a group of experts and stakeholders through a Delphi study and face to face panel meeting. This form has been adapted from Graham, Kennedy-Behr and Ziviani (2021) description of OPC.

What is brief online group Occupational Performance Coaching (OPC)?

OPC is described as a goal-orientated approach in which client agency is at the centre of goal selection, analysis of situations, prioritization of action to be taken and evaluation of success (F. Graham, 2021).

1. Name:
Brief online group coaching based on Occupational Performance Coaching
2. Why:
Brief online group coaching based on OPC draws on the dynamic systems perspective of enablement, ecological perspectives of learning and behavioral change, and humanistic and behavioral change principles to enhance client engagement in rehabilitation towards achieving personally valued occupation/ participation goals.
3. What Materials:
The therapist uses no specialized equipment or materials. No standardized assessments or other assessment of impairment is used. No hands on or directive (e.g. therapist arranging environment) methods are used with either the client or their dependent unless requested by the client in the context of trialing ideas within a coaching exchange.
4. What procedures
Brief online group coaching based on OPC commences with questioning to identify clients desired future stated goals. Goals may not be directly related to health conditions or impairments. Goals are expressed at the level of observable actions, comprising statement of an activity in a specific context which reflects personally meaningful change.

Therapists consciously express empathy and listen mindfully to enhance the conditions for client trust in therapist. Therapists engage the clients in a reflective discourse to explore potential actions that could lead to goal progress. Therapist questioning positions clients as knowledge holders and decision makers, thus as agents of change. Therapists may provide specialist knowledge to clients only if clients give permission for this, if a knowledge gap is apparent after exploration of what clients already know. Goal progress is evaluated regularly with clients as the evaluator of change.
5. Who provided
Brief online group coaching based on OPC was provided by an occupational therapist with 20 hours of training in OPC both face to face and through videoconferencing. The coach received online mentoring and feedback on videos during the intervention.
6. How delivered
OPC has previously been researched as a 1:1 and 1: family telephone/videoconferencing intervention. This study explored its use with a small group of mothers.
7. Where:
Brief online group coaching based on OPC is delivered via a videoconferencing platform into private spaces e.g. home environment.
8. When and how much
Brief online group coaching based on OPC can commence when clients have concern for themselves or their dependents. It is conducted weekly for 4 weeks and sessions typically last for 90 minutes
9. Tailoring
Brief online group coaching based on OPC questioning style is tailored to match client's language and cognitive ability and literacy level. For clients with significant cognitive impairment. OPC discourse is kept short and interspersed with active practice and goal-related activities.
10. Modification (During a study in response to study events)
Shared screen with goals at commencement of session. **Video screen** Group 1 goals left up. Group 2 goals taken down for clearer access to videos to support non-verbal communication.

Reassessment Group 1 first author completed all assessments, group 2 an independent occupational therapist completed reassessment with mothers. **Use of WhatsApp group** Group 1 - WhatsApp group set up at the end of the group to support mothers staying in touch, sharing resources and experiences. The OT coach participated for 4 weeks following the group. For group 2 - WhatsApp group was set up at the start of the group and mothers consented to download the content. OT withdrew after 4 weeks post intervention.
11. How well (Planned)
When working 1:1 or 1: family quality is assessed using the OPC Fidelity Measure. Fidelity scores of > 80% are estimated as required to elicit the desired client response. Testing of fidelity with group delivery has not yet occurred.
12. How well (Actual)
The OPC fidelity measure was used for Group 2 – Session 2 and 4 with fidelity respectively at 72 and 74%

5.7 Supplementary material 2: Retrospective Feedback and Reflections on Occupational Performance Coaching

To support quality of the intervention ‘coach’ received mentoring. As part of this mentoring process the fidelity tool developed by (Graham & Ziviani, 2021a) was used as a reflective tool to structure observations, reflections, and future recommendations. Qualitative reflections on group implementation each of the fidelity criteria are discussed below. The sessions reviewed were group 2, session 1 to 4.

1. **Therapist expresses empathy through comment & gesture, comprising non-judgmental responsiveness to the client’s emotional experience**.
   Reflections and learning points:
   It felt important to spend some time at the beginning of session 1 to frame the group as a safe space with confidentiality and that the goal was to support mothers in their own goal setting and achievement recognizing that they were experts in their own family lives. This was supported through a power point slide on shared screen. The next slide contained a list of all the goals set by all the mothers prior to the start of the sessions as a prompt if needed and a reminder that the focus was on daily occupations.
   When using telehealth through an online platform it is easier to express empathy and a non-judgmental response when cameras are on. The coach made the mistake of leaving up a power point which appeared to reduce non-verbal communication between participants. Mothers were encouraged to have cameras on, some came in and out and bandwidth was occasionally a problem. Encouraging cameras to be on appeared to support group cohesion.

2. **Therapist prompts client-led goal setting around a situation that is clearly highly meaningful to client.**
   Reviewer’s comments:
   More successful: Interactions checked in with previously identified goals and to ask if this was still the most important goal for this week.
   Least successful: A lack of clarity was observed with some of the goals discussed.

Reflections and learning points: The goals set prior to the intervention were not necessarily the goals raised the following week by the coachees'. It is important to spend enough time on goal setting as this is the foundation for what comes next. Keep asking questions until the goals are clear, stay focused on what is meaningful for the client. Do not forget to ensure the envisioning on not only the person and the task but also the environment.

3. **Therapist prompts occupation/participation focused (activity + context) expression of the goal**

   Reviewer's comments:

   Most Successful: Task, person, and context in mothers' own words.

   Least successful: Some interactions focused on the plan rather than the overarching occupational goal and some interactions considered the activity but not the context. Ask parent to tell you exactly what is doable this week. If parent gets stuck use the term 'moving forward…'

   Reflections and learning points: Aim to get clear articulation of the goal with every mother.

4. **The therapist prompts the client to envision the preferred, future goal situation. In subsequent sessions, the therapist refers to or prompts further clarification of the previously discussed vision.**

   Reviewer's comments:

   Most successful: Coach asked about the plan and the next step.

   Least successful: Problem based descriptions rather than envisioning.

   Suggested strategies "What will it look like when it will be better?" is a great question to get to envision. Tell me more about the times it went well. If it were a perfect outing (for example), what would it look like? Or - What's most important to you?'

   Reflections and learning points: Redirect coachee from problem-based description to envisioning. Coach needs to use more questions and reflective language to support clients envisioning. This is important to validate coachees' autonomy and sense of competence.

5. **Performance analysis is oriented mostly to the preferred (goal) situation and solutions leading to it (i.e.) performance analysis is not oriented to the problem or current situation)**

   Reviewer's comments:

   Most successful: Performance analysis around the goal not the problem, focused on solutions.

   Least successful: Not much opportunity for this discussion of performance since once they state what they want to work on, the other Moms are asked what they have as ideas. Sometimes mums were stuck on the present.

   Reflections and learning points: In group context aim to allow sufficient time to do collaborative performance analysis without the input of the group. Prompt to solutions focus. When a mother struggled to visualise a solution focused outcome it helped to ask questions e.g. where are you standing while she goes to the toilet, what does the sequence of actions look like? In other words, to support visualization ask about the social and physical environment.

6. **Therapist prompts client-led performance analysis of the goal situation. Therapist prompts relate to clients' perceptions and understanding of goal situations rather than therapists understanding and perceptions.**

   Reviewer's comments:

   Most successful: Interaction focused on mothers understanding not the therapists.

   Least successful: When the goal was not clear.

   Reflections and learning points: Other mothers asked questions to clarify their own understanding, this required the coach to bring it back to coachee mums' language. Listening to other mothers' performance analysis and goal setting can be hard when other mothers think they have the answer. It can be helpful to hear about other mothers' strategies, but it is so important that the coachee mother chooses her own plan for moving forward.

7. **Therapist prompts client's decision-making/ choices about identifying and selecting solutions/ strategies leading to goal achievement.**

   Reviewer's comments:

   Most successful: Mothers were given time to work out their own solution.

   Least successful: You ask each mom something like: From all of the suggestions, what do you think would work? What if the mom has already tried all these suggestions or what if she feels like they are not suitable for her child? They come from the other Moms, not from her. In OPC, the therapist asks questions to the client to help them reflect on their own child, their own situation. Although this is empowering for each mom because they feel like they are helping each other out, I wonder if the mom who is working on her goal feels empowered by her own competence and reflexion regarding her own child. Yes, you ask the mom to identify what she wants to try from the suggestions of others. What if she has her own suggestion that she is not shared, thought of when the others were speaking? Could you focus more on each mom/client longer with your own line of questioning?

   Reflections and learning points: There is a tension here between OPC principles and working with group dynamics. Time pressure is raised as an issue and watching the clock was an issue felt by the coach. Consider exploring how this is handled in future. Is this about an individual reaching their own plan or is this a group shared process in supporting the individual in identifying what is important to them?

8. **Therapist prompts client to specify details of their action plan (e.g. when, where, how, with whom).**

   Reviewer's comments:

   Most successful interaction is where the question is asked, and the answer is then followed up by the coach to probe for more details.

   Least successful is where the initial question is asked by the coach but the response from mother is unclear, and the coach does not then expand on the answer by asking more question.

   Reflections and learning points: As the coach it is important to hold the need in mind to consider not only the task and person but also the context or environment.

9. **SUBSEQUENT SESSION Therapist prompts client evaluation of planned strategies and outcomes after they are attempted.**

   Reviewer's comments: Mothers were keen to feedback on their experiences of the previous week and appraise progress.

   Suggested question 'Do you have any reflections around that?'. 'How do you know', 'What do you notice motivates XX?'

   Reflections and learning points: Spend more time on reflection.

10. **SUBSEQUENT SESSION Therapist prompts client generalizing successful strategies to other valued activities, contexts, and roles.**

    Reviewer's comments: Suggested question 'what you notice about what has worked'

    Reflections and learning points: The coach did not always remember to generalize, and it would be helpful to have a crib sheet to remember to do this. When remembered success rates were high.

11. **Client seems to trust therapist.**

    Reviewer's comments: Trust observed to therapist and to group members.

    Reflections and learning points: Emphasising confidentiality and supportive and validating approach feels important in the achievement of this. Each of the coachees' had an online meeting with the coach prior to the group sessions to complete initial assessment materials and set COPM goals. This also enabled them to see a known face when joining the group. It felt important to acknowledge that it is a big step joining the group and sharing your experience with a group of relative strangers. The level of trust amongst the group members was commented on by the expert therapist whilst the set-up of the group may have supported this, mothers expressed the value of shared experiences and of not being judged within to group. The sense of a safe space appears key.

12. **Client articulates specific reflections and analysis of goal related situations.**

    Reviewer's comments: Less effective interactions reflected statements of what happened but did not demonstrate further analysis by coachee.

    Reflections and learning points: Coachees' need more help to expand analysis. It may have been helpful to reflect with the client on the components of prompting exploration of the person task or environment. For example: trying to redirect a child's self-stimulation through use of oral chews and stated it had not worked, expand analysis by asking about what was going on in the environment, what the preceding tasks were considering the contribution of occupation and the environment to support expanded analysis and opening the opportunity for generation of possibilities by the coachee. OPC acknowledges that not all change will be positive, but the process of change enables reflection and refocus of goals and strategies.

13. **Client articulates specific planned actions within goal related activities outside of direct contact with the therapist.**

    Reviewer's comments: Successful interaction occurred where the therapist prompted coachee to expand on level of detail.

    Reflections and learning points: Mothers need time and prompts to be specific about their plans outside of direct contact with the coach.

14. **Client reports enacting actions intended to improve goal progress (including planned actions and innovations) in subsequent session.**

    Reviewer's comments: Most coachee were able to report effectively. It was less effectively applied where coachee had experienced major life events during the week or had experienced illness of themselves or their child in the week.

    Reflections and learning points: The group ran on a pre-set timetable that did not allow flexibility for the individual. Most coachee's remained engaged despite some experiencing major life events leading to some disruption on the process of OPC. This reflects a limitation of the brief group format.

15. **Therapist provides advice without implicit or stated permission**.

    Reviewer's comments: Coach asked permission to share information or resource links.

    Reflections and learning points: It is important to ask permission to enable coach's empowerment and avoid the coach shifting into the expert role.

16. **Therapist attempts to persuade client to agree with therapist's interpretation or ideas.**

    Reviewer's comments: None

    Reflections and learning points: This point fits with self-determination theory and the concepts of autonomy, relatedness, and competence. It was important to stay mindful about not slipping into a more directive style of interaction and remain fully centred on the mothers as experts of their own experience.

17. **Therapist summarizes or paraphrases in their own words, rather than using the client's words.**

    Reviewer's comments: None

    Reflections and learning points: Therapist needed to stay focused on exactly what mothers were saying to reflect their own language to support the equivalence of the power balance. This again supports autonomy from the concepts of self-determination theory.

18. **Therapist uses 'hands-on' techniques (e.g. hand over hand) on the goal subject for the purpose of directly improving performance (excluding teaching or demonstrating a strategy to the client).**

    Reviewer's comments: None

    Reflections and learning points: This was supported by the online context.

6 Chapter 6: Discussion

The primary goal of occupational therapy practice is to enable people, in this case children and their mothers, to participate in the activities of everyday life that they need and want to do (Royal College of Occupational Therapists, 2024). Data gathering in this thesis has been through mothers of children with sensory differences taking a family-centred rather than child-centred approach. There is debate about what a child-centred approach is (Carter et al., 2024). Traditionally a child-centred approach sought to change the child's underlying skills or performance. Despite an incomplete definition, there is now more emphasis on the child's active participation in goals and decisions about their care. This is captured in the government policy documents on 'No decision without me, without me' (Department of Health, 2012) that acknowledges the rights of the individual to have choice and control over their care. Family-centred care takes account of the family's unique experience and perspective. It acknowledges the family's expertise in their own experience and seeks to build a collaborative therapeutic relationship in addressing both the child and family needs. This generates benefit to both the child and the family (Dunst & Trivette, 2009). When the focus is on the carers or mothers the approach is on influencing the environment around the child, rather than the child themselves, taking a social rather than medical approach. More specifically utilizing an ecocultural approach. An ecocultural approach does not only consider the impact of the environment on the individual as in a social model, but also considers the interaction between the child with sensory differences and environment in which they are situated (Bronfenbrenner & Morris, 2006; Llewellyn, 2012). When we carefully consider the environment around the mother and child, we can begin to shift from an impairment or deficit focus to a participation or inclusion focus, in line with a neurodiversity affirming approach (Chen & Patten, 2024).

This thesis has uniquely explored what supports mothers of children with sensory differences value, and what further support they would like as described in Chapter 3 (Allen et al., 2024) and Chapter 4 (Allen et al., In preparation). It identifies gaps in the literature on parent coaching in Chapter 2 (Allen et al., 2021), and argues, for and then pilots the use of brief online group coaching based on Occupational Performance Coaching (OPC) for mothers of children with sensory differences - Chapter 5 (Allen et al., Under submission). At the time of writing no other studies have explored the experience of mothers of children with sensory differences in everyday life, their support experiences, and preferences, to this extent. No other studies to date have researched brief online group coaching for mothers of children with sensory differences. This discussion will now review the data generated in the context of current literature, implications for practice and recommendations for future research.

6.1 Occupations

Occupations are the everyday activities that people do. Participating in occupations enable us to attain health and well-being. Occupational therapists take an occupation focus rather than diagnosis focus to intervention through understanding the link between occupation, health and well-being (Rudman & Aldrich, 2017). Interviews were completed with 6 mothers of children with sensory differences to identify the everyday occupations and experiences of mothers and their children, and to identify what they found helpful or not, and finally what further support they would like. Mothers talked about the challenges that they themselves and their children faced in participation in everyday occupations at home, at school and in the community, and what was helpful to them in addressing these challenges as reported in Chapter 3 (Allen et al., 2024). The patterns of challenge and support were explored more widely across the population of mothers of children with sensory processing differences, through the Chapter 4 survey (Allen et al., In preparation). Areas of challenge that were identified covered the impact on daily routines and on relationships, the adaptions that mothers had to make to their child's and their own daily lives, and the impact of a lack of knowledge in themselves and the whole community around the child and mother. Two themes that helped mothers were 'Empowering mothers: An attitude of understanding and support' and 'Adaption of everyday occupations'. Empowering mothers was supported by mothers being listened to, supportive relationships, media resources, parent intervention, influencing knowledge and understanding within the family, community, health, and educational environments. Adaption of occupations and the environment was supported by knowledge and understanding, identification of child needs, flexibility in activity requirements, additional adult support, and government funding.

Through qualitative interviews mothers articulated making significant adaption to the environment and their own routines, increasing the complexity of daily routines, with consequential additional time and cost burden. The adaption required to meet the challenges of participation in everyday life is reflected in other studies. Caregivers of children aged 0-3 years with sensory differences were interviewed and described the accommodations made by themselves to meet their children's needs (Walbam, 2023). Accommodations led to learning new ways to understand and interact with their child. The impact of increased time and energy required of parents was observed within families of children with sensory differences for both preschool (Walbam, 2023) and school aged children (Schaaf et al., 2011). The disruption to and accommodation of child sensory differences in daily routines creates and additional practical burden for mothers. No literature to date has identified the cost burden in this population.

Mothering is described as a complex occupation (Sethi, 2020) which further intensifies when children face additional impairment, especially when that impairment is hidden (Cronin, 2004). In Chapter 4 (Allen et al., In preparation), mothers reported disruption to daily occupations at home, at school and in the community for themselves and their children. In the home setting, over 90% of respondents reported that their child's sensory processing differences had a negative impact on family mealtimes, morning, and evening routines, and over 77% experienced a negative impact on the child and parents' sleep. When the cohort was split by mothers of autistic versus non-autistic children there were some interesting variations in impact on daily life. Everyday activities at home for the autism group showed significant negative differences in mealtimes, screentime and parent sleep but no significant differences in morning and evening routine, child self-care, toileting, sleep, play and chores. At school and in the community most areas showed significant differences between mothers of autistic children versus non-autistic children with sensory differences.

The disruption to family daily routines has been observed in at least two qualitative studies on families of autistic children with sensory differences (Bagby et al., 2012; Schaaf et al., 2011). Home and leisure routines were disrupted, and parents undertook more preparation and accommodation for sensory needs in these daily occupation (Bagby et al., 2012; Schaaf et al., 2011). Whilst cause and effect were not established in these studies, both groups of investigators linked these disruptions to the identified sensory differences in the autistic child. However, no studies other than the current study in Chapter 4 survey (Allen et al., In preparation) have identified the reported severity of the impact of sensory differences on daily routines.

The concept of unfolding occupations (Segal, 2000) was discussed in Chapter 1: introduction. It remains unclear how parents adapt the activities, and if they are breaking down tasks to develop functional skills. That is whether they are using unfolding of occupations to support their child. Together, these data suggests that, when working with children with sensory differences and their families, occupational therapists should consider the impact of child sensory differences on family daily occupations regardless of child diagnosis. Looking further into the way that daily occupations are adjusted for all families of children with sensory differences will help professionals to improve their toolkit of support for children and families.

Child sensory differences have previously been identified as impacting family leisure choices through avoidance or adaptation (Bagby et al., 2012; Schaaf et al., 2011). Consistent with this research, the survey conducted in Chapter 4 survey (Allen et al., In preparation), illustrated that over 90% of mothers report that child sensory differences had a negative impact on choosing and participating in family leisure activities. The need for a balance between work, rest and leisure is recognised within the concept of occupational balance (Backman, 2004). Occupational balance is posited to support health and well-being. Conversely an occupational imbalance is observed when the allocation of time for an occupation compromises health or quality of life, (Chapter 1: introduction). Mothers that were interviewed and surveyed in this thesis, articulated the challenges that they and their children faced in fully accomplishing the daily occupations within home (e.g. morning and evening routines, parent, and child sleep), school (e.g. after school activities) and the community (e.g. meals out). However, it remains unclear if the causative factors were the child’s sensory differences or the knowledge and understanding from others of those sensory needs that exacerbate daily life challenges.

The phenomenon of occupational balance has been explored in relation to mothers of children with autism and their access to employment. Researchers found that the demands of accessing services created pressure on mother’s work roles. In other words, time spent meeting the child’s needs meant that mothers were less able to access work roles for themselves (Hodgetts et al., 2013). Whilst this thesis has not directly explored occupational balance in the population of mothers of children with sensory differences, the sensory needs of the child appear to act as a barrier to the occupational balance of their mothers. A recent editorial (McGrath et al., 2025) discussed the need to consider parents occupational needs, independently from that of the child. The interview and survey data in Chapters 3 interviews (Allen et al., 2024) and 4 survey (Allen et al., In preparation), support addressing the occupational needs of mothers of children with sensory differences with a parent-centric rather than child-centric perspective.

6.2 Relationships

In Chapter 3 interviews (Allen et al., 2024), mothers talked about not feeling heard and said that a lack of understanding led to difficulties in relationships within the family, social and professional networks. Where mothers were listened to and advocated for, whether by family or professionals, they felt supported. Other authors have previously identified the negative effect of a lack of acceptance or support from family members (Schaaf et al., 2011). In a qualitative study exploring the impact of a recognised physical disability versus more hidden disabilities, Cronin (2004) interviewed mothers of children with cystic fibrosis (recognised disability) and mothers of children with attention deficit and hyperactivity disorder (hidden disability). Findings suggested that mothers of children with recognised disability received increased family and social support and were able over time to establish daily routines. In contrast mothers of children with more hidden disabilities reported little family support and a lack of established normal routines. It is suggested that the sensory differences create a hidden disability and implicit discrimination.

Neurodiversity affirming practice guides us towards acceptance of the individual and their individual differences (Dallman et al., 2022). Findings of the studies, in Chapter 3 interviews (Allen et al., 2024) and Chapter 4 survey (Allen et al., In preparation), reported deficits in perceived family and social support. Mothers report that they would like further support in 3 ways. That is specialist support for the child, for themselves and the education of others. Both support for the mother and education of others influence change in the environment rather than the child supporting a neuroaffirming approach.

The link between social support and parent stress levels regardless of child diagnosis are established (Dunst, 2022). In studies of mothers of autistic children there are varying perspectives with authors suggesting it is only the perception of social support, e.g. Xing et al. (2025). Others suggest it is both the perceived support and the size of the social network that can impact mothers' well-being, e.g. Bi et al. (2022). Not only is reduced social support associated with raised parent stress but also associated with the physiological markers of a stress response in parents of autistic children and those with Attention Deficit and Hyperactivity Disorder (Lovell et al., 2012).

Social support can mitigate physiological stress responses implicating improved parent health and well-being. Whilst wider research supports the link between perceived social support and maternal stress this thesis has not looked directly at this relationship. However, it is apparent both in Chapter 3 interviews (Allen et al., 2024) and Chapter 4 survey (Allen et al., In preparation), that mothers perceive a lack of social support both from family, friends, education and healthcare professionals. Conversely when support is available particularly from family and healthcare professionals it is frequently highly valued. Therefore, a greater consideration of social support is important in addressing the needs of mothers of children with sensory differences. This reflects a social environmental approach to intervention aligned with an ecocultural perspective (Bronfenbrenner & Morris, 2006). Changing the narrative to one of acceptance and understanding of the needs of children with sensory differences and their mothers is vital if we are to break down the barriers of discrimination and support occupational justice. This requires a shift from viewing the child and their environment from an impairment lens to one of adapting the social environment to include the needs of all.

No literature was identified that explored the wider impact of child sensory differences on social and professional relationships. In a meta synthesis study, parents of autistic children identified the importance of healthcare staff being supportive, professional, and knowledgeable (Ooi et al., 2016). In contrast, healthcare staff who lacked knowledge were identified as unprofessional and dismissive of parental concerns, leading to parents feeling disrespected and disempowered (Ooi et al., 2016). The profile in parents of children with ADHD is similar with recognition of the potential value of support from healthcare professionals (Laugesen et al., 2017) but acknowledgement that healthcare providers are not always successful in developing a family centred supportive relationship (Davis et al., 2012; Fiks et al., 2011). The data in the Chapter 4 survey suggests that in many cases the relationship between mother and healthcare professionals is perceived as supportive. This is not universal and should however be addressed to better meet the needs of children with sensory differences and their mothers in the context of family centred care. The range of impact across both mothers and their children’s relationships with social networks and healthcare professionals has not been previously identified in the population of mothers of children with sensory differences and their children. This area warrants further exploration.

Mothers report the benefit of political and social structures that support financial support and adaptability of the activity and the environment. Small things make big differences, but the starting point is a promotion of understanding within social networks to reduce the barriers faced by children with sensory differences and their mothers. Mothers described the value of gaining knowledge and understanding for themselves and also, the need for extending knowledge of sensory differences in family, social and professional networks in Chapter 3 (Allen et al., 2024). Both family and professional relationships have the capacity to be supportive and helpful to mothers. Partners and family were reported to be the most helpful. The data presented reflects that relationships can act as a barrier or a facilitator in support of mothers. An example of a barrier is when mothers were criticized by grandmothers in dealing with child avoidant behaviour at mealtime or a General Practitioner dismissed mothers concerns. An example of a facilitating relationship again from a grandmother described the practical and emotional support as validating for the mother or when a school started to listen to mother and child’s concerns and experiences in Chapter 3: Interviews (Allen et al., 2024).

Building relationships with peer parents, education staff and healthcare professionals alongside direct child interventions are recognised as supportive of families of autistic children (Russa et al., 2015). Zablotsky et al. (2013) looked more specifically at mothers of autistic children and identified neighbourhood social support as a key factor in reducing mothers’ risk of high stress levels. The link between social support and mothers’ mental health is well established in neurodevelopmental populations and is observed in the cohort of mothers of children with sensory differences (Suzuki et al., 2019). Addressing the strengthening social relationships can be approached in a number of ways, for example through resilience training or the development of social capital (Schwartzman et al., 2021). Social capital is described as the family, community and service-related network that can provide valued emotional and instrumental support to families (Gulsrud et al., 2021; Wakimizu et al., 2017). Intervention, such as group coaching used in this thesis, have the potential to increase social capital, but mechanisms need further research.

Qualitatively in Chapter 3 interviews (Allen et al., 2024) and quantitatively in the Chapter 4 survey (Allen et al., In preparation) supportive relationships made a difference to mothers. The survey identified that partner/family rated most highly in relationships support. Friends, school staff, other parents and occupational therapists were also rated highly in terms of practical or emotional support. It is suggested that conversely, when these relationships are not present or actively unsupportive, a potential support mechanism is lost. Wider literature specifically identifies the value of connecting with other parents who share the same lived experience (Jones, 2018). Why does this matter? It matters because it is known that these mothers are more stressed, and this places both parent and child at greater risk of poorer mental health outcomes (Abidin, 2012; Allen & Knott, 2016; Nieto et al., 2017). A supportive social network is an important potentially protective factor. Therefore, in line with ecocultural theory when working with children with sensory differences, and their mothers the social environment and support network should be considered. Promoting understanding and positive engagement across these circles of potential support is in both mother and child's best interest. Group coaching has the potential to widen the peer support network.

6.3 Intervention

As discussed in Chapter 2 Scoping review (Allen et al., 2024) and Chapter 5 intervention study (Allen et al., Under submission) there are several ways to address intervention with parents of children with sensory differences. There is no doubt from the findings in the interviews and surveys in this thesis, that mothers value access to knowledge and that this has potential impact on child occupational performance and maternal satisfaction in that performance. However, there are several ways to gain that information. In Chapter 4 survey (Allen et al., In preparation) findings suggested low rates of access to direct parent intervention. In qualitative feedback mothers described wanting increased service in terms of specialist support for their child (specialist), practical and emotional support for themselves (targeted) and education of others (targeted or universal). Specialist support for the child might be delivered with a child or family centred approach. As previously discussed, there are advantages of placing delivery of services within family centred approach. Practical or emotional support for mothers of children with sensory differences is inherently family centred with consideration of the social environmental context. Education of other might be seen as a universal approach that is accessible to all and has the potential to change attitudes and understanding. These finding support the values of a tiered approach to intervention. In practice this is a work in progress with further research needed (Lynch et al., 2023). Whether the approach is centred on the child, the family or adapting the environment it should be neurodiverse affirming with the child and family at the heart of decision making.

In the Chapter 4 survey (Allen et al., In preparation) mothers indicated extensive use of websites, books, and social media networks (media) for accessing support and information. This suggests that mothers seek information from a variety of sources but does not elucidate if the knowledge or skill gained is applied in everyday life. Neither does it identify at what stage mothers seek intervention. That is, do parents seek information through media before approaching healthcare professionals or after? Certainly, accessing services for their children is identified as a challenge by many mothers. We do not know when mothers access media resources and whether it is whilst they await services or as an alternative. We also do not know what level and format of information sharing is most useful to mothers. We do know that mothers are motivated to learn more about sensory differences. However adult learning (Merriman & Baumgartner, 2020) and self-determination theory (Ryan & Deci, 2018) demonstrate that knowledge alone does not lead to change. Coaching aligns with adult learning and self-determination theory. The work in this thesis and that of others (Graham, Kennedy-Behr, & Zivianni, 2021) demonstrates the potential of coaching as a powerful tool in supporting mothers of children with sensory differences.

6.4 Coaching

Neurodiversity emphasises the strengths inherent in cognitive diversity. Interventions informed by neurodiversity aim to improve the goodness of fit between the physical or social-emotional environment and the child. These include interventions that support non-autistic people (e.g. carers) to build resilience, develop a positive philosophy and build relationships in a respectful, supportive and harmonious manner, e.g. coaching the caregiver. Interventions that encourage physical, sensory and emotional regulation are compatible with this stance (Leadbitter et al., 2021). The use of OPC with mothers of children with sensory differences supports a neurodiversity affirming approach.

The initial scoping review in Chapter 2 (Allen et al., 2021), identified evidence in support of individual family coaching to improve child goals, parent stress and parent sense of competence. There was a lack of evidence available to review the outcomes of group based coaching intervention for mothers of children with sensory differences. Since the scoping review was completed one peer reviewed study has trialled group parent coaching in a face-to-face context (Suja Angelin et al., 2021). It compared coaching based on OPC to standard care over a 10-week period. The participants were two groups of 9 mothers of children with disabilities, not per se sensory differences. Mothers set goals and in groups of 3, then discussed plans to enact those goals The occupational therapist gave input to each of the 3 groups in turn to guide their problem solving. There was a peer support therefore rather than coach-coachee component to the intervention, illustrating differences from one-to-one OPC (Graham & Ziviani, 2021a). Content analysis of the first 5 sessions supported meeting of the essential aspects of OPC. That is Connect, Share and Structure but the group was not compared to the full fidelity criteria (Graham & Ziviani, 2021a). There remains however a lack of literature on brief group online coaching with the population of parents of children with sensory differences.

Based on needs identified by mothers through Chapter 3 interviews (Allen et al., 2024) and Chapter 4 survey (Allen et al., In preparation), a pilot brief online group coaching intervention based on OPC with mothers of children with sensory processing differences was undertaken as described in Chapter 5 intervention study (Allen et al., Under submission). Two groups of 5-6 mothers completed 4 x 90-minute sessions over a 4-week period. Pre and post testing identified significant changes in child occupational performance and satisfaction as measured by Canadian Occupational Performance Measure (Law, 2014), and aspects of maternal stress as measured by Parent Stress Index – Short Form (Abidin, 2012). Parent sense of competence (Gibaud-Wallston & Wandersman, 1978) improved, but this was not statistically significant. Mothers feedback indicated that they found the sessions acceptable in terms of meeting online, timing and content, and valued the shared experience and social support. The findings of this study support further research into brief online group coaching for mothers of children with sensory differences.

Changes in child occupational goals (COPM) were reflected in several previous investigations into OPC. Bernie et al. (2022) provided four sessions of individual parent/family OPC intervention to families awaiting a child autism assessment. Suja Angelin et al. (2021) used a ten-session controlled trial group for mothers of children with disabilities. Ahmadi Kahjoogh et al. (2019) provided a ten-session randomised control trial for mothers of children with cerebral palsy. All studies resulted in child goal attainment. Interestingly, similar outcomes on COPM performance and satisfaction are also noted in a two-hour group-based parent training intervention (Heyburn et al., 2023). Although COPM is a well-accepted tool for measuring changes in occupation, where there is no control study it is not possible to say that the changes observed are due to the intervention or simply the mother having her concerns monitored. However, these findings may also reflect the variety of approaches available in meeting the needs of children and their families.

In each of the mother/ caregiver coaching format's goal setting was completed by parents for goals related to the child e.g. Bernie et al. (2022). Leadbitter et al. (2021) discusses the neurodiversity movement advocating for a positive psychology and strengths-based stance where an individual or family unit make their own choices. A strengths-based approach moves away from reducing deficits and towards enhancing activities or skills that naturally lead to learning and well-being. A strengths-based approach is preferable, but it is it is the choice of the individual/ family into what goal will most effectively impact quality of life (Dwyer, 2022; Leadbitter et al., 2021). The caregiver is closer to the child and therefore better able to identify need than the occupational therapist. This supports a neurodiversity family affirming practice. The goals of the caregiver may not however align with those of the child moving away from an individual neuro affirming approach. Where possible it is ideal to have the perspectives of the child with sensory differences at the heart of the goal setting process (Dallman et al., 2022). OPC requires that goals are valued and participatory (Graham & Zivianni, 2021). Valued goals are those that matter the most to the coachee which creates some tension may be the child has differing valued goals. This brings us back to the recent editorial (McGrath et al., 2025) that proposes when intervening with mothers we should take a parent centric approach. Participatory goals are those which are expressed in terms of occupation and participation. It takes time to support parents in their goal setting and in the Chapter 5 intervention study (Allen et al., Under submission) this process was undertaken individually prior to the start of intervention. A neurodiversity affirming approach advocates for the individual or family to have autonomy over their own goals.

Child sensory differences are associated with raised maternal stress above and beyond child diagnosis (Nieto 2019). In this brief online group coaching intervention study reported in Chapter 5 (Allen et al., Under submission), subsections of the Parent Stress index – Short form participants showed significant reduction in stress. Parent Distress, Parent-Child Difficult Interaction and Difficult Child demonstrated significant reduction, and the total score approached significance. Dunn and colleagues documented similar positive outcomes following a 10-session occupational therapy coaching intervention with families of children with autism and sensory differences (Dunn et al., 2012). Parent stress on the Parent Stress Index-short form was reduced from the 85th to the 50th percentile pre and post intervention (standard deviations are not reported) (Dunn et al., 2012).

The Bernie (2022) study of brief online one to one OPC whilst children were on a waiting list saw mean (standard deviation) score change from 54th (21.5) to 36th (30.5) percentile, whilst the control group saw an increase in scores reflecting increasing parent stress over the same time. This parallels findings in Chapter 5 intervention study (Allen et al., Under submission) that recorded changes in mean total parental stress from 92nd (11.0) to 84th (15.2) percentile. Changes observed were, in four cases, clinically as well as statistically significant. That is they went from above the 90th centile to below the 85th centile. Reducing parent stress reduces risk of abuse and mental health issues to both parent and child.

Qualitative findings of mothers' perceptions of changes following Occupational Performance Coaching indicated that mothers gained insights about themselves and their children, learnt specific strategies and experienced a calmer, happier emotional tone within the family (Graham et al., 2014). Across differing populations even short periods of coaching intervention based on OPC appear to have a statistically and to some extent clinically significant impact on parent stress (Allen et al., Under submission; Bernie et al., 2022).

The mechanisms of that stress reduction are not clear. OPC does not directly address the child's sensory differences but focuses on reducing barriers in daily occupations through supported coaching of the mother. There are many other mechanisms that could be at play including reframing of perception of the child's sensory differences or mothers' own perception of support. Reflecting on self-determination theory (Ryan & Deci, 2018) may shed some light on the observed change in maternal stress. OPC in a group context supports autonomy, relatedness and competence. 'Autonomy' through the process of mother's setting their own goals, identification, selection and implementation of own plan. In chapter 3 interviews mothers described not being listened to or advocated for, the group setting and coaching process address this through 'relatedness' as described by mother's qualitative feedback in Chapter 5 (Allen et al., Under submission). Finally, competence is embedded in the shared and repeated adult learning cycle experienced within the group coaching context. Although the outcomes of this intervention study focused on maternal stress and child occupational goals, qualitative findings suggest that this brief online group coaching intervention positively impacted maternal self-determination. This further supports adaption of the social environment around the child.

Coaching takes mothers through a process of reflection, whether goals are child focused or environment focused, the impact is reframing mothers' perception of the goal topic. Whilst the primary outcome or short-term goal in OPC is focused on the selected goal e.g. child hair washing. The secondary outcome in this study was reduced parent stress. Measured sense of competence did not statistically differ, but qualitative feedback indicated mothers growing confidence in their own parenting and sense of group support. In effect the mothers embodied the place of change. Reflecting on the ecocultural layers of micro/ macro environments we can see how mothers would advocate for environmental change

In a case report study of 3 mothers who received 4 individual sessions of telehealth coaching Parent Sense of Competence (PSOC) demonstrated improvement in all cases (Choi et al., 2023). However, a further study of group Occupational Performance Coaching for mothers of children with disabilities demonstrated significant changes in satisfaction pre and post intervention, but not when compared to a control group (Suja Angelin et al., 2021). PSOC changes are observed across studies with variable findings of significance. In the Chapter 5 intervention study (Allen et al., Under submission), changes in PSOC were observed but these changes were not identified as statistically significant. Whilst this may be linked to a small cohort, it may also be that group intervention is not effective at eliciting significant change in parent sense of competence.

It is suggested that group OPC would be possible with the condition that the group participants are working on the same goal (Graham & Ziviani, 2021a). Participants in the Chapter 5 Intervention study (Allen et al., Under submission), had individualised goals but, as one mother commented, ‘*Although certain issues were not my focus, I got lots of ideas and suggestions from listening to other people’s suggestions’* (Group 2, Participant 2). Despite individualised goals being set, it was apparent that the experiences underlying of many of the goals were shared amongst the mothers.

Whilst there are many advantages to the group context, there are also challenges. The Brief Online Group Coaching intervention in Chapter 5 (Allen et al., Under submission), raised the issue of exposure time to the intervention. Individual OPC has evidenced positive outcomes with child individualised goals and parents' sense of competence in as few as 4 x one hour session or less (Graham et al., 2013). The brief online group coaching session was scheduled for 4 sessions each of 90 minutes. As a comparison, the direct interaction between therapist and participant in individual coaching would be 4 hours per client. In the group context each participant would directly interact with the therapist for up to 15 mins within the session giving a maximum total of approximately one hour over the four sessions. However, the group dynamic allows for an interactive component between participants. Observing other mothers’ problem solving and the supportive interaction between mothers potentially increases the mother’s opportunity for reflection. It is proposed that the opportunity to share and reflect on experiences that other mothers are working through increases the time mothers have for contemplation, supporting their readiness for change. Group intervention also has the added advantage, as identified by mother in of Chapter 5 intervention study (Allen et al., Under submission), of widening the support bubble and helping mothers to feel that they are not alone.

6.5 Clinical implications

Occupational therapists support children and families to do the activities that they want and need to do. The Royal College of Occupational Therapist research agenda identified the need to work more effectually with families and carers (Micklewright & Farquhar, 2022). However recent data shows less than one third of children’s occupational therapists report providing direct intervention to parents (Gimeno et al., 2024). The figure of one third aligns closely with the number of mothers that reported receiving parent intervention in the Chapter 4 survey. This figure reflects a missed opportunity to positively impact the environment around the child and potentially alleviate parent stress as well as improve parent and child participation in meaningful occupation.

The data presented in this thesis demonstrates that from a mother's perspective, sensory differences impact daily occupations for the mother and child. This impact is observed at home, at school and in the community. Therefore, occupational therapists working with mothers of children with sensory differences, should consider daily occupations across environments for both the child and the mother e.g. impact on sleep, family mealtimes, morning and evening routine, leisure activities.

High rates of impact on everyday activities are reported in all subgroups. Mothers of autistic versus non-autistic children identified significantly greater impact of child sensory differences in many everyday activities at school and in the community. This suggests that with children with autism and sensory differences the school and community environments may need particular consideration. In the home environment the picture is more mixed with less difference between the subgroups. There is marked impact of sensory differences on everyday activities for mother and child across the full cohort. The Royal College of Occupational Therapists (2024) advocated for every school to have access to occupational therapy. This is a start but the scale of the impact of sensory differences suggests that access to occupational therapy services is equally important across home and community environments (e.g access to and participation in after-school and leisure activities) to enable occupational justice. Where child sensory differences are present it is important to consider both child and mothers everyday activities regardless of diagnosis.

The thesis provides evidence that mothers of children with sensory differences perceive a negative impact of child sensory differences on family, community and educational relationships. For mothers the most affected relationships appear to be within the family, friends and community. For the child the most affected relationships were within the family and with peers. This creates a barrier to potential supportive relationships for both mother and child. When assessing children with sensory differences from a family-centred perspective it is important to identify the impact of child sensory differences on both child and mother relationships to identify potential barriers to relationship support.

Despite the greater impact observed in many areas of daily functioning and relationships reported by mothers of autistic children with sensory deficits, mothers of non-autistic children also report impact. Sensory differences are only diagnostically recognized in autism (American Psychiatric Association, 2013). Whether a child has an autism diagnosis or not, sensory differences impact both everyday activities and relationships for both the child and mother. There is no significant difference in several areas. For everyday activities family morning and evening routine, child self-care routine, child toileting across all environments, child sleep, child being able to play independently, child chores, and participation in after-school or leisure activities the impact was equivalent across subgroups. For relationships: mothers' relationship with school staff was equivalent across subgroups. Regardless of diagnosis, mapping the quality of support in relationships may identify areas to reduce barriers and increase facilitators to family functioning, consequently changing the environment rather than the child.

National Institute for Health and Care Excellence (NICE) guidelines for support and management of autism spectrum disorder in under 19's instructs the promotion of functional skills and adaption to the social and physical environment (NICE, 2019). It appears that this approach is pertinent not just for autistic children but for all children with sensory differences. In the assessment stage of the occupational therapy process it is important that daily occupations across environments and social relationships are considered regardless of child diagnosis.

Provision of information alone is valued, but adult learning theory advocates for intervention to mothers that is focused on its application to everyday life. Mothers find a variety of interventions helpful from the provision of information to direct intervention for their child. Websites books and social media all provide forums for mothers to garner information and support. Wider consideration of how information is provided on sensory differences and strategies that can help through media is advocated beyond the use of websites. Mothers identified experience and preferred needs described in Chapter 3 and 4 suggests that stratified service delivery should take a multi-faceted approach. The evidence presented in this thesis supports sharing of information with communities and healthcare professionals at a universal level, and provision of targeted services that support group-based service delivery to families facing occupational challenges. This provides another strategy for environmental adaption rather than require the child to adapt to fit the environment.

Social networks around the mother and child are key to mothers' perception of support (Bi et al., 2022; Xing et al., 2025), and make a positive difference to parent stress levels (Allen & Knott, 2016; Dunst, 2022). As occupational therapists, it is important to take a wider perspective than just family centred practice. There should be consideration of the wider social network of support to mothers, including engagement of family and, where possible, peer and school networks.

Chapter 2 scoping review (Allen et al., 2021) identified gaps in brief group online coaching. There is support for coaching one to one as a concept. In practice however there are a number of approaches used to deliver coaching (King et al., 2023; Little, Pope, et al., 2018). The evidence base to date identifies OPC as the most researched in one-to-one parent coaching that focuses on both parent and child outcomes (Kennedy-Behr & Graham, 2021). The data presented in Chapter 5 intervention study (Allen et al., Under submission), supports the acceptability to mothers of brief online group coaching based on OPC.

The application of OPC to a group setting with only 4 sessions is novel. Recording of performance against the fidelity criteria in the Chapter 5 Intervention study (Allen et al., Under submission) demonstrated that many criteria were met, but not all were (See supplementary material 2: Retrospective feedback and reflections on Occupational Performance Coaching in Chapter 5). The challenges to fidelity maybe an issue of the level of training and competence of the OPC deliverer or may reflect the challenges of meeting fidelity criteria of OPC in a group context. As a tool that was designed for one-to-one intervention, it is suggested that some level of adaption may be required for delivery in a group context. The development of OPC as an individual tool is ongoing (Graham et al., 2024) in a cluster randomized control trial, the Meaning, Agency and Nurturing Autonomy (MANA) study. The MANA study is a realist process that aims to identify what works and for whom when working with caregivers.

The Chapter 4 survey reported that only 36% of mothers involved in parent intervention participated in goal setting (Allen, In preparation). Client centered goal setting is a key tool to support client sense of autonomy and is a well-supported practice when working with children and families (Zivianni et al., 2012). Goal setting is an important component of OPC as discussed in the Chapter 5 intervention study (Allen et al., Under submission) which required time before the start of the brief group intervention. Goal setting provides a focus for the OPC process and a method of outcome measurement. Future studies may wish to compare one to one goal setting through an online format with alternatives such as use of a survey tool or goal setting within the group.

Findings from Chapter 5 intervention study (Allen et al., Under submission) demonstrated positive changes in child occupation and aspects of maternal stress. As a pilot study, these findings may not yet be generalizable. However, the data presented does support cautious application of parent coaching for mothers of children with sensory differences and warrants further examination. Resources within occupational therapy services are increasingly stretched with 85% of occupational therapists reporting increased demand on services. Almost half of practitioners felt that they were not able to provide the level or type of occupational therapy input the children needed (Gimeno et al., 2024). There is a need to work smarter rather than harder. Whilst coaching mothers may not replace direct intervention it provides another strategy to meet child and mother occupational needs and address maternal stress.

6.6 Limitations and future directions

The scoping review in Chapter 2 (Allen et al., 2021) was completed with articles reviewed up to January 2020. The intervening years have seen an increase in the use of coaching in occupational therapy, with a variety of approaches and outcomes. In addition, OPC has seen an increase in implementation in several contexts. Future study will warrant a systematic approach to literature review of OPC for parents of children with additional occupational needs.

The interviews in Chapter 3 (Allen et al., 2024) were undertaken with a self-selecting sample of mothers. Sampling can be widened in several ways though, for example, accessing a clinical sample with stratified social and ethnic sampling, broadening the sample to all primary carers, identifying parents of children with sensory processing differences only. This would increase generalizability of findings. Mothers described the adaption of their own and their child's occupations to enable child participation and reduce the burden of care, specific qualitative exploration would further promote understanding in this area.

Chapter 4 describes a large-scale survey. The survey was developed based on previous interviews and review of the literature. The survey validity would be strengthened using a content validity index (Madadizadeh & Baharniya, 2023). Participants were a self-selecting community sample. Comparison with a clinical sample of mothers of children with formally identified sensory differences is supported. Findings on the impact of and on relationships are novel and require replication to confirm or refute. Whilst there is an apparent impact on relationships, relationships also act as a support to mother. Mechanisms for further building the social support networks around mothers of children with sensory differences are warranted. Media resources were identified as sources of support for mothers, but detailed analysis and comparison of effectiveness of website, books and social media is lacking in this population. Mothers who received direct intervention valued it but there are many variables including, approach, content, group size, length of exposure that are not established with this population.

The generalizability of the intervention study results (Chapter 5: Intervention study) is limited by a lack of control group, small sample size and in the first group non-blinded assessment and feedback. Future application of this approach would benefit from a full-scale feasibility study, with a control group or comparison group to support the validity of the findings. Since the planning of the intervention study in Chapter 5, the fidelity to intervention tool has been published (Graham & Ziviani, 2021a). The tool is designed for use in one-to-one contexts and would therefore require testing to check its applicability or more formally develop adaptations for use in a group context. Further research is needed to establish the fidelity of Group OPC, outcomes with a wider population and control group. Future studies should consider the dynamics of working with groups, the impact of peer support, and coaching vs education. In addition, it is pertinent to consider the longer-term impact of maternal coaching and if it reduces the demand for future service access, therefore having cost saving benefit for healthcare services.

Goals of intervention focused on the child’s occupational needs from the perspective of the parent. McGrath et al. (2025) suggest consideration of a parent centric rather than child centric approach. The possibility of a parent-centric approach warrants further investigation particularly considering findings of the impact of child sensory differences on the disruption to mothers’ occupations and relationships.

6.7 Conclusions

This thesis sets out to identify how we can better support mothers of children with sensory differences within the context of current practice. It was identified that child sensory differences have a pervasive impact on daily occupations for mother and child across home, school and community settings. Mothers of autistic children reported greater challenges in the school and community environment in everyday activities.

Mothers identified the importance of supportive relationships within social and professional networks and the importance of those networks for gaining knowledge and understanding. Partners and families offer the most direct and helpful support to mothers but friends, school staff, other parents and allied health professionals also have a positive role to play. Mothers value access to books, websites for information and social media, for information and support.

The capacity to adapt activities and the environment support both mother and child participation in everyday occupations. Findings support building social networks around the mother and child and thinking more broadly in the way that services are delivered. Sharing information through books and websites, supporting social networks through social media, and sharing knowledge through social and professional networks around the mother and child, all have the potentially to positively impact the mother and child’s occupational participation and well-being.

The small pilot study demonstrated that coaching can be effectively delivered in a group and online format over a 4-week time span and provides a perceived socially supportive learning environment. Mothers reported on acceptability and preliminary data demonstrated positive changes in child participation in occupation and aspects of maternal stress. Coaching using brief online group based on OPC has the potential to be a valuable component of graded intervention delivery in the context of increasing demand for services in resource constrained environments. Online delivery increases sustainability of service delivery in line with NHS service drivers. Finally, this brief online group intervention has the potential to reach large numbers of mothers were there is unmet need, increasing service accessibility.

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8 Appendices

8.1 Table of ethical approval and factors considered.

Ethics Table

Chapter	3: Interviews
Title	Mothers’ perspectives: daily life when your child has sensory differences.
Ethics code	2018-083-FK
Key points	Recruitment Interview participants were recruited as a convenience sample through social media networks, and the Centre for Autism mailing list and website. An information sheet was made available to parents to support informed consent, and informed consent will be sought prior to start of study Parent participants were sent a study information sheet by email. Mothers contacted the investigator if they were interested in taking part. Written informed consent was obtained for all participants. Electronic signatures and online consent were gathered for clinician interviews. Participants were emailed a copy of the information sheet and consent form to keep. All participants were free to withdraw at any time. Risks to participants There were no foreseeable potential risks to participants, however any issues that arose such as parent distress were be addressed as for standard clinical practice. For example: making parents aware of resources available e.g. Developmental Paediatrician, Occupational Therapy or CAMHS services. The investigator was an Occupational Therapist with 30 years' experience and is aware of local referral routes in UK. Storage of data Audio recordings were held on a password protected computer. The interviews were transcribed verbatim and did not include any confidential information. Recordings will be destroyed following completion of the project.

All data is kept confidential and securely stored. No identifying information was recorded during transcription. Participants were given an anonymity number and Information linking that number to their name are stored securely and separately from the data on a password protected computer. Audio recordings were deleted following anonymised transcription. All information collected for the project will be destroyed after a period of 5 years from the completion of the project has elapsed. Clinic staff supported transcription and followed clinical confidentiality procedures.

Chapter	4: Survey
Title	Mothers’ perspectives: Child sensory processing, daily life, relationships, media resources, and parent intervention. A survey
Ethics code	2019-191-FK
Key points	Recruitment Recruitment was through online means including - Parent social media groups, Professional social media groups, University of Reading Centre for Autism, and other. Recruitment process as follows: 1. An advert was posted as listed above. 2. The advert invited contained a link for one document containing participant information sheet consent form and survey @ online surveys.co.uk. Full completion of the consent form enabled access to the survey. Participants were asked to confirm prior to completion of the survey. - That information sheet has been read, - That participants understand participation is voluntary and that they are free to withdraw at any time, - That information stored will be held securely. - That they agree to take part. 3. Snowball sampling was employed where participants are invited to forward the link to other people.

4. Questions were kept to a minimum in order not to burden participants. The parent questionnaire took approximately 15 minutes to complete. Participants were able to see survey progress, move forwards and backwards and have a ‘finish later’ option to provide user friendly engagement.

4. Participants were able to withdraw at any time prior to final submission. From this point data is non-identifiable therefore cannot be removed.

The aim of these questionnaires was to recruit a representative sample of views and therefore data collection will be completed to point of saturation. During data collection process responses will be monitored to help gain a representative sample e.g. geographically.

Risk to participants

There are no foreseeable potential risks to participants as questions are not intrusive.

Storage of data

Results were transcribed anonymously and will therefore be non-identifiable. Data’s is held on the University One Drive and investigators password protected computer for 5 years following completion of the study. Contact information for the investigator was made available to participants in the Information Sheets and at the end of the Questionnaires.

Chapter	5: Pilot Intervention Study
Title	Brief online group coaching for mothers of children with sensory processing differences
Ethics code	2021-116-FK and 2022-024-FK
Key points	**Recruitment:** A flyer was sent to potential participants through the parent support voluntary sector organizations. Those who expressed an interest were forwarded a link to the Participant information sheet, Consent form and

Demographics questionnaire hosted @ onlinesurveys.co.uk. Mothers were invited to ask questions by email. The participation information sheet and consent form make it clear that consent was voluntary, and the participants were free to withdraw at any time. Participants were recruited chronologically.

Data Collection and storage of data

Data will be stored in an anonymised format on a password protected computer and university one drive. Group 2 consent to analyse videos held on One Drive for comparison with fidelity criteria by expert clinician. Zoom recordings deleted on transfer. Data reviewed annually.

Pre group Questionnaires will be made available through participants preferred format. These were offered for completion face to face in person or online with the primary researcher, by mail or electronic format. However, due to COVID-19 restrictions all were completed online. Completion was a pre-requisite of attendance.

Sensory Processing Measure (Child home form) (Parham et als. 2007). This is a standardised measure which identifies the presence of child sensory integration difficulties.

Participation and Environment Measure (Children and Youth) (Coster, Law & Beddell, 2010). This standardised assessment evaluates participation at home, school and the community) dropped after Group 1.

Canadian Occupational Performance Measure (COPM) (Law et als., 2000) is a standardised individualized measure designed for use by occupational therapists to detect change in a client of child's self-perception of occupational performance over time.

Goal Attainment Scaling (GAS) (Turner-Stokes, 2009). This tool helps to measure individualized goals for intervention. Dropped after Group 1.

Parent Stress Index -Short form (PSI-SF) (Abidin 1983) a standardised measure of parenting stress.

Parent Sense of Competence (PSOC) (Gibaud-Wallston & Wandersman, 1978) a standardised measure of parents' sense of satisfaction and efficacy within parenting role.

Post group questionnaires. The measures described above will be repeated within 2 weeks after the group finishes, except for the sensory processing measure. Additionally, mothers will be asked for feedback about the group using a post attendance questionnaire. Post attendance questionnaire. In group 2 an additional item was added to mother's feedback questionnaire: 'Do you wish to receive further occupational therapy services for your child? Yes/No'. For Group 2 post session assessments were completed with an independent occupational therapist.

Intervention:

On Zoom one morning a week for 4 weeks based on Occupational Performance Coaching (OPC). OPC had been described as an effective intervention by Graham et al. (2018) and Dunn, Little, Pope & Wallisch (2018) but only in the context of one-to-one intervention rather than a group intervention. In this study, mothers were, in turn, be invited to share the daily participation challenges that they are facing with their child. A problem-solving approach was facilitated, with engagement of peer support. Reflective questioning was utilized to support analysis and identification of alternative strategies for action. Participants were invited to share their experience of applying and refining strategies as the group progresses.

The primary researcher kept an anonymised diary of the intervention process, with feedback from participants also recorded. With consent from participants one session was recorded to identify the coaching processes that are utilized. In Group 2 all sessions were recorded. The recording will be stored on the secure University One Drive for the duration of the study.

Risk to participants

Confidentiality: The requirement to maintain confidentiality and not share group information outside of the group was part of the patient Information Sheet and Consent process. In week one this requirement was reiterated. Online service delivery: Participants were sent the Zoom link weekly, and a waiting room was set up to ensure only those invited joined the group. Participants were invited to have their cameras on and microphones on when they were speaking. As cameras/ microphones were in family home settings mothers chose whether to obscure background. Some mothers turned cameras off to cover interruptions e.g. attending to child's needs or answering the doorbell. Participants were asked to listen whilst each person worked through their individual goal and then invited to share their own experience. Chat function was available for sharing resources and the coach shared any resources identified by email at the end of the session. Maternal distress: It is possible that describing the challenges they face at home caused some distress to the mothers. It is also possible that some may found the group coaching model difficult because of the need to share their experiences with other mothers. Mothers were supported during the group by the researcher, who is a highly experienced occupational therapist. Mothers may of course be free leave the group at any point; any departures were followed up afterwards to make sure they are all right. A proviso that should concerns about participants well-being or that of their children be raised, following discussion with the primary researcher (highly experienced clinical psychologist), referral to voluntary or statutory health organizations would be signposted.

8.2 Development of Thematic Analysis

Chapter 2: Mothers' perspectives: daily life when your child has sensory differences

Analysis Round 1

Mealtimes
Selfcare
Sleep
Play
Screen time
Chores
Parent employment
Time and cost of administration and meetings
School uniform
Finance
Sensory seeking
Finding the right activity
Accessing the right activity
Sound
Touch
Movement
Visual
Heat
School support
Self-awareness
Sensory needs
Mums
Dads
Grandmothers
Extended family
Siblings
Listen to me and my child

Frequent GP visits – What's wrong with her now?
I hadn't got a clue
It's bad parenting
If someone had known more
I'm not having this
Who's helped?
Funding
Accessing Occupational Therapy or not
Sensory or not - We don't provide sensory services
Dip in and out
WOW! I feel like I understand
Autism vs sensory
What next
What's important?
People are not joining the dots
I am helping with …a social network …. because I think it is important that other people understand these kids
Through Facebook
Parent support groups
Parent training – understanding and sign posting
Books
Facebook groups
Online support for the young people themselves

Blaming parents	Parent support groups
Child picked on or bullied	Meeting up with other parents
Social network	You can treat people, and you can solve it
Finding the right attitude	

Themes	Subthemes
Family	Family Life experience
	Family relationships and diagnosis process
	Family occupations
	Safety
Occupations	Sleep
	Dressing/ Self care
	Play/ Leisure
	Community interaction
	School experience
	School facilitators
	Peer relationships
	Impact of knowing
Facilitators and Barriers	Facilitators
	Barriers
	Attitudes
	Home environment
Diagnosis	Complex pathways
	Interaction with other diagnosis
	Parent aspirations
	Support others learning

Analysis Round 2

Initial themes had areas of crossover leading to further refinement:

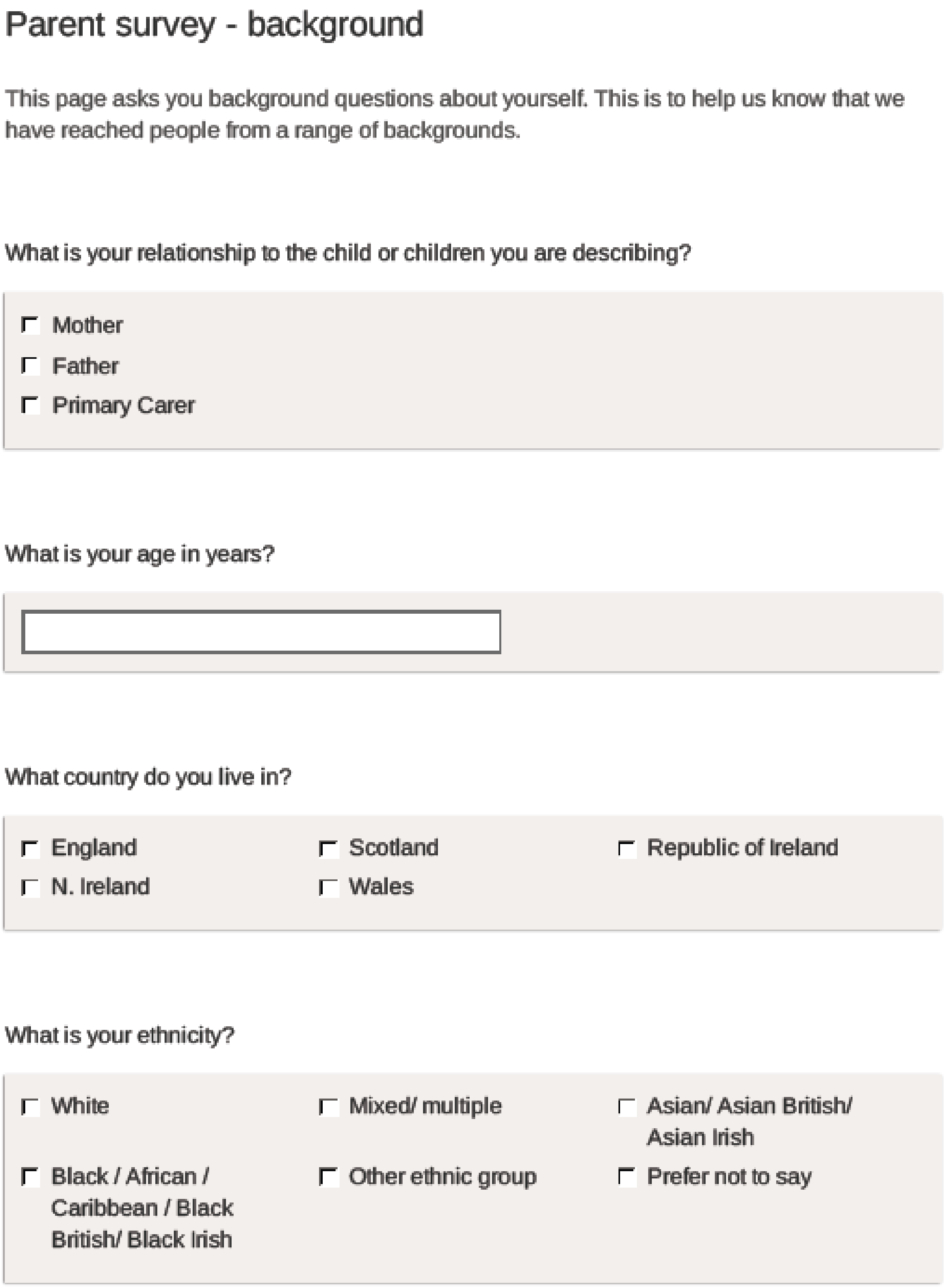
Themes	Sub themes
Barriers and Facilitators to participation in everyday life	Occupations
	Home
	School
	Community
	Relationships
	Home
	School
	Community
	Environment
Diagnosis	Not Knowing
	Accessing services
	Impact of knowing
Future	Raising awareness
	Practical and emotional support

Analysis Round 3

In this round of analysis, the experiences of everyday life across environments and relationships were more clearly observed. The impact of knowing and not knowing remained a theme but as this was reviewed the authorship group reflected that the diagnosis process reflected more widely the experience of both social and professional relationships with lacking knowledge and understanding or taking the time to listen and learn to empower mothers as seen below.

Themes	**Subthemes**	**Description**
1. The impact on everyday life	Changes in daily occupations (*She's screaming like she's been attacked) **	Daily occupations are the activities that we want or need to do every day. The impact of children's sensory processing differences on these activities has an impact on mothers.
	The things we have to do *(Anything to get a night's sleep*)	Choices or actions that mothers made as a direct consequence of their child or children's sensory processing differences.
	A lack of knowledge and understanding *(People still don't get it*)	How a lack of knowledge or understanding impacts everyday life for the mother.
2.What helps?	a. Empowering mothers: An attitude of understanding (*I found my voice*)	Mothers are empowered when they and those who can support them and their child, gain knowledge and understanding.
	b. Adaption (*That's a game changer*)	Strategies and adaptions to daily life that support their participation in everyday life.

8.3 Mothers Survey



Parent survey - background

This page asks you background questions about yourself. This is to help us know that we have reached people from a range of backgrounds.

What is your relationship to the child or children you are describing?

- ☐ Mother
- ☐ Father
- ☐ Primary Carer

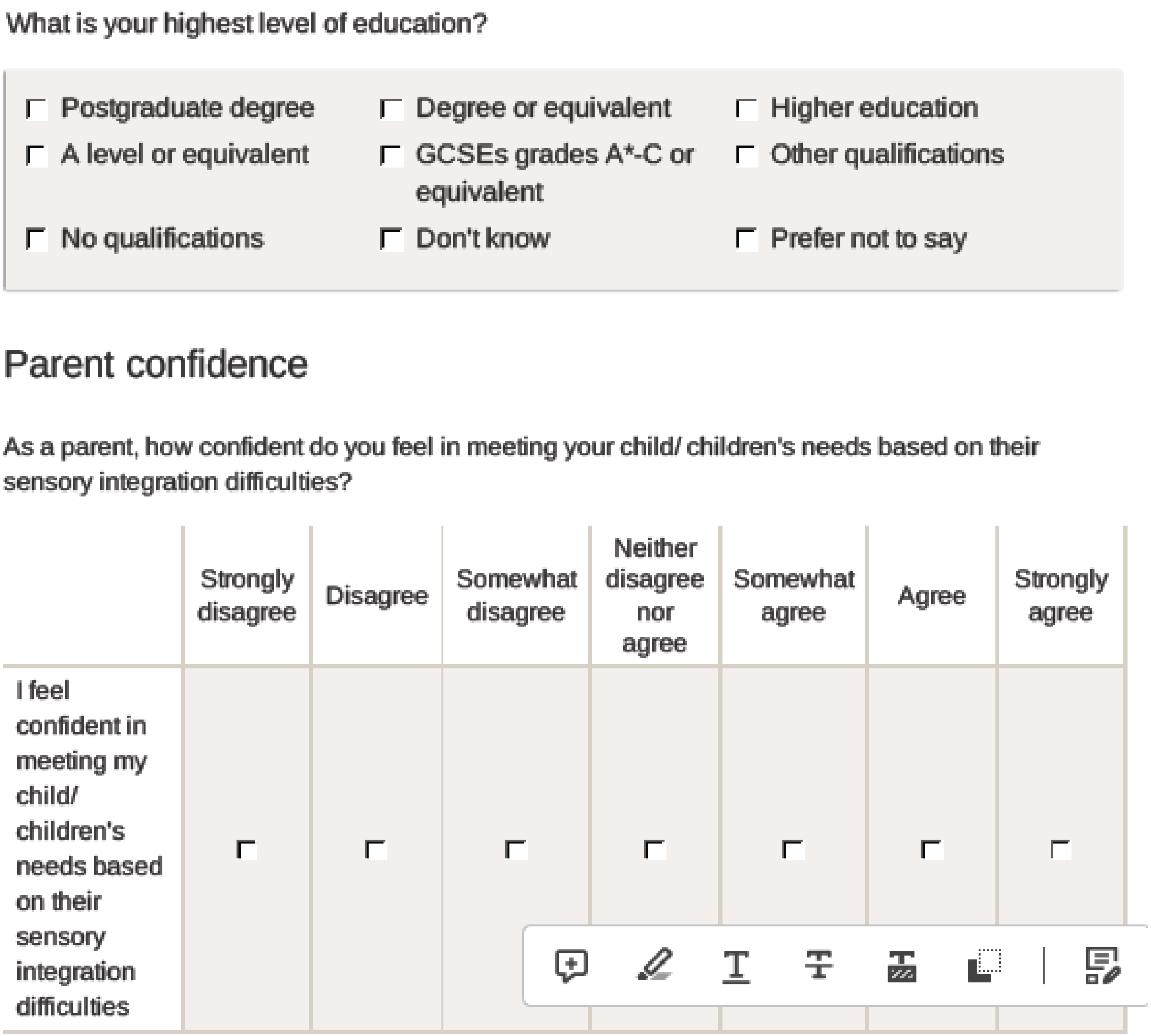
What is your age in years?

What country do you live in?

- ☐ England
- ☐ N. Ireland
- ☐ Scotland
- ☐ Wales
- ☐ Republic of Ireland

What is your ethnicity?

- ☐ White
- ☐ Black / African / Caribbean / Black British/ Black Irish
- ☐ Mixed/ multiple
- ☐ Other ethnic group
- ☐ Asian/ Asian British/ Asian Irish
- ☐ Prefer not to say



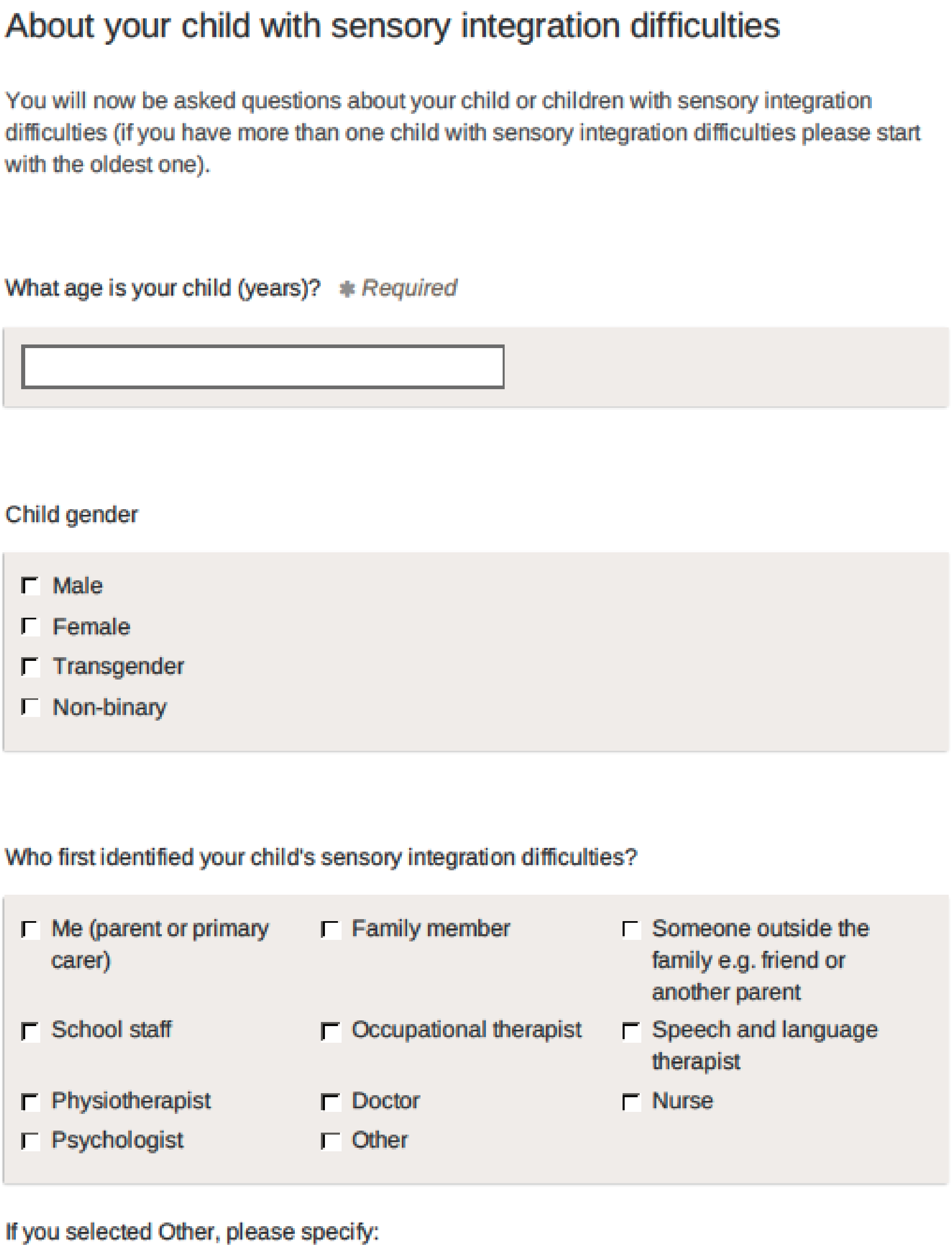
What is your highest level of education?

☐ Postgraduate degree
☐ Degree or equivalent
☐ Higher education
☐ A level or equivalent
☐ GCSEs grades A*-C or equivalent
☐ Other qualifications
☐ No qualifications
☐ Don't know
☐ Prefer not to say

Parent confidence

As a parent, how confident do you feel in meeting your child/ children's needs based on their sensory integration difficulties?

	Strongly disagree	Disagree	Somewhat disagree	Neither disagree nor agree	Somewhat agree	Agree	Strongly agree
I feel confident in meeting my child/ children's needs based on their sensory integration difficulties	☐	☐	☐	☐	☐	☐	☐



About your child with sensory integration difficulties

You will now be asked questions about your child or children with sensory integration difficulties (if you have more than one child with sensory integration difficulties please start with the oldest one).

What age is your child (years)? ✱ *Required*

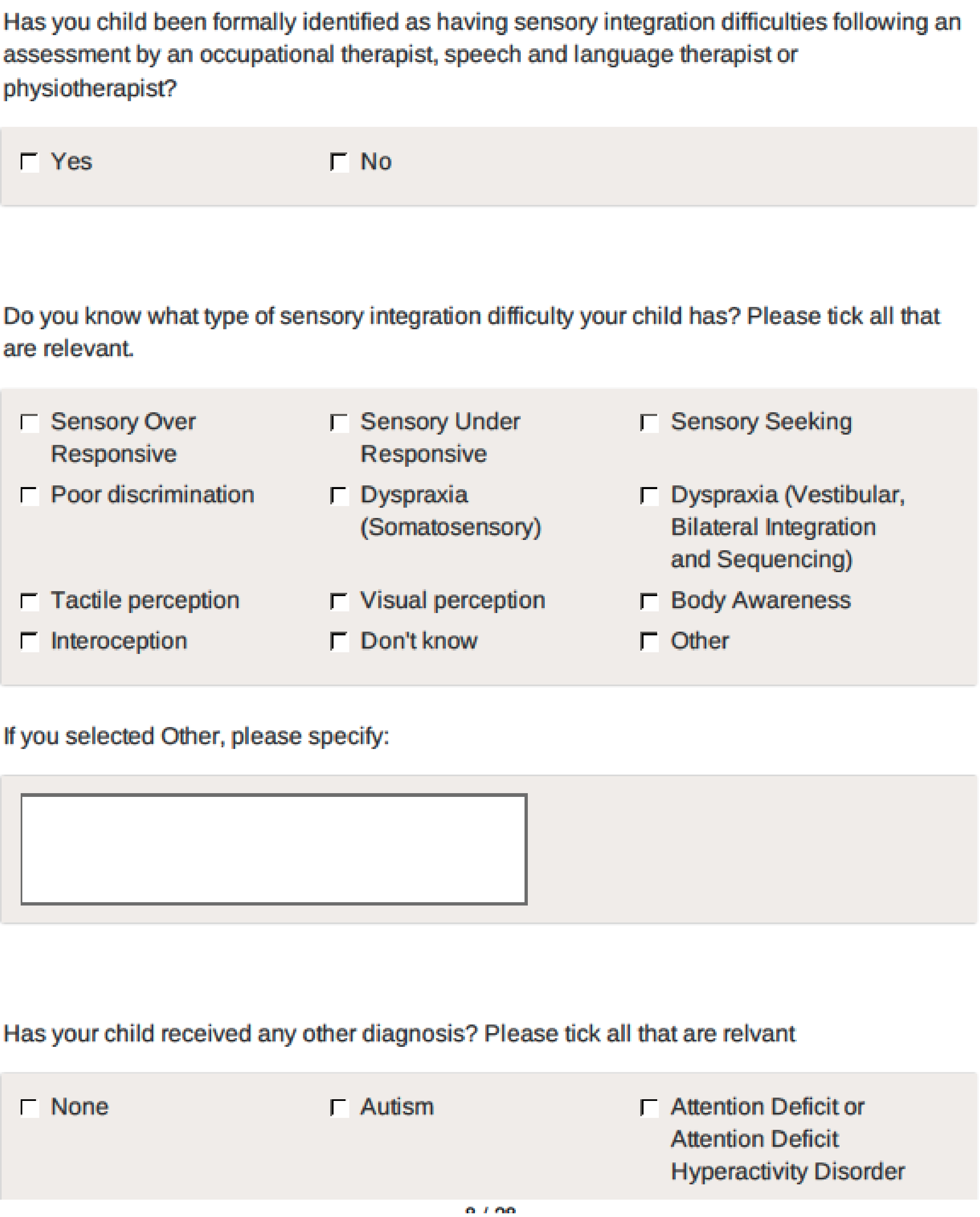
Child gender

☐ Male
☐ Female
☐ Transgender
☐ Non-binary

Who first identified your child's sensory integration difficulties?

☐ Me (parent or primary carer)
☐ Family member
☐ Someone outside the family e.g. friend or another parent
☐ School staff
☐ Occupational therapist
☐ Speech and language therapist
☐ Physiotherapist
☐ Doctor
☐ Nurse
☐ Psychologist
☐ Other

If you selected Other, please specify:



Has you child been formally identified as having sensory integration difficulties following an assessment by an occupational therapist, speech and language therapist or physiotherapist?

☐ Yes ☐ No

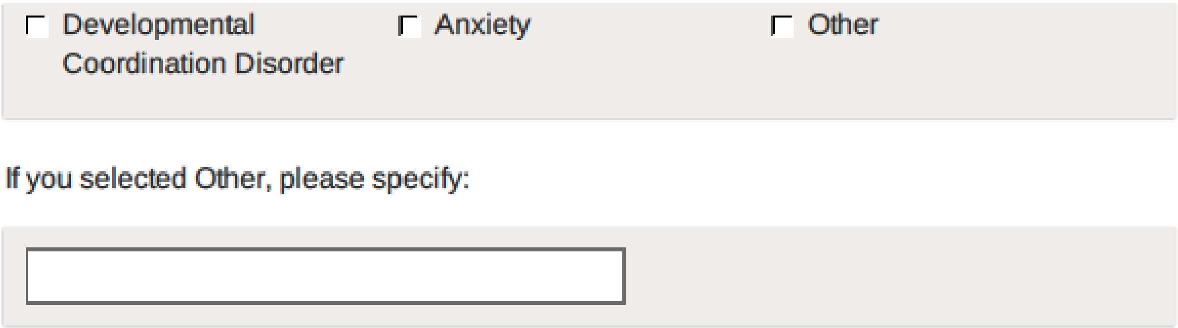
Do you know what type of sensory integration difficulty your child has? Please tick all that are relevant.

- ☐ Sensory Over Responsive
- ☐ Sensory Under Responsive
- ☐ Sensory Seeking
- ☐ Poor discrimination
- ☐ Dyspraxia (Somatosensory)
- ☐ Dyspraxia (Vestibular, Bilateral Integration and Sequencing)
- ☐ Tactile perception
- ☐ Visual perception
- ☐ Body Awareness
- ☐ Interoception
- ☐ Don't know
- ☐ Other

If you selected Other, please specify:

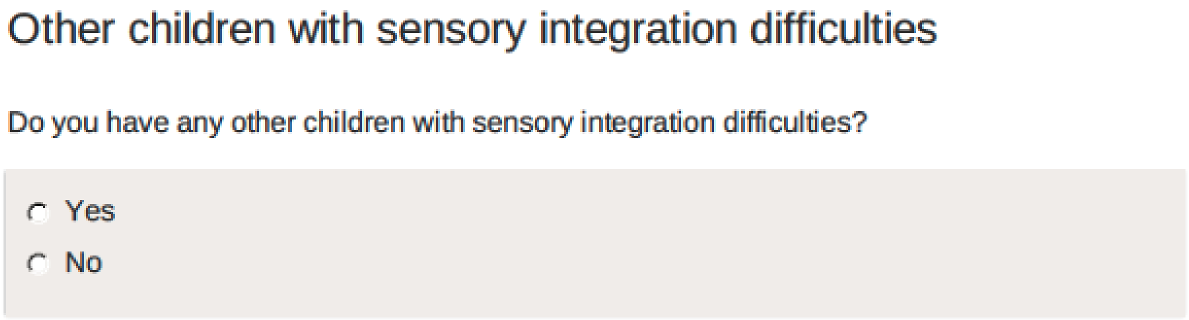
Has your child received any other diagnosis? Please tick all that are relvant

- ☐ None
- ☐ Autism
- ☐ Attention Deficit or Attention Deficit Hyperactivity Disorder



- ☐ Developmental Coordination Disorder
- ☐ Anxiety
- ☐ Other

If you selected Other, please specify:

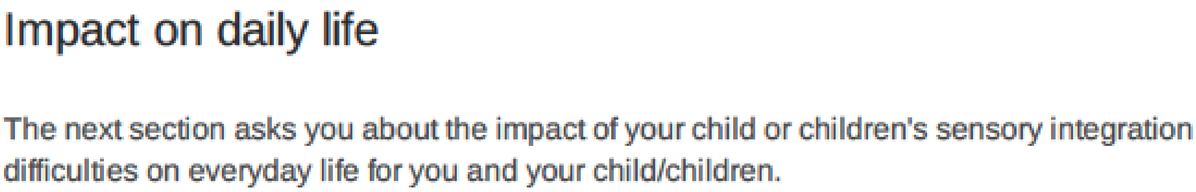


Other children with sensory integration difficulties

Do you have any other children with sensory integration difficulties?

○ Yes
○ No

The child section was repeated up to a further two times according to response above



Impact on daily life

The next section asks you about the impact of your child or children's sensory integration difficulties on everyday life for you and your child/children.

Impact on daily life

Please think about the impact of your child/ children's sensory integration difficulties on life at home. Focus on the present time and life over the last 12 months for any of your children's sensory intgration difficulties. Please give a rating for each of the areas mentioned.

	No impact	Minor negative impact	Moderate negative impact	Major negative impact	Unable to participate in this activity due to child's SID	Not applicable
Family Mealtimes	☐	☐	☐	☐	☐	☐
Family morning or evening routine	☐	☐	☐	☐	☐	☐
Self-care routine (e.g. washing and dressing)	☐	☐	☐	☐	☐	☐
Toileting	☐	☐	☐	☐	☐	☐
Child/ children's sleep	☐	☐	☐	☐	☐	☐
Parents' sleep	☐	☐	☐	☐	☐	☐
Being able to play independently	☐	☐	☐	☐	☐	☐
Time spent on screen time	☐	☐	☐	☐	☐	☐
Allocation of chores	☐	☐	☐	☐	☐	☐
Family finances	☐	☐	☐	☐	☐	☐

Please think about the impact of your child's/children's sensory integration difficulties on life outside of the home, now or in the past 12 months. Please rate each of the following areas.

	No impact	Minor negative impact	Moderate negative impact	Major negative impact	Unable to participate in this activity due to child's SID	Not applicable
Wearing school uniform	☐	☐	☐	☐	☐	☐
Dressing or undressing at school	☐	☐	☐	☐	☐	☐
Toileting at school	☐	☐	☐	☐	☐	☐
Mealtimes at school	☐	☐	☐	☐	☐	☐
Time spent by parent dealing with school matters (e.g. school meetings or homework time)	☐	☐	☐	☐	☐	☐
Teachers coping with child's/children's behaviour	☐	☐	☐	☐	☐	☐
Choosing after-school activities or leisure activities	☐	☐	☐	☐	☐	☐
Participating in after-school or leisure activities	☐	☐	☐	☐	☐	☐

Toileting in the community (e.g. when undertaking leisure activities or shopping)	☐	☐	☐	☐	☐	☐
Mealtimes in the community (e.g. going to a restaurant)	☐	☐	☐	☐	☐	☐
Parent coping with child's/children's behaviour	☐	☐	☐	☐	☐	☐
Choosing family leisure activities	☐	☐	☐	☐	☐	☐
Being safe in community activities (e.g. not running away, harming self or others)	☐	☐	☐	☐	☐	☐

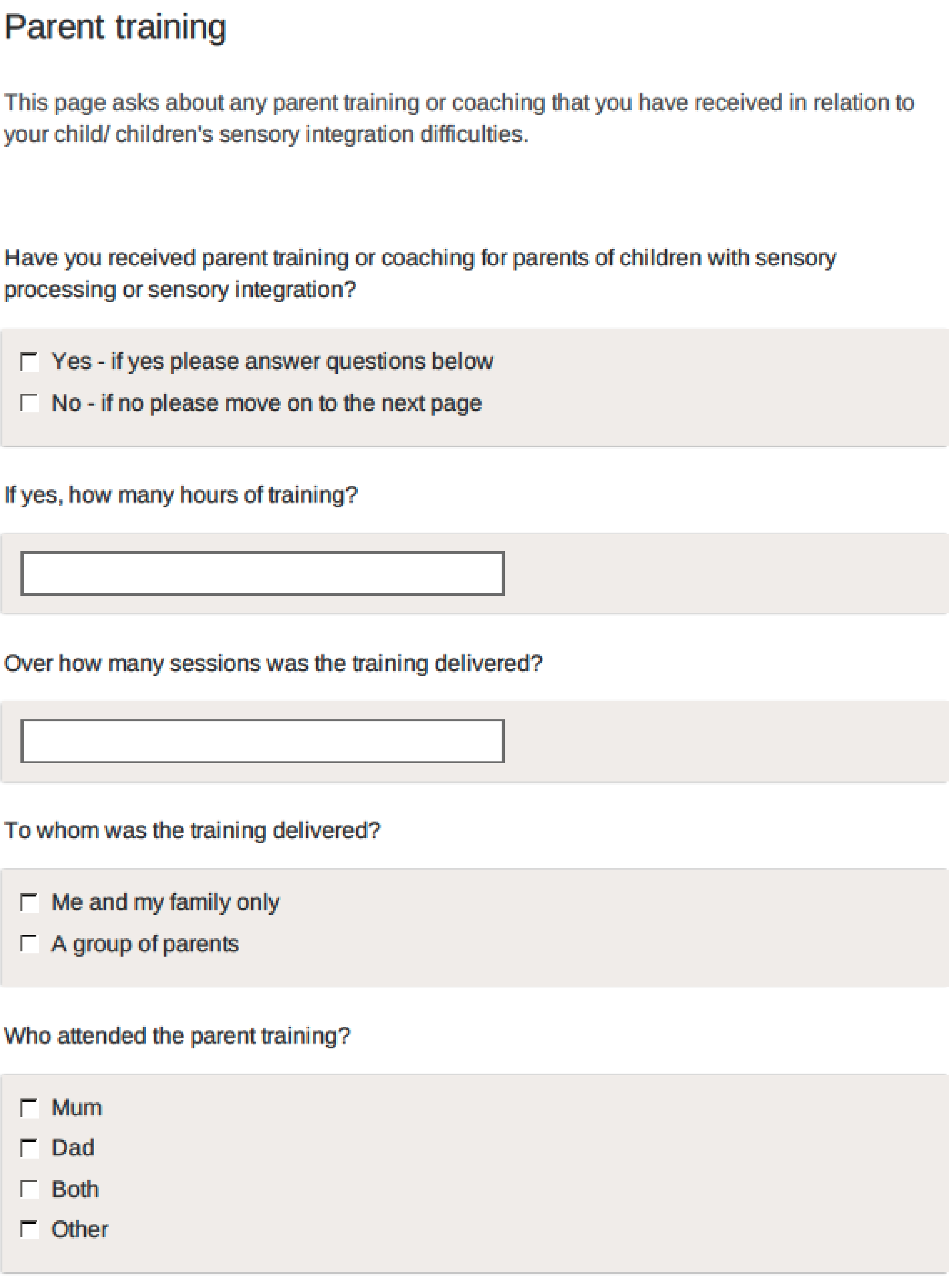
Please think about the impact of your child's/ children's sensory integration difficulties on yours or your child's/ childen's reationships with others now or in the last 12 months. Please rate each of the following areas.

	No impact	Minor negative impact	Moderate negative impact	Major negative impact	Not applicable
Your relationship with your partner	☐	☐	☐	☐	☐
Your relationships with family and extended family (e.g. siblings, aunts, uncles, cousins and grandparents)	☐	☐	☐	☐	☐

Your relationships with your friends	☐	☐	☐	☐	☐
Your relationships with school staff	☐	☐	☐	☐	☐
Your relationships with other parents	☐	☐	☐	☐	☐
Your relationships within your community	☐	☐	☐	☐	☐
Your child's relationship with you	☐	☐	☐	☐	☐
Your child's relationship with your family or extended family	☐	☐	☐	☐	☐
Your child's relationship with school staff	☐	☐	☐	☐	☐
Your child's relationship with peers.	☐	☐	☐	☐	☐

Are there any other areas of daily life for you or your child/children that are impacted by sensory integration difficulties?

☐ Yes - please specify below
☐ No



Parent training

This page asks about any parent training or coaching that you have received in relation to your child/ children's sensory integration difficulties.

Have you received parent training or coaching for parents of children with sensory processing or sensory integration?

- ☐ Yes - if yes please answer questions below
- ☐ No - if no please move on to the next page

If yes, how many hours of training?

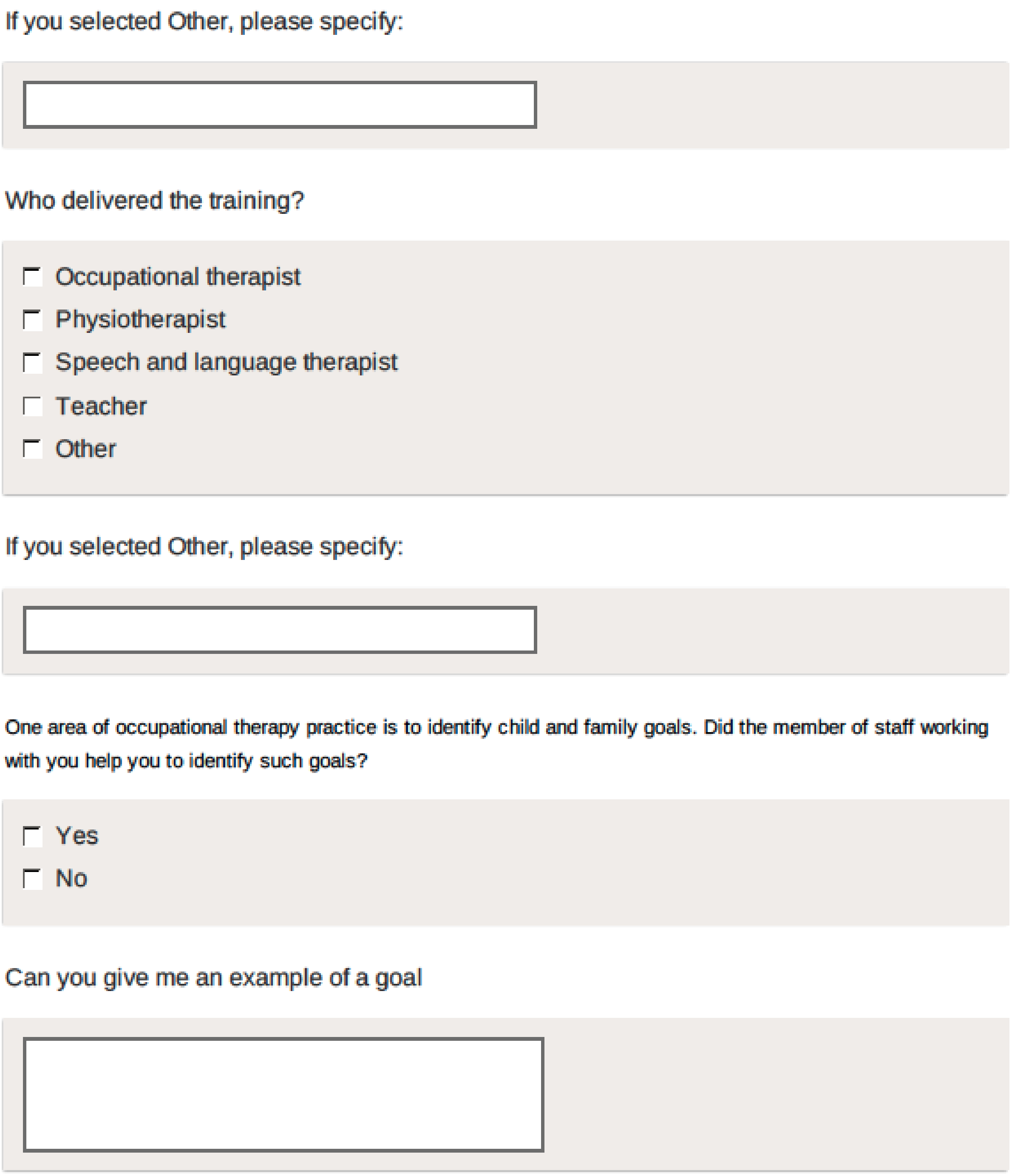
Over how many sessions was the training delivered?

To whom was the training delivered?

- ☐ Me and my family only
- ☐ A group of parents

Who attended the parent training?

- ☐ Mum
- ☐ Dad
- ☐ Both
- ☐ Other



If you selected Other, please specify:

Who delivered the training?

- ☐ Occupational therapist
- ☐ Physiotherapist
- ☐ Speech and language therapist
- ☐ Teacher
- ☐ Other

If you selected Other, please specify:

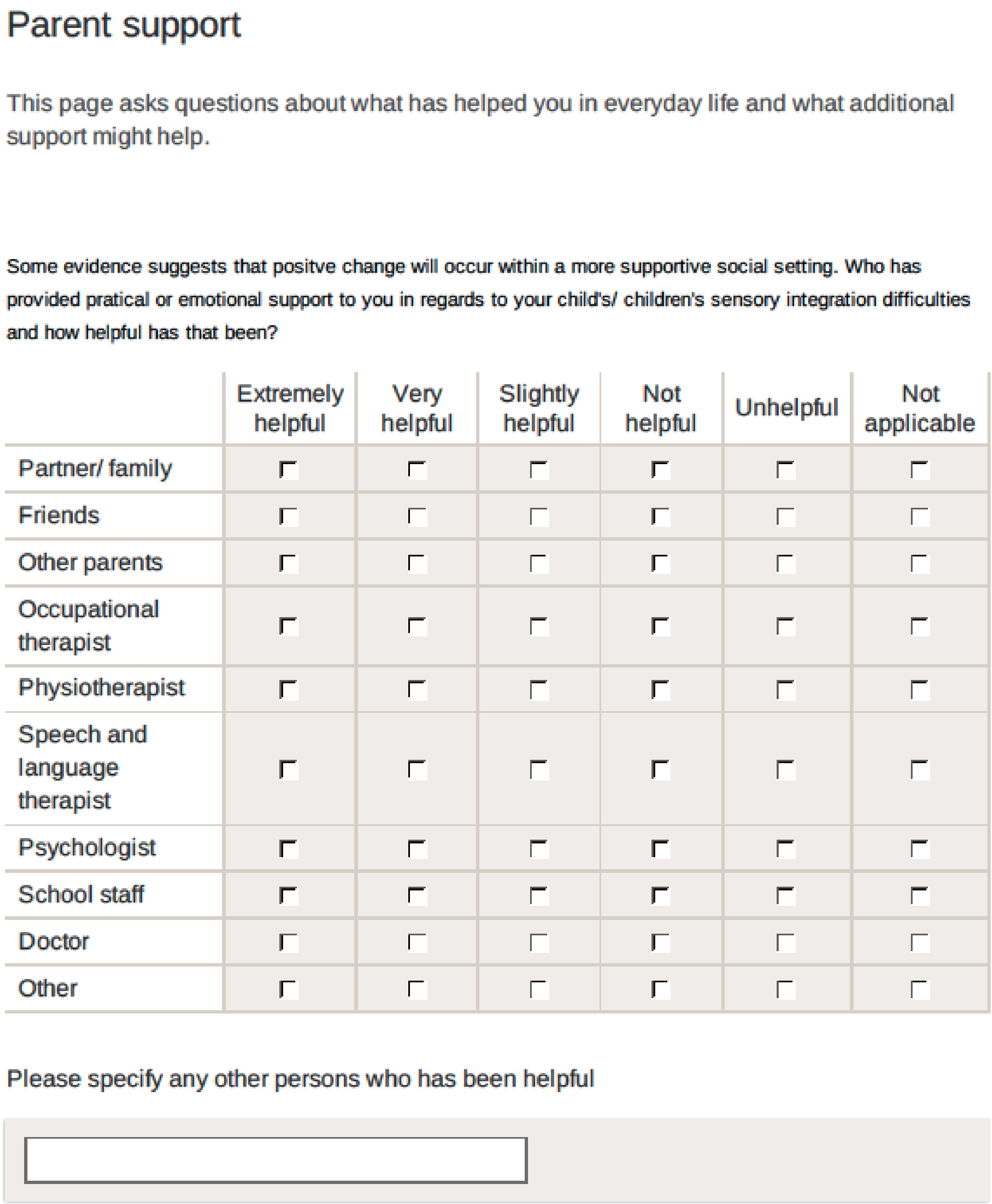
One area of occupational therapy practice is to identify child and family goals. Did the member of staff working with you help you to identify such goals?

- ☐ Yes
- ☐ No

Can you give me an example of a goal

Please indicate what was covered in the parent training and how useful that was for you.

	Very useful	Moderately useful	A little useful	Not useful	Not covered	Don't know
Types of sensory integration or sensory processing difficulties	☐	☐	☐	☐	☐	☐
Muscle and movement systems (proprioception)	☐	☐	☐	☐	☐	☐
Balance and movement systems (vestibular)	☐	☐	☐	☐	☐	☐
Touch systems (tactile)	☐	☐	☐	☐	☐	☐
Hearing System (auditory)	☐	☐	☐	☐	☐	☐
Visual System	☐	☐	☐	☐	☐	☐
Smell and Taste	☐	☐	☐	☐	☐	☐
Sensation form inside our body (interoception)	☐	☐	☐	☐	☐	☐
How SID can affect everyday life (e.g. washing, dressing, mealtimes, going out, going to school)	☐	☐	☐	☐	☐	☐
Sharing your experiences with other parents	☐	☐	☐	☐	☐	☐
Practising use of sensory strategies	☐	☐	☐	☐	☐	☐
Practising problem solving	☐	☐	☐	☐	☐	☐



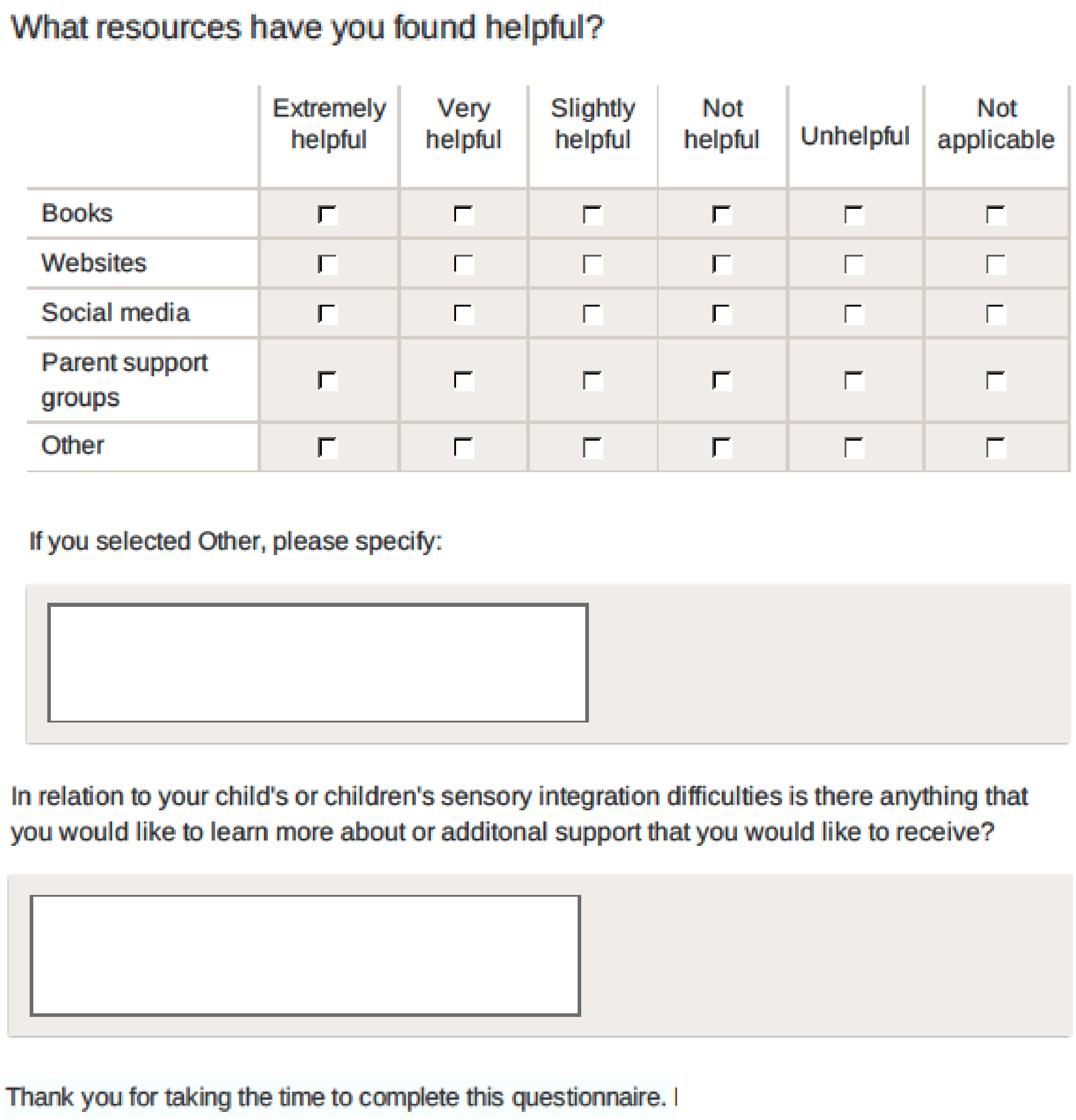
Parent support

This page asks questions about what has helped you in everyday life and what additional support might help.

Some evidence suggests that positve change will occur within a more supportive social setting. Who has provided pratical or emotional support to you in regards to your child's/ children's sensory integration difficulties and how helpful has that been?

	Extremely helpful	Very helpful	Slightly helpful	Not helpful	Unhelpful	Not applicable
Partner/ family	☐	☐	☐	☐	☐	☐
Friends	☐	☐	☐	☐	☐	☐
Other parents	☐	☐	☐	☐	☐	☐
Occupational therapist	☐	☐	☐	☐	☐	☐
Physiotherapist	☐	☐	☐	☐	☐	☐
Speech and language therapist	☐	☐	☐	☐	☐	☐
Psychologist	☐	☐	☐	☐	☐	☐
School staff	☐	☐	☐	☐	☐	☐
Doctor	☐	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐	☐

Please specify any other persons who has been helpful



What resources have you found helpful?

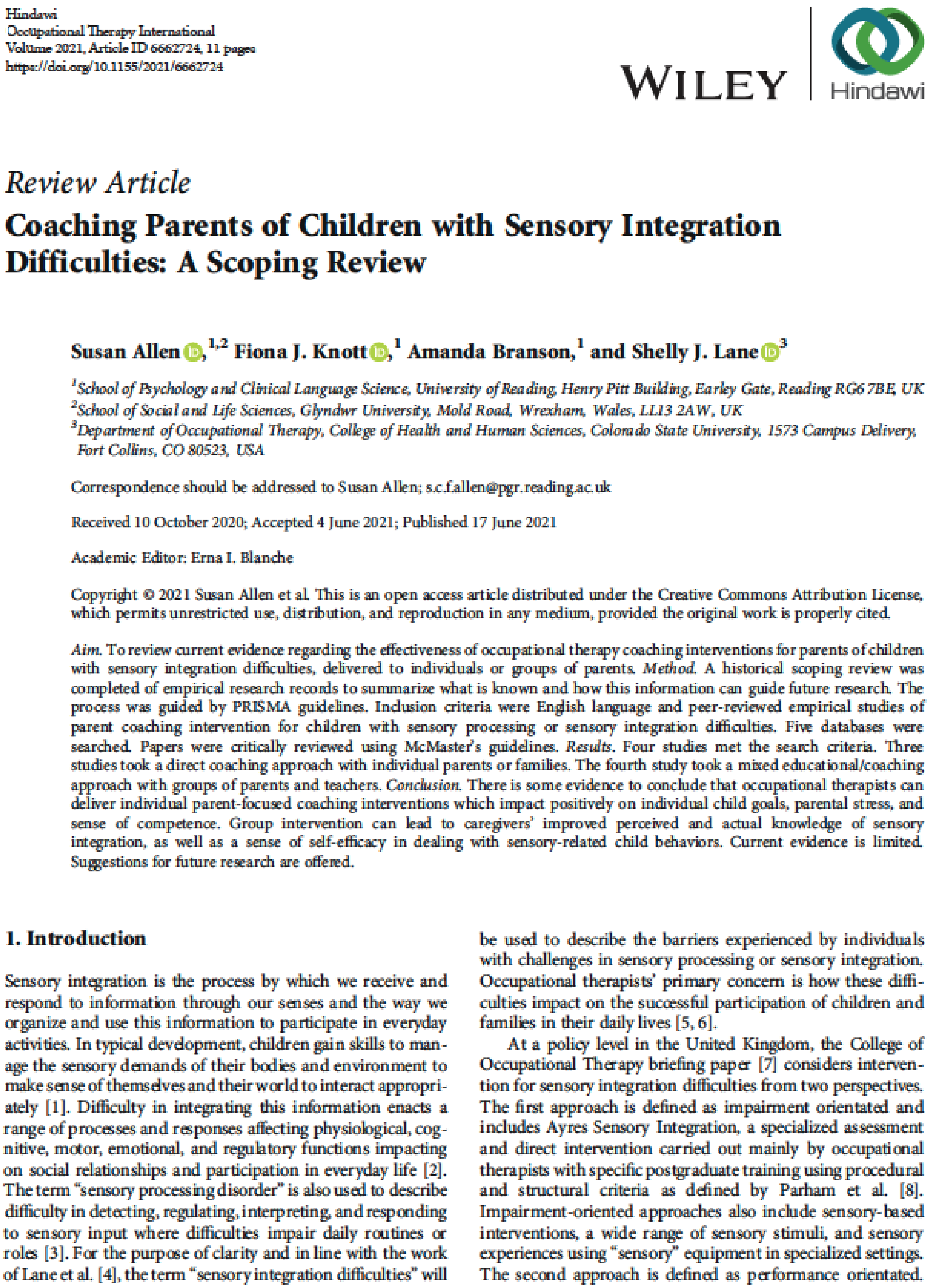
	Extremely helpful	Very helpful	Slightly helpful	Not helpful	Unhelpful	Not applicable
Books	☐	☐	☐	☐	☐	☐
Websites	☐	☐	☐	☐	☐	☐
Social media	☐	☐	☐	☐	☐	☐
Parent support groups	☐	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐	☐

If you selected Other, please specify:

In relation to your child's or children's sensory integration difficulties is there anything that you would like to learn more about or additonal support that you would like to receive?

Thank you for taking the time to complete this questionnaire.

8.4 Published paper: Coaching Parents of Children with Sensory Integration Difficulties: A Scoping Review



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Review Article

Coaching Parents of Children with Sensory Integration Difficulties: A Scoping Review

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Aim. To review current evidence regarding the effectiveness of occupational therapy coaching interventions for parents of children with sensory integration difficulties, delivered to individuals or groups of parents. *Method.* A historical scoping review was completed of empirical research records to summarize what is known and how this information can guide future research. The process was guided by PRISMA guidelines. Inclusion criteria were English language and peer-reviewed empirical studies of parent coaching intervention for children with sensory processing or sensory integration difficulties. Five databases were searched. Papers were critically reviewed using McMaster's guidelines. *Results.* Four studies met the search criteria. Three studies took a direct coaching approach with individual parents or families. The fourth study took a mixed educational/coaching approach with groups of parents and teachers. *Conclusion.* There is some evidence to conclude that occupational therapists can deliver individual parent-focused coaching interventions which impact positively on individual child goals, parental stress, and sense of competence. Group intervention can lead to caregivers' improved perceived and actual knowledge of sensory integration, as well as a sense of self-efficacy in dealing with sensory-related child behaviors. Current evidence is limited. Suggestions for future research are offered.

1. Introduction

Sensory integration is the process by which we receive and respond to information through our senses and the way we organize and use this information to participate in everyday activities. In typical development, children gain skills to manage the sensory demands of their bodies and environment to make sense of themselves and their world to interact appropriately [1]. Difficulty in integrating this information enacts a range of processes and responses affecting physiological, cognitive, motor, emotional, and regulatory functions impacting on social relationships and participation in everyday life [2]. The term "sensory processing disorder" is also used to describe difficulty in detecting, regulating, interpreting, and responding to sensory input where difficulties impair daily routines or roles [3]. For the purpose of clarity and in line with the work of Lane et al. [4], the term "sensory integration difficulties" will be used to describe the barriers experienced by individuals with challenges in sensory processing or sensory integration. Occupational therapists' primary concern is how these difficulties impact on the successful participation of children and families in their daily lives [5, 6].

At a policy level in the United Kingdom, the College of Occupational Therapy briefing paper [7] considers intervention for sensory integration difficulties from two perspectives. The first approach is defined as impairment orientated and includes Ayres Sensory Integration, a specialized assessment and direct intervention carried out mainly by occupational therapists with specific postgraduate training using procedural and structural criteria as defined by Parham et al. [8]. Impairment-oriented approaches also include sensory-based interventions, a wide range of sensory stimuli, and sensory experiences using "sensory" equipment in specialized settings. The second approach is defined as performance orientated.

This approach emphasizes managing, rather than changing, the sensory needs of the individual through adapting the environment, modifying the task, or developing strategies for the individual to self-manage the task. A variety of interventions have been developed for children and their families with varying effectiveness [9, 10]. This paper explores parent-focused coaching intervention, a relatively underused approach with parents of children with sensory integration difficulties.

Parent engagement in therapy sessions is seen as desirable [11], and at least one child-centered approach explicitly identifies the importance of collaboration and problem-solving with parents [12]. However, impairment-orientated and performance-orientated approaches primarily focus on the child rather than the parent's needs. The impact of sensory integration difficulties on parents has been investigated in a number of papers demonstrating high levels of parent stress as well as challenges to daily occupations. Parents at times use negative coping strategies that can exacerbate the impact of stress for both the parent and the child [13, 14]. Despite research recognizing the impact on parents, there is little evidence about the best way to support parents. Ecological theory [15] reflects the interactive nature of the child with their social and physical environment. Parents experience higher stress and may use negative coping strategies but can nonetheless be positive agents of change for themselves and their children. There is therefore a need to move beyond child-focused work and to explore the value and effectiveness of parent-based interventions. Such interventions include those which increase parental knowledge and understanding to enable parents to gain confidence and competence in developing strategies to better manage their family and children's participation in daily activities.

Two papers have proposed frameworks of intervention for children with sensory integration difficulties and their families. Both frameworks [16, 17] advocate direct interaction with parents using a coaching-based approach, either with parents alone or in addition to intervention with the child or environmental adaptation. It is acknowledged that one approach to intervention cannot meet the whole needs of clients across the variety of settings that we practice in. Multicomponent approaches have the flexibility to allow the needs of children and families to be met in a way which is both cost effective and acceptable to the family. Some parents, for instance, may benefit from support to identify and manage environmental challenges, while for other families, direct intervention with the child may be the most appropriate starting point. We therefore need to consider, develop, and evaluate a variety of intervention approaches in our practice, and coaching is one of these. Coaching has roots in fields outside occupational therapy, e.g., sports and business. It has been simply described as unlocking people's potential to maximize their own performance [18] and is founded upon the relationship between coach and coachee [19]. Reynolds et al. [16] describe coaching as a structured process including emotional support and information exchange. Caregiver interventions are recognized to build on family strengths, occur in natural contexts, and are embedded in daily occupations which support goal acquisition [16]. Caregiver interventions offer the opportunity to empower families in generating strategies compatible with their own routines as well as to be generalized to other situations [17]. Miller-Kuhaneck and Watling [20] systematically reviewed the outcomes of both parent education (didactic teaching) and parent coaching studies for parents of children with autism and sensory integration difficulties and found that although limited there is some evidence to support parent training. They recommend that occupational therapy is well suited to providing parent training. These papers have opened an exploratory door on parent interventions. Notably, they included only one paper on parent coaching. The remaining studies were concerned with teaching parents an activity to apply to the child (e.g., massage or applied sensory stimuli) or addressing sensory integration difficulties as part of a broader intervention for parents of children with autism. Interventions described either did not specifically address the wider population of parents of children with sensory integration difficulties or did not explore coaching as proposed by the recommended frameworks [17].

The overall aim of this study is to review the literature available to support future development of a parent coaching intervention for parents of children with sensory integration difficulties. Specific aims are to synthesize and appraise what we know about parent coaching interventions for parents of children with sensory processing and integration difficulties and to define gaps in the literature to inform future research.

2. Methods

To map the literature, identify gaps in our knowledge and understanding of the field, and make recommendations, a scoping review was conducted. PRISMA guidelines for scoping reviews were followed [21].

Eligibility criteria were designed to be inclusive. Selected settings included time period (all years to 1 January 2020), peer-reviewed English speaking, empirical papers. To explore a wide and occupational therapy-focused range of literature, five databases were selected. These were Web of Science, CINAHL, PsycINFO, OTDBase, and OTseeker. In addition, reference lists and citations of the identified key papers were hand searched. A search strategy was developed by the research team and supported by a specialist librarian. Search terms were as follows: sensory processing OR sensory integration AND parent# OR famil# OR child# AND intervention OR treatment OR therapy OR coaching. Inclusion criteria were parents of children [22] with sensory processing or sensory integration difficulties and parent-focused coaching intervention. Papers were excluded if programs taught the parents an intervention to be applied to the child, e.g., Qi Gong massage [23], as the focus of this review is coaching. Screening and eligibility were undertaken by authors 1 and 4. Level of evidence was identified using Oxford Center for Evidence-Based Medicine Levels of Evidence [24]. Data was charted by two authors using McMaster University's Critical Review Form for Quantitative Studies [25]. This form consists of eight sections (study purpose, literature, design, sample, outcomes, intervention, results, and conclusions or clinical implications), which included questions that prompt the evaluation of the quality of the study.

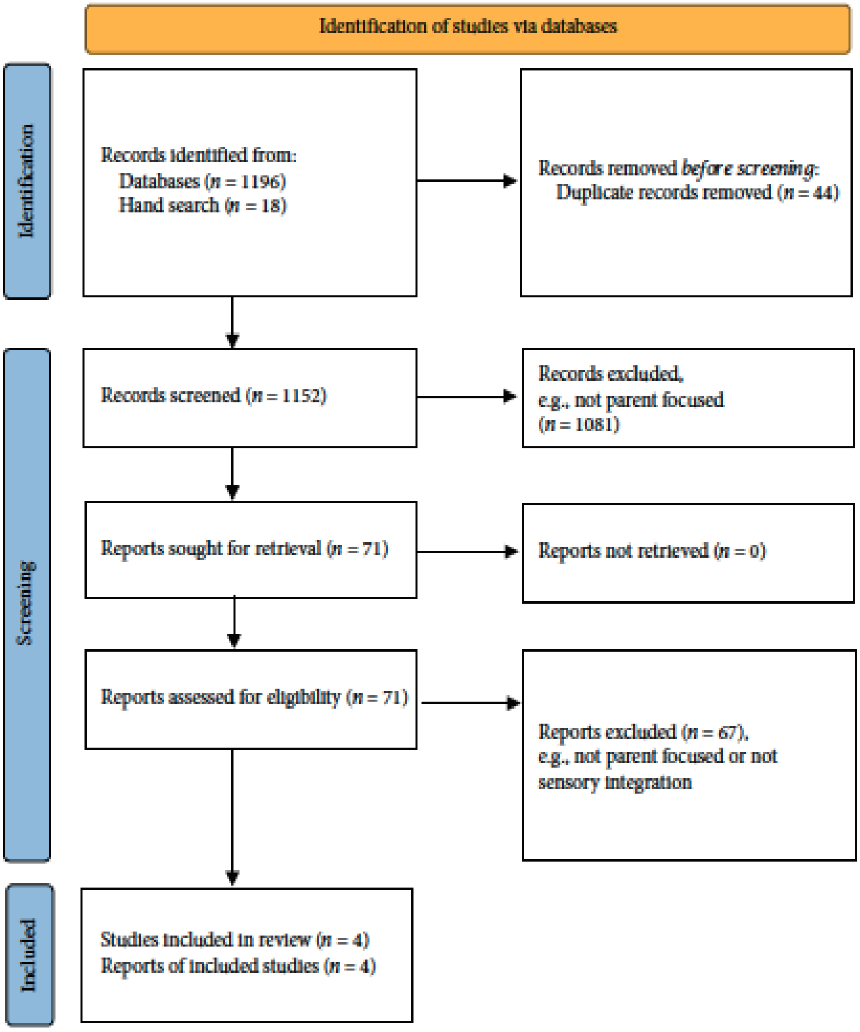

Figure 1: PRISMA 2020 flow diagram. Systematic review of interventions for parents of children with sensory processing and integration difficulties.

3. Results

As indicated in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram (Figure 1) [26], 1196 articles were identified from the databases and a further 18 from hand searches. Following the removal of duplicates, 1152 articles were screened by title and abstract. Seventy-one papers were read in full, to determine relevance to the research questions; of these, four studies met all inclusion criteria, cross-checked by the second author. Table 1 provides a summary of the final four papers.

3.1. What Do These Four Studies Tell Us?

The four studies each used, at least in part, a coaching or problem-solving approach to support parents in developing skills to better manage their children, all of whom had autistic spectrum disorders and sensory integration challenges that caused disruption to daily activities. Three of the four studies were based at home, school, or an environment selected by parents supporting a naturalistic setting. All four studies reported improvements in child behavior or parent knowledge and self-efficacy. Three of the four studies supported parents in their own goal setting. Once the studies started, three studies identified that no dropouts were reported in any of the interventions. Study design was highly variable with evidence between levels 4 and 2 [24]. Participants, when reported, were generally of a higher level of education than the general population. Sample sizes were small, increasing the risk of low generalizability and type II error (failure to reject a false null hypothesis). Follow-up was limited or missing. Demonstration of fidelity to a manualized intervention is present in at least three of the four studies. In the following section, each study is briefly described and appraised in turn; after which, the findings and application to practice are discussed to identify gaps and key areas for future research.

3.1.1. Study 1.

Bulkeley et al. [27] aimed to explore the hypothesis that mothers will better manage their child's behavior challenges in the context of daily routines following intervention. Participants were recruited through two child

TABLE 1: Summary of papers.

Authors	Design	LoE* (20)	Sample	Format and environment	Frequency, intensity, and duration	Approach	Outcome measures	Results
Bulkeley et al. [27]	Single case experiment design using an ABA protocol	4	$n = 3$ mothers of children with autism; age range 3-5 y Child sensory issues identified through the Infant/Toddler Sensory Profile	Individual family-centered coaching based on principles of sensory integration theory as their initial intervention Environment: home	4 × 1 hour per intervention, 1 week or more apart	Brief family-centered coaching using a sensory-based framework	Visual analogue scale for target individual behaviors (1) Tolerance of the sound of a hairdryer (2) Reduced rigid eating behavior (3) Reduced reckless and dangerous behavior	All three participants showed positive response to sensory-based intervention. Maintenance of gains was evident in only one case.
Dunn et al. [30]	Repeated measure pretest/posttest (1) Baseline (2) Preintervention (3) Postintervention (4) 4-week follow-up	3	Individual family intervention; $n = 20$ (19 mothers, and one father) of children with autism spectrum disorders; age range 3-10 y Child sensory issues reported through Sensory Profile [32]	Individual family-centered coaching The intervention reflected principles of context therapy Environment: a location of their choosing, in person or via telehealth	10 × 1-hour weekly sessions with some flexibility to meet scheduling needs	Coaching in family context within daily routines informed by the child's sensory patterns	(1) Individual goals: Canadian Occupational Performance Measure (COPM); Goal Attainment Scaling (GAS); e.g., dressing, eating, having injections, riding in car, and transitioning for bus to home (2) Parent Stress Index-Short Form (PSI-SF) (3) Parent Sense of Competence Scale (PSOC)	(1) Individualized COPM and GAS goals demonstrated a significant improvement between pretest and posttest, sustained at 4-week follow-up (2) PSI-SF: significant improvement in parental defensiveness and parental distress from measurement 1 to 4 (3) Significant increase in parent sense of efficacy from first to last assessment?
Gee and Peterson [34]	Pretest-posttest (1) Week 1 (2) Week 6	3	$n = 7$ parents, $n = 3$ teachers of children on the autism spectrum; age range 5 to 10 years Child sensory issues reported by parent or through child Short Sensory Profile [53]	Group intervention Environment: conference room in a college campus	6 × 1 hour per week 6 weeks	Education Weeks 1–5: promoting parent's knowledge Week 6: promoting problem-solving (A SECRET [54])	Adapted parent completed questionnaires on (1) Self-perceived knowledge of sensory processing concepts (2) Actual knowledge of sensory processing concepts (3) Self-rated competency for dealing with children exhibiting behaviors related to sensory processing disturbances and/or disorders	(1) Significant increase in self-perceived knowledge (2) Significant increase in actual knowledge (3) Significant increase in confidence and satisfaction in own ability to handle child's behavior; no significant change in belief that ability to deal with sensory-related behaviors had a positive impact

Table 1: Continued.

Authors	Design	LoE* (20)	Sample	Format and environment	Frequency, intensity, and duration	Approach	Outcome measures	Results
Pashazadeh et al. [36]	Randomized control trial	2	Parents of children diagnosed with autistic spectrum disorder with at least one sensory pattern outside the typical range as measured by Short Sensory Profile II [55]; $n = 15$ intervention group, $n = 16$ wait list control group	Group sessions plus individual coaching sessions Environment: rehabilitation center	2 sessions of group training sessions plus 10 × 45-minute weekly individual session	Three treatment characteristics (1) Sensory processing knowledge (2) Coaching (3) Social support	(1) COPM (2) GAS (3) Parent sense of efficacy measure	(1) Significant increases in child participation, performance/satisfaction, and individualized goal attainment for the intervention group as compared to the control group, sustained at 4 weeks of follow-up (2) Significant increase in the intervention group of parent self-efficacy from pre- to postintervention, maintained at 4 weeks

LoE*: levels of evidence.

development centers and screened for eligibility for a larger study and then randomly allocated to this intervention. The intervention used a family-centered approach to coaching, based on the principles of sensory integration theory, involving five components adapted from Anzalone and Williamson [28]. These components were observing and reframing sensory processing challenges in context, modifying the environment, modifying the activity, managing the activity, and promoting agency in the child in response to a sensory challenge. Participants were mothers of three children aged three to five, with autism and atypical sensory processing that impacted on behavior and daily routines. Using experimental single case studies with an A-B-A design, the study examined changes in child behavior based on individualized goals selected by the mothers. During the baseline phase (A), mothers rated their perception of the child's target behavior each day using a visual analogue scale (VAS) modified specifically for this study. Following the baseline phase, each mother worked with an occupational therapist for four, hour-long sessions approximately a week apart (B). Mothers completed VAS daily to report their rated perception of the child's targeted behavior. Following the intervention, the baseline phase (A) was repeated without the support of an occupational therapist. Data were graphed and inspected visually, supported by descriptive visual analysis using the median and range of VAS. Improved maternal ratings of child's behavior were observed between the baseline and the end of the intervention phase for all three children; however, improvements were only maintained for one child during the final return to the baseline phase. Strengths of this study include the use of the Infant/Toddler Sensory Profile [29], a standardized tool to identify sensory challenges, supporting the definition of the population being studied. Strategies to support adherence to the intervention protocol or fidelity were described including the use of a checklist against audio recordings of intervention sessions. Finally, the structured use of A-B-A design enabled the isolation of one behavior for measurement demonstrating changes in this small cohort. The primary limitation was the variability in child behavior before the start of the intervention phase.

3.1.2. Study 2. The goal of Dunn et al.'s study [30] was to explore the hypothesis that a contextual occupational therapy intervention delivered individually to families would increase child participation and parent sense of competence to support positive child and family outcomes. Context therapy is an intervention approach that focuses on changing the characteristics of the task and/or environment, rather than the child's impairment, as described by Darrah et al. [31]. The intervention contained three elements: activity settings, daily life routines, and sensory processing patterns. Participants were parents of children with autism, atypical sensory patterns, and self-reported unmet needs in their family life. Working with twenty parents (mother $n = 19$, father $n = 1$), using a pretest/posttest follow-up design, the study examined changes in child behavior (based on individualized goals) and parent competence (based on standardized parent reports of sense of competence and stress). Data were gathered at four time points: four weeks prior to the intervention, at the start of the intervention, at the completion of the ten one-hour sessions of contextual intervention, and, finally, at four weeks' follow-up. Significant improvements in individual self-care, productivity, leisure, and desired behavior goals were reported from pre- to postintervention, which were sustained at follow-up. Post hoc analysis revealed significant differences, with large effect sizes between preintervention and postintervention as well as preintervention to follow-up for individualized child participation goals. In addition, parental defensive (underreporting of difficulties) responding and sense of competence improved significantly from prebaseline to follow-up. Total parental distress demonstrated clinically significant improvement between baseline and follow-up. Strengths included the use of a standardized measure of sensory difficulties, i.e., the Sensory Profile [32], staff training, and a similar manualized procedure reported in a subsequent publication [33].

3.1.3. Study 3. The goal of Gee and Peterson's study [34] was to explore the effectiveness of caregiver psychoeducation groups in increasing the caregiver's perceived and actual knowledge of sensory processing difficulties and their perceived competency in managing the sensory-related behaviors of children with autism. The sample was primarily parents but also included some school staff. The intervention was based on the work of Bailer and Miller [35] and consisted of five sessions of instructional content with one final session focused on a reasoning approach for addressing challenging behaviors related to sensory processing as outlined by Bailer and Miller [35]. No written manual or measurement of fidelity was reported. Outcome measures of parent perceived knowledge, actual knowledge, and self-perceived competence were adapted from previously designed parent survey questionnaires and which demonstrated face validity. A pretest/-posttest design was used to measure change between the first and last sessions of intervention. Actual and perceived knowledge of caregivers improved significantly, as did confidence, satisfaction, and feelings of being in control of sensory-related behaviors. However, parents' perception that they possessed the necessary skills to positively manage their child's behavior did not change significantly. Limitations included there being no measure of the child's sensory challenges, limited evidence of the reliability or validity of the study's measurement tools, lack of detail to support replication, and no follow-up.

3.1.4. Study 4. Pashazadeh et al. [36] aimed to identify if Contextual Intervention Adapted for Autism Spectrum Disorder (CI-ASD) promotes child participation in family activities and routines and promotes parenting sense of efficacy. In addition, in Pashazadeh et al.'s study [36], intervention acceptability and participation were explored. The sample was recruited from two rehabilitation centers in Tehran. Parents were randomly allocated to an intervention or wait list control group. Intervention was reported to be based on a wide range of coaching approaches [37–39]. Key characteristics of the intervention are described as (1) sensory processing knowledge, (2) coaching, and (3) social support. No measure of fidelity was reported, but future publication of theoretical underpinnings of the intervention and how the contextual intervention was adapted for this population was reported to be in print. The authors kindly shared the intervention protocol. Data were gathered at three time points: prior to the intervention, at completion of two group and ten one-hour sessions of contextual intervention, and, finally, at four weeks' follow-up. Both the intervention and control groups demonstrated positive changes in individualized participation and functional goals, with statistically significant greater gains in the intervention group between pre- and postintervention and in postintervention to follow-up. Parent self-efficacy was significantly higher in the intervention group versus the control group both at postintervention and follow-up. Attrition was low with 89% of the parents completing the intervention protocol. A treatment acceptability questionnaire demonstrated that most participating parents rated the intervention acceptability as high. Limitations were that the assessment was not blinded and follow-up was short.

4. Discussion

This scoping review has identified preliminary but positive findings on the impact of coaching parents of children with sensory integration difficulties. Improved outcomes were observed in child functional skills and behavior as well as parent sense of competence and reduced parent stress. Where measured, the acceptability of one-to-one coaching intervention was reported to be high. However, there are a number of threats to the validity of these findings. Each study took different approaches to the intervention with variety in approach and dosage. It is not therefore possible at this stage to pool data for analysis or to compare the effectiveness of approaches. Only one study used a control group, while the other studies used single case or single cohort designs. Without comparison or further controlled trials, we cannot be confident that the changes did not occur by other mechanisms. Follow-up was either not present or of short duration. Parent and child changes occurred, but we do not have demonstrable evidence that the impact is maintained over more than 4 weeks post intervention.

Transferability of the findings is limited by small underpowered samples, volunteer participants across limited social economic status groups and educational levels. Additionally, all children were reported to have a comorbid diagnosis of autistic spectrum disorder. While a high proportion of children with autistic spectrum disorders experience sensory integration difficulties, not all children with sensory integration difficulties have autistic spectrum disorders [40]. Therefore, we have no evidence as yet that this approach could be applied to a wider cohort of parents of children with sensory integration difficulties that impact participation and function in everyday life.

4.1. Points for Practice. Given the preliminary nature of the use of coaching approaches with parents of children with sensory integration difficulties, it is unsurprising that the content of the intervention and ways of working differed. All studies identified the need for shared problem-solving. Information sharing was a component of each of the studies either as a taught component or as a tool for activity analysis and reframing behavior. It is not possible to identify the active ingredients from this review. However, Pashazadeh et al. [36] identified four guiding principles as follows: to situate coaching in everyday life, to seek understanding by working collaboratively with the client, to foster clients' deep thinking about their own life, and to explore resources with clients. Pashazadeh et al. [36] then go on to specify what does and does not constitute Occupational Performance Coaching (OPC). If we consider wider evidence within occupational therapy on Occupational Performance Coaching, the work of Graham et al. [41] provides an alternative detailed description of Occupational Performance Coaching (OPC). They identified three enabling domains of OPC (emotional support, information exchange, and a structured process) and applied techniques of collaborative performance analysis, questioning, listening, observing, modeling, explaining, and in vivo coaching to assist mothers in identifying strategies that support their child's performance. Graham et al. [42] demonstrated preliminary evidence supporting the effectiveness of OPC in improving child and mother occupational performance and mother parenting self-competence in families of children with occupational performance concerns. More recently, Bundy and Bulkeley [43] have expanded the original work of Rush and Sheldon [38] to identify the coaching process as joint planning, action, observation, reflection, and feedback with the addition of reframing (behavior). Robust fidelity to a manualized intervention is key to replicability and evaluating future research.

The goal of occupational therapy is to support participation in daily occupations, and indeed, recent frameworks [17] suggest that the best starting point for an intervention might be goals that focus on participation in a family routine or occupation rather than on behavior. In Bulkeley et al.'s study [27], all child behavioral goals improved, but these improvements were not sustained in two of the three cases following the intervention. While this might stem from the brevity of the intervention with only 4 sessions, the authors suggested that sensory strategies may become embedded more easily in family routines if the goal is focused on increased participation rather than on behavior.

The utility of family participation-based goal setting was demonstrated by Dunn et al. [30] who reported increased participation both at home (e.g., dressing and play) and within the community (e.g., grocery shopping) according to family set goals. Goal setting appears to be an important part of the coaching process. In terms of problem-solving, strategies goal setting helps parents to perceive that they have control and supports change [44, 45]. This empowers parents to be agents of change within their own families [46]. However, goals alone may not be enough, as habits and the environment can act as a barrier to change [47].

There is a need to consider the wider social context or how the social network around the family acts as a barrier or facilitator to potential change. Interestingly, Gee and Peterson [34] involved teachers widening the scope of engagement in intervention for the child and family. There is no evidence from these papers, but other papers consider parent training support engagement with a wider social network [48]. While we can change knowledge and/or intention, this needs to be supported by the empowerment of the individual and their (social) environment in order for that knowledge or intention to be applied to everyday life.

The high attendance rate reported in all studies reviewed is notable (89 to 100%), in comparison with behavioral parent training studies which report attendance ranging from 37% to 98% (mean attendance of 73%) [49]. This may reflect the selective nature of the research samples or a significant level of motivation among parents of children with sensory integration difficulties to engage with intervention opportunities. Pashazadeh et al.'s study [36] explored engagement by identifying the acceptability of the intervention to participants. High acceptability further supports the value of this coaching approach to parents.

The papers reviewed considered both group and individual approaches. It is difficult to compare the impact of group versus individual intervention in this context due to the lack of detail of content and variety in dosage of interventions. While individual intervention allows focus on family-centered goals, there are advantages of a group intervention in terms of access to peers and social support networks. Group parent intervention may be more readily available in resource-restricted contexts. Wymbs et al. [50] surveyed parents of children with ADHD and found that 85% choose group intervention over paper information. A further study that considered group and follow-up individual parent intervention for parents of children with autistic spectrum conditions supported the social validity of the group-based approach [51]. However, the message from both papers was that the group intervention did not substitute the need for direct one-to-one intervention for the parent or child.

Three studies explored intervention in home, school, or parent-selected setting away from home and one study was based in a clinic environment. The move towards intervention in a more naturalistic environment reduces the demands for time, travel, and finance on families who are already experiencing additional demands and is advocated in the wider occupational therapy literature [31]. Interventions varied in length from four to ten hours for individual coaching and six hours for group parent/teacher training. Bulkeley et al. [27] suggest that a longer period of intervention may be required to sustain changes postintervention than the 4 hours of intervention in their study. Indeed, Vismara et al. [52] found that parents acquired strategies by the fifth to sixth hour of a 12-hour group-based education program for parents of autistic children. This would suggest that four hours of intervention may be too little to support sustained changes, while six hours plus may be more effective in facilitating longer term strategies, but this assertion has not been tested with parents of children with sensory integration difficulties.

4.2. Limitations. From the perspective of the studies reviewed, there are a number of limitations. Most of the studies rely on volunteers which may limit the generalizability of findings. Sample size for the combined studies remains small. Data collection was either parent led or therapist led and nonblinded. Findings are limited by the lack of control in three of the four studies. Methods of data collection varied, although three of the four studies considered goals that were individualized to the child or family. From the perspective of the scoping review, there are also a number of limitations. Due to the variety of approaches to intervention, it is not possible at this point to compare or combine data from these articles. As a scoping review, this paper provides an initial mapping of the information currently available.

4.3. Gaps in the Literature and Areas for Further Research. All studies reviewed identified the need for further research in this area. Three of the four studies incorporated an element of parent goal setting enabling parents to identify and address parents' own agenda. However, parents were not invited to indicate their own preferences in terms of support delivery. Identification of what support parents do or do not value provides the foundation for meeting parent-identified needs. Do parents want support, and if so, what is their preferred format to receive it?

Design of interventions was based on coaching literature and sensory integration knowledge and understanding. It is difficult to identify from the current studies which aspect promotes change in child or parent outcomes. In order to identify the contribution of each component of intervention, it may be pertinent to consider the impact of sharing information on sensory integration versus only coaching parents without framing within the context of sensory integration concerns. A manual of the intervention is important to demonstrate replicability. Evaluation of consistency between manual of intervention and actual intervention scored by an independent assessor can assure implementation fidelity. Evidence of group parent intervention is scant with only informal measurement of parent knowledge and competence. There is a need to consider the impact of group versus individual intervention. Given the differences in staff costs and the additional benefits of peer support, further investigation of group-based parent coaching might be considered as an area for further exploration.

In measuring outcomes, there is inconsistency. Group-based intervention may have an impact on parent stress and coping alongside child functioning and the wider health outcome of family participation, but this has not yet been explored.

Parent coaching needs to be considered in the context of the range of services available to families [16, 17]. Reynolds et al. [16] see coaching as one piece of multifaceted intervention. This assertion is supported by the findings of Rivard et al. [51] who suggest that parent coaching while children were on a waiting list provide benefits to the child, but may be detrimental to parent stress if child-focused early intervention services are not concurrently available [51]. In contrast, Ashburner et al. [17] suggest coaching as an appropriate starting point alongside universal design approaches. In addition to the evidence base, health economic drivers and context of delivery will influence approaches to service delivery. That is, coaching provides one approach to intervention that may also include, for example, direct intervention to the child or adaption to the environment. At present, we do not have sufficient evidence to comment on whether concurrently using multiple interventions, sequencing a series of interventions, or utilizing a single intervention in isolation best meets the needs of children and their families as no direct comparison studies have been undertaken. At this stage, it is not about one approach to intervention replacing another but understanding what each approach contributes.

Finally, there is little long-term follow-up and application to wider social economic status participants would increase our understanding of the relative merits of a parent coaching intervention.

5. Conclusions

These studies demonstrate that it is possible in families of children with sensory integration difficulties to increase a parent's knowledge and understanding through education but that approaches benefit from a coaching perspective so that the knowledge gained can be applied to everyday life. It is also possible to improve child behavior, reduce parental stress, and increase a parent's sense of competence through parental coaching. Evidence for one-to-one intervention with parents of children with SID is limited but promising. There is scant evidence to support group parent intervention in parents of children with sensory integration difficulties.

Data Availability

The review data used to support the findings of this study are available from the corresponding author upon request.

Conflicts of Interest

The authors declare that they have no competing interest in this research.

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8.5 Published paper: Mother's perspectives: Daily Life When Your Child Has Sensory Differences

Original Article

Mothers' Perspectives: Daily Life When Your Child Has Sensory Differences

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Abstract

A child's sensory processing and sensory integration (SP-SI) differences can be a barrier to participation in daily life for both child and mother. Supporting mothers is advocated for, but little is known about the everyday experiences of these mothers. To gain an understanding of daily life for mothers and their children with SP-SI differences. Qualitative semi-structured interviews with six mothers were analyzed through thematic analysis. Theme 1 described the impact of child SP-SI on daily life, including challenges in occupations across environments, adaptations required, and the lack of knowledge and understanding from social and professional networks. Theme 2 identified what helps: empowering mothers through relationships based on listening, gaining knowledge, and understanding, and adapting the activity and the environment. Mothers report that their child's SP-SI differences impact daily occupations and social relationships. In addition, supportive relationships, adapting activities, and adapting the environment, support participation.

Plain Language Summary

What Is Daily Life Like When You Have a Child With Sensory Processing and Sensory Integration Differences?

To develop a better understanding of everyday life with a child with sensory processing and sensory integration (SP-SI) differences, mothers were asked about their experiences. Six mothers were individually interviewed. They reported challenges to everyday life at home, at school, and in their local communities, for example, sleep, mealtimes, and leisure choices were impacted for both themselves and their child. They faced a lack of understanding from family, friends, and professionals, and had to adjust their activities and routines to accommodate for their child's needs. It helped mothers to be listened to and to interact with other people who had knowledge and understanding of SP-SI differences. It also helped to be able to adjust activities, routines, and their environment to better suit their child's sensory needs.

Keywords

parenting, sensory integration, participation, occupation

Introduction

Sensory processing and sensory integration (SP-SI) differences (Watling et al., 2018), also referred to as sensory differences (Royal College of Occupational Therapists, 2021) impact many aspects of children's participation in everyday activities. Areas affected include play, social participation, activities of daily living, sleep, engagement in learning (Parham & Cosbey, 2019), and shared family occupations (Schaaf et al., 2011). Much of the existing literature focuses on addressing the specific needs of the child, with limited attention paid to the perspective of parents. The focus of this study is the daily life experiences of mothers of children with reported SP-SI differences. Understanding mothers' experiences will help to inform future strategies for supporting mothers in their daily occupation of parenting.

As occupational therapists, our goal is to enable participation in daily occupations in a way that supports the health and well-being of children and their families (Law, 2002). SP-SI differences are one factor impacting participation in daily occupations, such as mealtimes and homework (Ben-Sasson et al., 2013). The complex interaction between the child and family, and their social and cultural context has not been unpacked in the literature. What we do know is that where child SP-SI differences are reported, investigators often view findings through a deficit lens, identifying elevated levels of parent stress and caregiver strain (Kirby

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et al., 2019), along with altered family and social relationships, for example, juggling the needs of siblings (Schaaf et al., 2011). Mothers are frequently blamed for their child's behavior within family and school settings (Chiu, 2013). To shift the narrative and promote participation in daily occupation for children and families following a socioecological perspective (Curtin et al., 2017), a broader understanding of both daily life and the factors that might support mother and child participation is needed.

A number of approaches to working with children with SP-SI differences and their families are available, including environmental adaptation, working directly with the child or working with parents (Reynolds et al., 2017). Individual parent coaching interventions can improve child participation in daily occupations, reduce parental stress, and reinforce a parent's sense of competence (Miller-Kuhaneck & Watling, 2018). Parents report strategies they have developed themselves to help with everyday life, such as controlling their child's sensory environment or maintaining a proactive attitude (Schaaf et al., 2011). Mothers also report the importance of continuing an employment role outside the family home (Dunstan & Griffiths, 2008). However, while we know that mothers of children with SP-SI differences face additional demands to those experienced by other mothers, there are few in-depth explorations of their experiences and the strategies they employ.

Thus, the purpose of this study was to examine the experience of daily life for mothers of children with SP-SI differences. Secondarily, we explored what mothers identify as supportive with regard to the impact of their child's SP-SI differences.

Method

Design

It is acknowledged that a wide range of terminology is used in this field. In light of this, and in keeping with person-centered practice, we have chosen to use the phrase "SP-SI differences" in this article. Mothers are experts in their perception of the impact of their child's SP-SI differences to daily family life. This study uses an inductive approach and qualitative design to understand mothers' perspectives through one-to-one interviews. Participant involvement was guided in line with CONSORT, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Booth et al., 2014) and the National Institute for Health briefing (INVOLVE, 2012). Ethical approval was granted through the University of Reading Research Ethics Committee.

Participants

A purposive community sample (Bowling, 2014) was recruited by convenience through specialist online parent forums in the United Kingdom. No prior contact between researchers and mothers occurred prior to invitation to participate. Inclusion criteria were: mothers who reported SP-SI differences in their children (aged under 19) and resident in the United Kingdom. Exclusion criteria: non-English speakers and, in this exploratory phase, primary carers other than mothers. As an initial exploratory study, a sample size of six or more was identified as appropriate (Braun & Clarke, 2022).

The research team brought a range of backgrounds to this study and all contributed to the study's research design and data collection. The first author is a female occupational therapist with over 30 years of clinical experience and a postgraduate research student with an interest in parent stress, family support and sensory differences. The second author is an occupational psychology academic and researcher with an interest in learning, motivation and performance. The third author is an occupational therapy academic and researcher with over 40 years of experience and a special interest in sensory integration and neuroscience. The fourth author has over 30 years of experience as a clinical psychologist. She is also an academic with a special interest in autism, anxiety and families.

Fifteen mothers expressed initial interest. Seven completed consent forms but one withdrew from interview due to child illness. Table 1 describes demographics. Pseudonyms are used for confidentiality. All mothers described themselves as white with graduate or postgraduate levels of education. Mothers ($N = 6$) were all in their own homes at the time of interview and either alone or with their direct family. Children ($N = 10$) had been identified as having SP-SI differences by a parent, nurse, or occupational therapist. Mean lifetime access in the United Kingdom (Royal College of Occupational Therapists, 2022) to occupational therapy was 8 hours.

Procedure

Following written informed consent, online or telephone interviews were arranged according to each mother's preference. Interviews were conducted prior to the COVID-19 pandemic and guided by the evidence base on qualitative interviewing (Howitt, 2010).

The interview guide of semi-structured questions was developed by the authorship team. The guide was reviewed by two community partner mothers: no changes were suggested. Primary guide questions are given in Table 2. It is acknowledged that it can be difficult to identify whether sensory or primary diagnosis factors drive functional difficulties. Mothers were asked to focus on their child's sensory processing difficulties, rather than difficulties primarily associated with other conditions, such as autism.

Interviews were completed in a single session and their duration varied from 30 to 75 minutes. The first author completed audio recorded interviews. Field notes were taken to support understanding. Probe questions were used as needed

Table 1. Participant and Child Demographic Characteristics.

Characteristics	*N* or *M* (*SD*)
Mother	6
Mothers age	45.5 (7.4) years
Highest educational level	
High school or college	—
Bachelor's degree	1
Master's degree or doctorate	5
Ethnicity—White	6
Employment	
Employed	4
Self employed	1
Unemployed	1
Child with reported SP-SI differences	10
Age	12.2 (3.6) years
Child gender	
Female	6
Male	4
Child diagnoses	
Autistic spectrum condition or awaiting assessment	6
Developmental coordination disorder or dyspraxia	3
Dyslexia	2
Irlen syndrome	2
Specific language Impairment	2
Selective mutism	1
Slow processing speed	1
Anxiety	1
Learning disability	1
School setting	
Specialist	3
Mainstream	7

Note. SP-SI = sensory processing and sensory integration.

Table 2. Primary Guide Questions.

Primary guide questions
a. What is life like for you for you with a child with sensory integration difficulties?
b. How does this impact daily life? That is to say, are there things that you or your children are not able to do in everyday life because of their sensory processing and integration difficulties?
c. What has been useful to you? What has not been useful? What support would you like to have had?

to allow mothers to develop their responses more fully, and interviewees were encouraged to add areas of importance to them if these were not already covered in the interview. Recordings were transcribed blindly by a medical secretary and then checked for accuracy by the first author. One participant requested a copy or her transcript. All documentation was anonymized for confidentiality. The first author carried out all interviews. Participants were aware of the interviewer's occupation and research background, in particular, her interest in mothers' experience of family life when a child has SP-SI differences driven by the goal of service improvement.

Data Analysis

Transcriptions were uploaded by the first author into NVivo12 and analyzed using the six-phase framework of thematic analysis (Braun & Clarke, 2022) process. These phases involve familiarizing yourself with the data set, data coding, initial theme generation, theme defining refining, theme naming, and write up. To support reflexivity (acknowledging the researcher's role), all four researchers considered codes and themes. Coding was latent, with meaning being sought within content. Themes and subthemes were reviewed and refined by all four authors to ensure the thematic structure provided a systematic interpretation of the data (data available on request from first author). Theoretical sampling requires sampling and analysis of data until no new codes are identified and conceptualization is well-developed. The content of the data related closely to the researchers' questions and supported the sample size. Themes were consistent across interviews, although it is acknowledged that in interpreting the meaning of data, it is never possible to reach an absolute endpoint. A journal was collated by the first author, to record reflections on key points of interviews and to document the progression of code and theme development. Two volunteer participants reviewed and provided feedback on a written summary of results.

Quality can be affected by credibility, transferability, dependability, and confirmability. Each of these quality factors was considered as follows (Hannes, 2011). Credibility reflects whether the data represent the views of the participants and was assured by repeated analysis across time and person and by participants checking findings. Transferability evaluates whether findings are transferable to other settings. This was explored by understanding the demographics and context of participants. Dependability evaluates whether the research is logical, traceable, and clearly documented. In this study, it was supported through an audit trail of code and theme development supported by participants' quotes. Finally, confirmability (or the extent to which the findings are grounded in the data) was supported by the description of the theoretical basis and methodological process, along with identification of the researcher's backgrounds.

Results

Initial thematic analysis led to 56 codes which were grouped into four themes. Two further iterations led to the identification of two overarching themes with five subthemes. Findings are described in Table 3. Italicized words are direct quotations from the mothers.

Table 3. Daily Life When Your Child Has SP-SI Differences: Themes, Subthemes, and Description With Example Quotes.

Themes and subthemes	Description	Example quotes
1. The impact on everyday life		
a. Changes in daily occupations	The child's SP-SI differences have an impact on mother's ability to participate in daily occupations	*It can be like walking on eggshells* (Eve) *She has really extreme reactions to self-care. Teeth . . . wash . . . hair . . . .nails it's a fight even having breakfast* (Ceri) *Family days out I just wouldn't do with all three of them. It wouldn't be worth the risk* (Anne)
b. The things we have to do	Choices or actions that mothers have made as a direct consequence of their child or children's SP-SI differences	*Both of the grandmas got concerned and they would try to put a spoonful of food into her mouth, but she never swallowed this food. She would retch, and I decided that I had to put a stop to this because it obviously wasn't helping anything—I just hated it . . .* (Deb) *When we were choosing a house to move to, the criteria really was about how much noise she would be exposed to and things like that . . . Anything to get a good night's sleep* (Anne)
c. A lack of knowledge and understanding	A lack of knowledge or understanding by others about everyday life for a mother of a child with SP-SI differences	*It's the lack of understanding from other parents which is hard* (Bonnie) *I was made to believe that it was all behavioural because I was doing the wrong things as a parent . . . again, and again* (Ceri) *I would have liked a much greater awareness in the professionals including teachers and doctors* (Deb)
2. What helps?		
a. Empowering mothers: An attitude of understanding	Mothers are empowered when they and those who can support them and their child gain knowledge and understanding	*Once you understand a bit of why children are behaving the way that they are, it is much easier to manage.* *Thankfully school is very supportive* *My Mom, she kept backing me . . . she is a kind of lifeline* (Ceri) *I think the only thing about SPD is that it should be education, education, education for everybody . . . Because you need it* (Bonnie) *I found my voice, oh my . . . I didn't stop* (Fiona)
b. Adaptation	Strategies and adaptations to daily life that support their participation in everyday life	*Finding the right toothpaste, that's a game changer* (Fiona). *Soundproofing . . . wooden shutters . . . white noise maker improve it (sleep). . . . In the school holidays we go out every single day* (Anne) *We aim to have one of us here when our daughter comes in . . . It sounds crazy, she forgets to drink . . . I make sure the first thing I do is give her a drink* (Eve)

Note. SP-SI = sensory processing and sensory integration.

Theme 1: The Impact on Everyday Life

This theme describes the experience of daily life for mothers of children with sensory processing differences.

Challenges in Daily Occupation. In the home, sleep, self-care, mealtimes, play, and chores were all identified as areas of challenge, with impacts on both child and mother. Deb shared her experience of both "meltdowns" at mealtimes—both from her and her child—"when (my) anger would come from nowhere." Anne further reflected: "If there's the slightest noise, she's awake and then doesn't go back to sleep. It . . . affects the whole family's mood." Unaddressed sensory needs place additional practical and emotional demands on mothers.

Mothers described the impact of sensory processing differences on their child's role as a student including self-care. Fiona gave the example of her child's difficulty in dealing with the sensory environment of the school toilets, which resulted in him avoiding the facilities all day, then rushing out and urinating outside school. She said: "They didn't see it as a school issue. . .totally as a parenting problem." Bullying was also identified as a problem in the school environment, resulting in a negative impact on social engagement.

Mothers also talked about restrictions to their own social, leisure and work opportunities. Difficulty coping with their child's behavior led to avoidance of participation in community activities. Child safety concerns were highlighted, with a number of children running away from unanticipated or overwhelming sensory stimuli, for example, an ice-cream van (Bonnie) or a busy toy shop: "He put himself in so much danger" (Fiona). Safety was a factor in mothers' decisions to participate or otherwise in shared leisure activities.

The Things We Have to Do. Mothers reflected on the challenges they faced in finding the right environment and/or support for their child. Support struggles ranged from minor (e.g., persuading school to allow a pencil topper) to extreme. One mother said,

> We'd have meltdowns nearly everyday and I feel like we can't live like this. We need to make some changes and I didn't know how. So, I gave up my job. I sold my house and we moved to the coast. (Fiona)

Thus, not only are mothers making significant changes to their child's environment and daily occupations but also to their own.

Additional resources needs were associated with raising a child with SP-SI differences. Parents "spend a fortune" (Eve) as well as time and emotional energy on "letters, reports and phone calls" (Deb). Where a child's SP-SI differences have led to additional care or supervision requirements, mothers reported applying for government financial assistance, for example, Disability Living Allowance (DLA) (Bonnie). Unfortunately, despite meeting the criteria, it can be a challenge to access financial support:

> It took a lot of effort and tears and formal complaint . . . It would have been much better if that kind of support had been more easily available. (Anne)

Mothers report that the impact of increased costs associated with meeting the needs of a child with SP-SI differences are exacerbated by difficulties in sustaining employment outside the home.

A Lack of Knowledge and Understanding. Mothers described their initial struggles to understand why their child was behaving in an atypical manner, before SP-SI differences were identified. Not understanding the reasons for their child's "unusual" behavior left mothers frustrated:

> She'd launch herself onto the sofa with a massive bounce and then her legs would be flying in front of you . . . it's hard to refrain from shouting at the child for being in the way, when you just want a bit of downtime yourself. (Deb)

A lack of knowledge and understanding within family, social and professional networks impact how both mother and child are perceived. Reflecting back on her efforts to explain her child's needs at school, Bonnie said: "It's the lack of understanding that's hard." Deb described both grandmothers' concerns over her child avoiding food, which led to criticism and a breakdown in these relationships. At times, the pattern of broken relationships extends beyond the family. Bonnie shared the experience of a community barbeque organizer who said: "I think it's just naughty boy syndrome." Bonnie's response was to go elsewhere. Explaining, she said: "I just don't want my son to be around (them) 'cos they need education themselves."

Inconsistent levels of knowledge, understanding and empathy from trained professionals were also reported by mothers. Moreover, pathways to identifying SP-SI differences were complex. Frequently, mothers were told their child's behaviors were due to "bad parenting" (Ceri), with both health care and education staff showing a lack of awareness. Deb said: "it's horrible not being believed" and said she reached the point where she felt "so angry at not being listened to . . . that there would be even more delay in getting my child what she needed." The emotional impact on mothers was clearly expressed by Fiona when she said: "I didn't know how to deal with it. I took it personally. I had lots of experts around me that laughed at me whenI suggetsed that there was something not quite right." Both Deb and Eve expressed fears that reports or observations filed by third parties about their child's sensory-related behavior would elicit child-protection concerns. Many mothers indicated that, as a consequence of poor understanding of their child's behaviors, they felt isolated and alone.

Theme 2: What Helps?

This theme explores factors that mothers said they found helpful in everyday life.

Empowering Mothers: An Attitude of Understanding and Support. An understanding and supportive attitude from family, school and the community empowers mothers. Describing the value of being listened to and understood, Deb said: "It was helpful to have an intelligent adult . . . our OT . . . listen to us about our child, take in what we were saying . . .not blanking us."

Ann explained that a sensory profile completed by a nurse practitioner was "The most useful report we had ever read on her" and that it " explained . . .behaviours . . . it was transformative for the whole family." Being heard and understood, and gaining understanding, empower action and choice for mothers.

Mothers advocated for their own "social networks" (Anne) and "teachers" (Deb and Eve) having wider knowledge and understanding of the impact of SP-SI differences. Mothers identified both fathers ("Dads often get overlooked . .he's very good" [Ann]) and grandmothers as key players in providing practical and emotional support to them. "If it wasn't for my mum, I probably would have thought, uh, hang on,uh, I'm a really bad parent. . . she's really supportive." (Ceri)

An attitude of understanding, when it exists, supports valued participation by children with SP-SI differences. Bonnie describes how such an attitude helped her child in his leisure activity: "Thankfully we have an amazing . . .instructor – she gets him completely . . .she will be understanding in terms of what he needs to get in the zone."

When the mother or child's voice is heard, positive learning is gained. Ceri struggled with her daughter's sensory-related issues after school meltdowns. School staff dismissed her concerns until a member of staff saw one such meltdown on the way home from school. After this, Ceri's concerns were validated and her daughter was given a voice.

They actually said, when she left school, that they'd learned a lot from her...to develop their understanding of sensory: (Ceri)

Several mothers took direct action when they did not feel heard. Describing the steps she took, Fiona said: "Complain! . . .nothing changes unless you make those in the right places aware of what's going wrong."

Others actively searched for support and validation for themselves and their children. Bonnie said she felt very alone until she met "up with other parents". Additional resources were cited as helpful, including books, social media groups, online resources, and support groups for parents, children, or teenagers.

When mothers and children are listened to, those around them gain knowledge and understanding. Helping family, friends, community leaders, education, and health care professionals be aware of their own value in supporting the child and the mother can lead to increased participation in everyday life for both.

Adapt. Adaptation of everyday occupations was described as an important way to support participation in daily life. In an unexpected example, mothers made adjustments to their infants' breastfeeding habits to soothe a dysregulated child. "he was constantly (breast)feeding," (Fiona). Often, this increased participation in breastfeeding also served the mother well, providing her with a period of calm. "Breastfeeding . . .gave me a kind of sensory reward . . I cannot imagine how I would have survivied parenting without (it)." (Deb).

Mothers also recognized the importance of adapting their environments, for example by providing a safe but challenging play space where, "you can move or crash about" or by establishing a "sound and light proofing bedroom" (Anne). Some families were able to adapt and tailor their routines to support the child, for example, by seeking out alternatives to homework (Eve). Physical activity was often seen as a key strategy, Anne reported that: "We are . . .an active family . . . we have to be to keep her regulated."

Mothers can sensitively identify the impact of SP-SI differences, but it can remain challenging to adapt the activity or environment sufficiently. Potentially problematic situations are made easier when the parent understands their child's preferences and responds accordingly, for instance, by knowing "what clothes to buy" (Anne). However, the best laid plans can be thwarted by factors that remain difficult, or even impossible, to control, such as the weather. "because of the heat, he could not tolerate clothes, we were housebound" (Fiona). Even in these situations, however, small adaptations can renew the possibility of participation, as one mother discovered when her child's school showed some flexibility toward his sartorial needs. "He's not tolerating school trousers – they're quite lenient and he's allowed to wear towelling shorts" (Fiona).

Access to intense outdoor physical activity was cited as important through either mainstream activities, such as gymnastics or through a specialist provision. Whether active or more relaxation-focused, leisure activities are appreciated by mothers for the value they bring their children with SI-SP differences. However, even when participation is possible and successful, accessing these opportunities brings an additional implications to mothers in terms of time, energy, and financial resources.

Over time, some mothers have been able to identify their child's cues and to adapt an activity through preparation. An example of an area of adaptation was highlighted by Anne, Bonnie, and Fiona who all raised strategies to ensure "safety" in the community. Strategies included control of the sensory qualities of the environment, additional adult support and being able to attend activities at a quieter time (Ann, Bonnie, Fiona).

A successful application for government financial support (e.g., DLA) supports participation. Mothers not only use this funding for safety-related choices but also make decisions about how to spend the money based on what is meaningful to the family. Typical examples of how funds are spent include: additional childcare so the mother can work, fleece bedsheets, adapting toys, additional driving/swimming lessons, and multidisciplinary team meetings. Bonnie said: "I know we get DLA for both of them, and people feel guilty about claiming it, but I don't for one minute because what I do spend the money on (is) these sorts of things."

Activity/environmental adaptation and additional resources, both financial and emotional, provide valuable tools for mothers to support participation in everyday occupations for both of them and their children.

Discussion

In mothers' own voices, this study highlights the pervasive impact on everyday life of a child's SP-SI differences on both the child and their mother. Mothers described their child's SP-SI differences as presenting significant challenges for participation across all areas of occupation, including activities of daily living, work roles, and leisure activities at home, at school, and in the community. However, they also described the creative solutions they had found, including seeking out strong social networks and adapting everyday routines, even when these were at the expense of the mothers' own work and leisure time.

These findings reflect an ecocultural perspective (Bronfenbrenner & Morris, 2006; Llewellyn, 2012) and how the mother and child interact with an environment that can act as a facilitator or a barrier to participation. At a microsystem level, mothers are helped by a supportive family network and the capacity to adapt both their environment and occupation. At an exosytem level, friends, school staff, health care staff, and community leaders with knowledge, understanding, and empathy support participation for both mother and child. At a wider mesosystems level, health, education, and social care policy influence accessibility to care, support, and financial opportunities. Occupational therapists have a role to play in direct intervention with the child and also in providing education to the communities and organizations around the child and family unit.

Everyday Life

A child's SP-SI differences create a barrier to participation in everyday life and increase caregiver strain with a changing pattern over time (Kirby et al., 2019). Our study further identifies the extensive practical and emotional experiences of everyday family life and illustrates the means by which mothers adapt their own occupations from the child's infancy onwards. For example, at home, parents accommodate and adjust activities of daily living, such as dressing, sleep, and mealtimes. Outside the home, mothers negotiate the child's needs at school. They also appear to face additional demands in the identification of, and access to, family leisure activities and in maintaining safety. Disruptions in daily occupations impact an activity and the secondary opportunities linked to it. For instance, shared mealtimes provide time for socialization and communication (Ochs & Shohet, 2006), however, where this occupation causes distress, the opportunity for positive interaction and social development is lost. Identification of such disruptions in daily life gives an opportunity for early intervention.

What Helps?

Empowering Mothers. The experience of mothers in our study highlights how a lack of knowledge and understanding of SP-SI differences by both education and primary health care professionals impacts families. This has two implications. The first reflects an ongoing need to share information and offer education to our health care and education colleagues to facilitate development of knowledge, understanding, and empathy toward families. The second implication is that there are missed opportunities in reducing parental stress and enabling child/family participation in daily occupations. Mothers strongly identified the importance of being listened to and validated. Professionals who do not listen can hinder access to services and limit parents of disabled children in their decision-making capacity (Lundeby & Tossebro, 2008). In our study, mothers articulated the positive impact of an open and respectful dialogue with medical and educational professionals. The importance of listening has been raised at a policy level for autistic individuals in the United Kingdom, with specific focus on sensory sensitivities or overload (Pelicano et al., 2013). Mothers also strongly identified the importance of positive relationships across family, professional, and social networks in facilitating participation in daily activities. Showing respect and listening to individuals and families is at the heart of family-centered practice (Pozniak et al., 2023) and the importance of applying these principles to mothers of children with SP-SI differences is reinforced by the findings of our study.

Mothers in our study spoke of being judged and blamed, and this is reflected in other studies of mothers of children with SP-SI differences (Chiu, 2013) and more widely by parents of children with disability (Pozniak et al., 2023). The expectations placed on mothers act as a social barriers to participation. Conversely, social relationships can act as facilitators to participation. Our study uniquely reported the importance of fathers and grandmothers in providing both emotional and physical support, highlighting the value of developing positive relationships within social networks as an intervention strategy. Worth exploring is the potential of intervention practices that engage the wider family. Alternatively building a friendship/peer networks, such as occupational performance coaching groups (Suja Angelin et al., 2021). Another potential avenue for exploration is text-based communication networks for fathers (Ismael et al., 2018) .

The benefits, for both parents and society, of empowering parents are recognized in a study of parents' experiences of advocating for their autistic child (Boshoff et al., 2016). Adult-learning theory suggests that providing information alone does not elicit change. The value of education with coaching is supported in studies with both individual parents of children with autism (Foster et al., 2013) and teachers of children with self-regulation issues (Hui et al., 2016). Coaching is a promising route to supporting the empowerment of mothers of children with SP-SI differences when these differences are impacting both mother and child's participation in daily occupations.

Adaptation. To support and improve participation, mothers highlighted the need to combine forward planning and adaptation of the environment. Adaptation of the environment has previously been identified to support participation in events, such as a community-based program to enhance access to museums (Silverman & Tyszka, 2017). As is central to occupational therapy practice (American Occupational Therapy Association [AOTA], 2020), the need to adapt the environment is valued by mothers across home, school, and community.

A notable support identified by mothers in this study was breastfeeding as a facilitator of maternal well-being and child self- or co-regulation. In typically developing infants, mother–child touch can reduce a mother's anxiety and improve her child's behavioral and emotional outcomes (Pickles et al., 2016). In infants or mothers themselves (Talcer et al., 2021) who struggle to tolerate touch, typical regulatory strategies, such as hugs may not support co-regulation. The data presented suggest that breastfeeding provided a strategy to some dyads, as a means of both connection and co-regulation.

Mothers continuously adapt their own occupations to support the child, including by applying limitations to their own work roles. In particular, the challenge of supporting a child's education means mothers are forced to reduce their work hours or even resign from employment outside the home.

The ramifications of restricted access to employment and earnings are lifelong. In research on the financial impact on mothers of having an autistic child, it was found that earnings were 56% lower than for mothers of typically developing children (Cidav & Mandall, 2012). In our study, mothers were very clear about the value of additional government funding in supporting parent and child occupations that would otherwise be inaccessible.

Limitations

Recruitment via specialist online parent forums identified mothers who were actively seeking out support or further information on the topic, future clinic-based recruitment may lead to a wider sample. The study focused only on mothers. To represent a wider population of caregivers, it would be necessary to look at all those who carry primary carer or shared carer responsibilities. In this small-scale study, participants were self-selecting and displayed limited social and ethnic diversity. Research with a more diverse populations is indicated. Most of the participants reported that their children had a diagnosis of autistic spectrum disorder. While it is difficult to fully separate the impact of a neurodevelopmental diagnosis from the impact of SP-SI differences, all participants attributed increased burden of care specifically to their child's SP-SI differences.

Conclusion

Mothers report that their child's SP-SI differences impact daily occupations and social relationships. Mothers face additional demands to their parenting role from birth onwards, and advocate for early intervention. They adapt daily activities and their environments to meet the needs of their child and family, with varying levels of success. Mothers report that it is helpful when they and their children are listened to, when there is a supportive social and professional network, and when the activity and environment can be adapted to accommodate the child's sensory needs. This study supports engaging with social and professional networks around the mother and child to promote knowledge and understanding of SP-SI differences and the impact these have across home, school and community settings.

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Supplemental Material

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