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Autistic Parents' Experiences Accessing Parenting Support: A Systematic Review and Meta-synthesis of Qualitative Research

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Abstract

The experiences of autistic adults accessing parenting-related support remain underexplored, particularly in relation to how formal systems shape access and engagement. This qualitative systematic review and meta-synthesis synthesized 12 studies to examine how autistic parents perceive, navigate, and engage with formal parenting supports. Using thematic synthesis, five interrelated themes were identified: (1) judged, dismissed, and misinterpreted as parents; (2) the emotional and practical labor of accessing support; (3) doing it alone: self-reliance, preparation, and emotional cost; (4) service misfit; and (5) when support works: respect, clarity, and autism-informed adaptation. Findings highlight how barriers to parenting support arise through interactions with formal systems, extending prior research on autistic parenting and underscoring the need for rights-based, neurodiversity-affirming, and parent-centric approaches to parenting support, including autism-specific training, co-designed services, and accommodations that reduce burden and foster safe, collaborative partnerships with autistic parents.

Lay Abstract

Many autistic adults are parents, but their experiences getting help with parenting are not well understood. Most parenting programs and services were designed with non-autistic (neurotypical) parents in mind. This can make support feel confusing, overwhelming, or even unsafe for autistic parents, especially when services do not consider sensory needs, communication preferences, or fears about being judged. In this study, we brought together findings from 12 qualitative research articles that shared the voices of autistic parents. We read the parents' own words and the original authors' descriptions, then used a structured approach to identify patterns across the studies. We identified five main ideas. First, many autistic parents felt judged or misunderstood by professionals, who sometimes questioned their parenting ability because of their autism. Second, parents often had to spend a lot of time and energy explaining their needs, pushing for help, and navigating complicated systems. Third, when support was not available, or they did not feel safe, parents often "did it alone," researching and problem-solving by themselves, sometimes at the cost of their own well-being and family enjoyment. Fourth, services often did not fit the needs of autistic parents. Finally, parents also described what good support looks like: clear and honest communication, respect for their expertise, practical help, and professionals who understand autism. Overall, this review shows that systems need to change, not autistic parents. Services should be designed with autistic parents, not just for them, and should recognize parenting as an important and meaningful part of autistic adults' lives.

Keywords

autism, parenting, qualitative research, supports, systematic review

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Introduction

Autism is a neurodevelopmental condition that is present across the lifespan, and many autistic adults become parents. However, despite the increasing recognition of autism across the lifespan (Wright et al., 2016), autistic individuals remain underrepresented in parenting research (Pohl et al., 2020), which has historically framed them primarily as care recipients rather than acknowledging their role as caregivers themselves (Dückert et al., 2023; Hwang & Heslop, 2023; Putnam et al., 2025). This gap extends to a limited understanding of how autistic parents access and experience parenting-related support within formal systems. As the neurodiversity paradigm continues to evolve, it is essential to acknowledge that autistic parents may approach parenting in ways that differ from those of neurotypical parents—not as deficits, but as variations in needs, strengths, and the types of supports that influence parenting experiences and outcomes (Den Houting, 2019; Fletcher-Randle, 2022; Kapp, 2020).

Emerging literature has begun to document both the strengths and challenges of parenting as an autistic person. Autistic parents often describe a strong sense of connection with their children, a commitment to structure and routines, and unique insights into their child's experiences, particularly when the child is also neurodivergent (Fletcher-Randle, 2022; Lockington & Gullon-Scott, 2025; Pohl et al., 2020). At the same time, sensory processing differences, executive functioning demands, social communication challenges, and stigma can present barriers to navigating systems and engaging with conventional parenting support services (Crane et al., 2021; Fletcher-Randle, 2022; Lockington & Gullon-Scott, 2025; Pohl et al., 2020; Thom-Jones et al., 2024). Parenting itself is inherently complex, requiring physical, emotional, and cognitive effort that is influenced by each parent's context and identity. A parent-centric approach, one that affirms the expertise and lived experiences of parents and considers their individual needs in the context of parenting, is essential to ensuring services are supportive, accessible, and meaningful for diverse families, including those headed by autistic individuals (Kapp, 2020; McGrath et al., 2024).

Existing systematic reviews have begun to synthesize the broader experiences of autistic parents across the parenting journey (Thom-Jones et al., 2024) and specifically the experiences of autistic mothers (Lockington & Gullon-Scott, 2025). These reviews highlight important themes related to identity, sensory and communication differences, strengths in parenting, and experiences of being misunderstood, pathologized, or unsupported within broader systems. However, they primarily examine parenting experiences at a general or identity-based level and do not specifically focus on how autistic parents access, navigate, and engage with formal parenting-related support services. As a result, the ways in which systems and services facilitate or hinder parenting participation among autistic individuals remain insufficiently understood. A focused synthesis of parenting-related support is needed to identify service-level barriers and facilitators that shape access, engagement, and participation in parenting roles, and to inform the development of more accessible autism-informed supports for parenting.

Given these gaps, a systematic synthesis of qualitative research is needed to integrate autistic parents' perspectives, identify shared patterns and gaps, and generate implications to guide autism-affirming support practices for parenting. Centering the lived experience is particularly important for understanding how parenting support is accessed and experienced within systems, and for generating practice-relevant insights to inform autism-affirming service design and delivery.

This qualitative systematic review and meta-synthesis aimed to explore what is known about the experiences of autistic parents in accessing and engaging with formal support services specifically related to their parenting roles. By synthesizing first-person perspectives from qualitative studies, this review provides a deeper understanding of both the barriers and facilitators that influence service access and engagement. These findings can inform more inclusive, affirming approaches to parenting support that recognize the diversity of neurodevelopmental needs within families.

Methods

This meta-synthesis is derived from a larger systematic review registered with PROSPERO (https://www.crd.york.ac.uk/PROSPERO/view/CRD42023396592), which explored the experiences of parents with disabilities or long-term health conditions in accessing formal parenting support (Rider et al., 2025). The Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) was followed for the preparation and reporting of the review (Page et al., 2021). As this study was based on published literature, no ethical approval was required.

Search Strategy

The search strategy was developed collaboratively with a research librarian and refined through pilot searches in two databases to identify additional keywords and optimize sensitivity. Given the diffuse nature of the literature, in which formal parenting support was often not the central focus of the studies, we designed the search around three intersecting domains: parenting, disability/long-term health condition, and qualitative research. The search was completed on September 12, 2024, covering MEDLINE, Embase, PsycINFO, Scopus, and CINAHL. An example of the MEDLINE search strategy is available in Appendix 1. An updated search was completed on August 24, 2025 (see Figure 1).

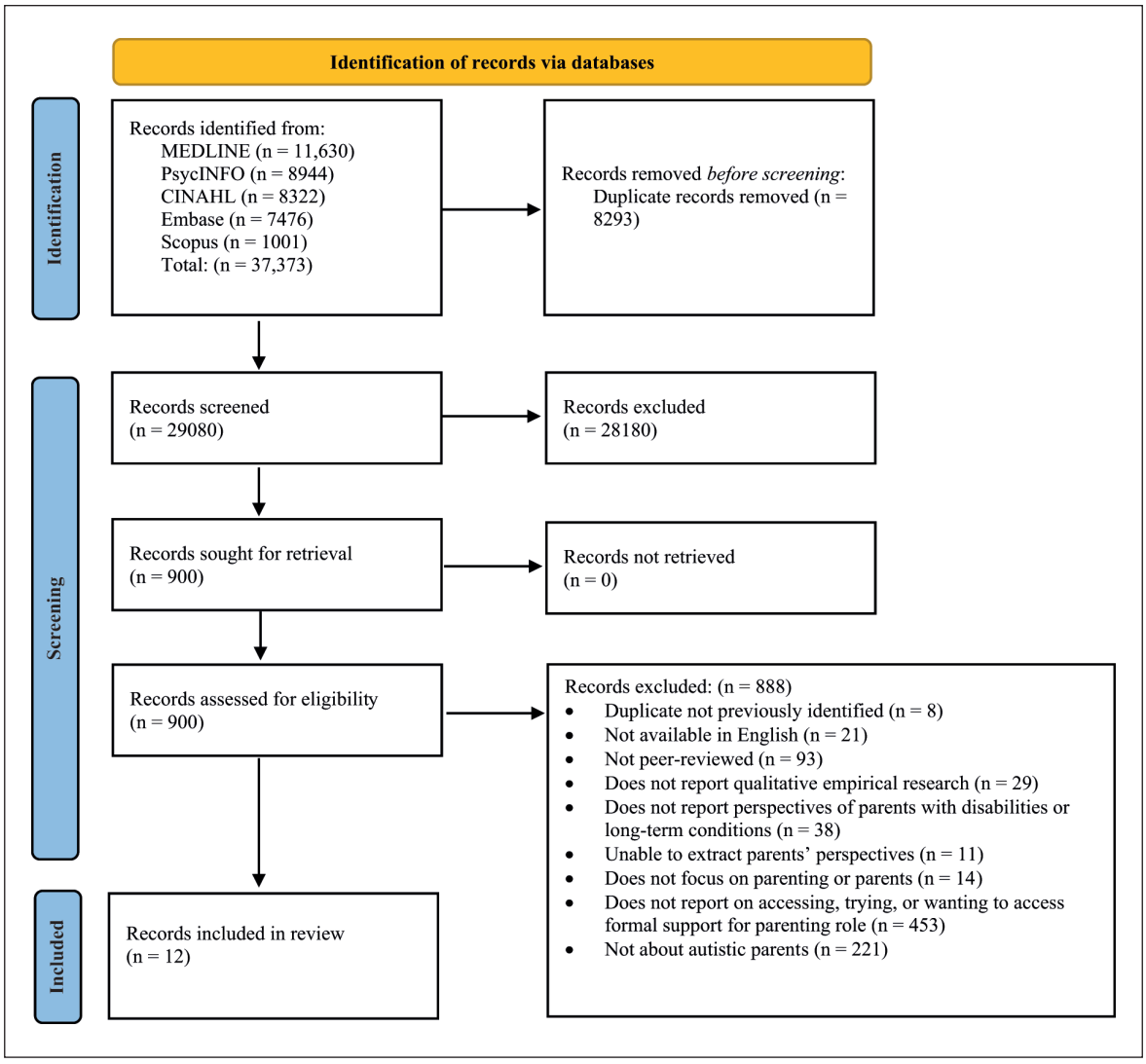


Figure 1. PRISMA Flow Chart.
Source: Page et al. (2021).

Screening and Selection

Search results were imported into Covidence (Covidence Systematic Review Software, Veritas Health Innovation, 2024) for systematic screening. All identified citations were first screened by reviewing titles and abstracts to assess relevance to the inclusion criteria. Articles that appeared eligible were then reviewed in full to determine final inclusion. At each stage, two reviewers independently assessed the studies using the predetermined criteria. Discrepancies were discussed and resolved through consensus.

Inclusion Criteria

Studies were eligible for inclusion if they were peer-reviewed, empirical qualitative research articles published in English, with no restrictions on publication date. Eligible studies focused on parents with a long-term health condition or disability who were caring for children aged 18 years or younger. To be included, studies needed to report on parents' own perspectives and experiences related to seeking, accessing, or needing access to formal support for their parenting role. For this review, formal parenting support was broadly defined as services, programs, or professional interactions delivered through formal healthcare, social care, or community systems to support individuals in their parenting role.

Exclusion Criteria

Studies were excluded if the findings did not clearly distinguish parents' perspectives from those of professionals or other stakeholders. Articles were also excluded if they focused on interventions delivered exclusively within the context of a research study, as these may not reflect typical service experiences. In addition, studies were excluded if

they focused solely on monitoring or surveillance activities (e.g., child protection investigations or statutory safeguarding oversight) without providing supportive services. During screening, this distinction was made based on whether the interaction was primarily evaluative or risk-focused, rather than supportive of the parenting role. Studies were also excluded if they did not clearly distinguish between formal and informal support. For example, informal supports such as assistance from family members, friends, or peer networks were excluded. Finally, studies were excluded if they only included support to parents for concerns not directly related to parenting (e.g., general mental health care or treatment for unrelated health conditions).

From the broader systematic review, data extraction was performed independently by two reviewers using Covidence (Covidence Systematic Review Software, Veritas Health Innovation, 2024). This process included documenting the nature of participants' long-term health conditions or disabilities. Discrepancies were discussed and resolved through consensus. For the current synthesis, only studies involving autistic parents were retained, and only data that conveyed participant perspectives (autistic parents) were included in the analysis.

Quality Appraisal

The methodological quality of the included studies was appraised using the Critical Appraisal Skills Programme (CASP, 2023) Qualitative Checklist, comprising 10 items that assess the strengths and limitations of qualitative research methodology. Each item is rated as "yes," "no," or "can't tell." Two reviewers independently assessed each study, and any discrepancies were resolved through discussion. Consistent with Cochrane guidance (Noyes et al., 2018), an overall score was not calculated; instead, individual item ratings are presented to allow readers to interpret the quality of the included studies.

Data Extraction and Analysis

Data pertaining to autistic parents' experiences with accessing, attempting to access, or identifying a need for formal parenting support were extracted from the results and discussion sections of the included studies. Both first-order constructs (direct quotations from participants) and second-order constructs (authors' interpretations, descriptions, and paraphrased representations of participants' views) were included in the analysis. Particular attention was paid to ensure that only the perspectives of parents themselves were considered, excluding interpretations or assumptions made by researchers or third parties that were not grounded in participant data.

An inductive thematic synthesis approach was employed, following established guidelines for qualitative synthesis (Butler et al., 2016; Thomas & Harden, 2008). Thematic synthesis is a recognized method for systematically integrating findings from individual qualitative studies to generate broader themes and insights that extend beyond those reported in the original research (Hannes & Lockwood, 2011; Thomas & Harden, 2008). Two researchers independently performed line-by-line coding and assigned initial codes based on the concepts represented in the text, including first- and second-order constructs. Initial descriptive codes were then compared across researchers, examined for similarities, and grouped into broader conceptual categories. From these categories, overarching themes were identified to represent patterns and shared meanings across studies. This process enabled us to synthesize individual experiences to answer our review question: "What is known about the experiences of autistic parents in accessing and engaging with formal support services specifically related to their parenting roles?"

Findings

A total of 12 studies were included in the final analysis. Figure 1 depicts the flow of studies into and out of the review. Table 1 summarizes the included studies. Of the included studies, most ($n = 8$) were conducted in the United Kingdom. Where race or ethnicity was reported, participants were predominantly White. Eleven of the studies focused exclusively on mothers, while one included both fathers and mothers.

Methodological Quality

CASP ratings for the included studies are presented in Table 2. Overall, the included studies demonstrated moderate to high methodological quality. Most studies had clearly stated aims, appropriate qualitative designs, and data collection methods aligned with the research questions. Ethical considerations and the value of the research were consistently addressed. However, reporting was less consistent regarding reflexivity and the relationship between researchers and participants, and in some cases, the rigor of data analysis and clarity of findings were insufficiently described.

Five interrelated themes were generated through the thematic synthesis: (1) judged, dismissed, and misinterpreted as parents; (2) the emotional and practical labor of accessing support; (3) doing it alone: self-reliance, preparation, and emotional cost; (4) service misfit; and (5) when support works: respect, clarity, and autism-informed adaptation.

Judged, Dismissed, and Misinterpreted as Parents. Across studies, autistic parents described feeling that their parenting was evaluated through a lens of suspicion and deficit once their diagnosis or difference was known. Encounters with professionals were often experienced as critical rather than collaborative, with parents anticipating that their decisions and behavior would be negatively interpreted. Judgment was not only about specific incidents but about their overall capacity to parent, frequently linked directly to autism.

Table 1. Summary of Included Papers ($n = 12$).

Author/year	Country	Research question/aim	Methods: Design; data collection; analysis	Number of participants in scope	Age range of children
Benson (2023)	United Kingdom	To explore the experiences of autistic mothers who were subject to social work intervention for reasons related to parenting	Constructivist grounded theory; interview; situational analysis	$n = 7$	Not specified
Donovan et al. (2023)	United States	To describe the experiences of autistic women bonding with their newborns after delivery in an acute care setting	Interpretive description; interview; descriptive analysis	$n = 24$	6 months to >20 years
Dugdale et al. (2021)	United Kingdom	To better understand and identify themes related to the experiences of motherhood by autistic women	Phenomenology with a participatory research approach; interview; interpretive phenomenological analysis	$n = 9$	5 to 15 years
Gardner et al. (2016)	United States	To describe the childbearing experiences of eight women with Asperger syndrome	Secondary analysis of qualitative data; unclear; thematic analysis	$n = 8$	Not specified
Grant et al. (2024)	United Kingdom	To understand autistic people's experiences of the maternity period and associated health care	Qualitative; survey; inductive thematic analysis	$n = 152$	2 months to 25 years
Hampton et al. (2022)	United Kingdom	To explore childbirth and postnatal experiences, including healthcare experiences, and the benefits and challenges of parenthood among autistic women	Qualitative; interview; thematic analysis	$n = 21$	2 to 3 months
Hwang & Heslop (2023)	United Kingdom	To explore autistic parents' experiences of parenting and support	Qualitative; focus group; thematic analysis	$n = 7$	4 to 25 years
Radev et al. (2024)	United Kingdom	To investigate the experiences of autistic parents' interactions with statutory services, including education and healthcare, in relation to their autistic children	Phenomenology; interview; interpretative phenomenological analysis	$n = 10$	5 to 17 years
Rogers et al. (2017)	Australia	To explore the particular issues and experiences of birthing women who have autism spectrum disorder, through pregnancy, birth and early mothering	Case study; interview and email exchange; thematic analysis	$n = 1$	0 to 1 year
Sutcliffe-Khan et al. (2024)	United Kingdom	How does being autistic impact women's experience of parenthood?	Mixed methods with a participatory research approach; survey and interview; inductive reflexive thematic analysis	$n = 9$	2 months to 24 years
Talcer et al. (2023)	United Kingdom	To explore the sensory experiences of autistic mothers and investigate if those sensory experiences have any impact on the participant's role as a mother and what the consequences of this may be	Qualitative; interview; thematic analysis	$n = 7$	2 to 22 years
Wilson & Andrassy (2022)	United States	To explore the experiences of autistic women who breastfed	Phenomenology; interview; thematic analysis	$n = 23$	Not specified

Table 2. Critical Appraisal Skills Programme (CASP) Qualitative Checklist Scores for Included Studies ($n = 12$).

Author and year	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Benson (2023)	No	Yes	Can't tell	Yes	Yes	Yes	Yes	Can't tell	No	Valuable
Donovan et al. (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Valuable
Dugdale et al. (2021)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Gardner et al. (2016)	Yes	Yes	Yes	Yes	Can't tell	No	Yes	Can't tell	No	Valuable
Grant et al. (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	No	Valuable
Hampton et al., 2022	Yes	Yes	Can't tell	Yes	Yes	No	Yes	Yes	Yes	Valuable
Hwang & Heslop (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Radev et al. (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Rogers et al. (2017)	Yes	Can't tell	No	No	Yes	No	Yes	Yes	Yes	Valuable
Sutcliffe-Khan et al. (2024)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Talcer et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Wilson & Andrassy (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable

One participant reflected on how asserting parental authority was reframed as pathology, expressing worry that support systems were trying to find reasons to take their child away: ". . . the more I strongly asserted my decisions on how to raise my own child, the more they put my behavior down to some dysfunctional behavior due to Asperger's Syndrome . . . they were questioning my function as an effective parent. I think they were trying to build up a case against me to report us to DOCS (Department of Child Services)" (Rogers et al., 2017).

Others spoke broadly of "feeling misunderstood, judged or dismissed" (Dugdale et al., 2021), describing how their concerns about their children's needs were met with minimization or disbelief, including being constantly pushed away or accused of making stuff up (Dugdale et al., 2021). Differences between internal experience and outward expression created further misunderstandings; participants noted that their feelings or needs and outward expression of these were two very different things, leading professionals to assume they were aggressive or experiencing anxiety when they were upset or needed certainty (Dugdale et al., 2021).

Participants also described explicit prejudice in health and social care encounters: "Prejudice – as an autistic woman and a parent, I find I'm just not taken seriously . . . my legitimate concerns are dismissed or minimised" (Hwang & Heslop, 2023). For some, the risk of being pathologized or mislabeled deterred help-seeking: "You fear that if you speak to the general practitioners (GP) or whoever, or the midwife they're immediately going to go, 'Postnatal depression', (and think you are a) risk for this family or child or whatever" (Talcer et al., 2023).

Others emphasized the impact of being reduced to a diagnostic label: "I would like to see changes from how the process is done . . . not to be judged by your label straight away by professional people. Not all of us are the same and shouldn't be treated the same. Plus, we shouldn't get treated like we are different from any unlabelled parent" (Hwang & Heslop, 2023). Finally, autistic parents of autistic children reported that navigating services for their children was compounded by systemic barriers that also affected them as autistic adults, resulting in layered and ongoing challenges in accessing appropriate support. One parent reported feeling like a "rubbish mum because I feel like we didn't have enough fun" and noticing "much less space for creativity and spontaneity and just joyous stuff" because time was spent "on navigating systems to get the right support and delivering therapy at home, rather than on family life" (Radev et al., 2024).

These accounts show that autistic parents often encounter services as spaces where their parenting is scrutinized and devalued, with autism used to explain away their concerns and capacities. Rather than being treated as legitimate experts on their children and parenting approaches, they are positioned as less credible or inherently risky, which undermines trust and creates a significant barrier to accessing support.

The Emotional and Practical Labor of Accessing Support. Seeking support was often described as a prolonged and exhausting effort rather than a straightforward process. Autistic parents recounted needing to persistently explain, justify, and escalate their needs to obtain even minimal assistance. Advocacy involved emotional labor (managing fear of judgment and preparing for confrontation) and practical labor (gathering information and navigating fragmented systems), often with little payoff.

Several participants described clear requests being rejected: "Sometimes support was denied even when requests were very clear" (Dugdale et al., 2021). "I find I very often get my concerns dismissed," shared one parent (Sutcliffe-Khan et al., 2024). One mother gave a vivid account of repeatedly requesting respite in the context of severe child behavior: "A few times over the years, I called Children Services and said 'Look, I'm desperate for help. I don't know what to do with this kid. Can I have some respite care?' To which the answer is always 'No, you can't have respite care' . . . So I had a breakdown. Because I thought this child is going to kill me one day . . . There's no level of desperation underneath this. This is it. And they're like 'Yeah . . . no'" (Benson, 2023).

Instead of practical support, which mothers say they needed and valued, they were often offered interventions that implicitly located the problem within them: "it just seems like the first port of call is putting the family on a course and then it feels like it's the family who lacks skills" (Benson, 2023).

Parents also described needing to approach appointments in a state of heightened preparedness, which caused a further emotional toll: "You got to be on the ball all the time to get the right support," and they "often attended appointments prepared with facts and research" (Sutcliffe-Khan et al., 2024). System navigation itself was burdensome, with agencies deflecting responsibility: "they just pass us back and forth between teams, blaming the other entity . . . saying, 'Well, they need to deal with it'" (Radev et al., 2024). Repeated dismissals shaped expectations over time: "I'm used to asking for help and being fobbed off" (Hwang & Heslop, 2023). Other parents emphasized how formal support was ineffective, and they had to "teach" professionals how to support their sensory needs, due to a lack of awareness (Talcer et al., 2023).

This theme shows that accessing parenting support requires autistic parents to expend substantial energy advocating within systems that are not designed with them in mind. Rather than relieving burden, services often add to it, leaving parents to fight for what is framed as a limited or discretionary resource and negatively impacting their family life.

Doing It Alone: Self-Reliance, Preparation, and Emotional Cost. In the context of limited or unsafe support, many autistic parents described relying heavily on their own efforts to manage parenting demands. Self-education, preparation, and persistence were prominent, sometimes framed as strengths, but they also carried emotional and relational costs.

Despite wanting formal support, many parents reported not receiving any support for parenting or being provided with information about possible support. "I haven't got anyone. I need supports as my child needs supports . . . I don't know where I can get supports. I have seen no support" (Hwang & Heslop, 2023). Others reported insufficient support, needing to "handle many issues, such as mental health, practical assistance for parenting, and difficulties arising from their disabilities" on their own (Hwang & Heslop, 2023). One parent shared, "I haven't requested any help, as I was told after diagnosis (around 2 years ago) that there was no help available beyond 3 one-hour sessions" (Hwang & Heslop, 2023).

Several participants described engaging in extensive preparation: "Most of the participants read a lot of literature and research to help them prepare for their role as a mother" (Talcer et al., 2023).

"I went literally everywhere to get the information I needed and craved . . . I now have an almost encyclopaedic understanding. But so much support was lacking. I had to seek it out" (Grant et al., 2024). Other parents reported that parenting skills, such as breastfeeding, became areas of hyperfocus, and they spent considerable time researching support (Wilson & Andrassy, 2022).

Parents described determination and a need for control: "I kept with it because that's how my brain is wired . . . once I do I go full force" (Wilson & Andrassy, 2022). "I pushed through without asking for help, I wanted to do so much myself. I stayed with it, I wanted control over it" (Wilson & Andrassy, 2022). However, these efforts did not always translate into emotional ease or positive self-perception. One participant reflected on reading normative parenting books: "They talk about that rush of love and all that sort of stuff, and I just used to think, 'I feel awful'" (Talcer et al., 2023).

This theme underlines that autistic parents are frequently capable, resourceful, and highly motivated, but are left carrying disproportionate responsibility for securing and structuring parenting support, sometimes without any formal support or without the type of support they desire. Their self-reliance is not purely a personal trait; it is often a response to systems that do not reliably recognize or meet their needs.

Service Misfit. Breastfeeding was one of the most common areas for parenting support and emerged as a key context in which autistic parents' sensory profiles, communication preferences, and expectations of consent were at odds with standard care practices. This mismatch often transformed what could be a supportive intervention into a source of distress, shame, or avoidance, even when parents were highly motivated to breastfeed.

Several mothers described intense sensory experiences and pain, including hypersensitivity of their breasts during breastfeeding (Gardner et al., 2016); "I felt sensory overload from being touched all day by my baby and the nurse. I didn't like the nurses touching me" (Wilson & Andrassy, 2022).

Touch without consent or warning was a recurrent issue. One participant noted: "The midwives would physically grab my breast to try and get him to latch. I felt so uncomfortable having her touch me but I didn't feel confident enough to tell them to stop" (Wilson & Andrassy, 2022). Another recalled an incident in which a nurse lifted her shirt to assess the latch without asking for her permission, indicating that this situation occurred frequently (Donovan et al., 2023).

Some women explicitly linked their needs to sensory differences, as in a request for assistance with breastfeeding using direct pressure since the mother found light touch unbearable (Donovan et al., 2023). Yet these sensory reasons were not always recognized as valid by healthcare professionals, with one account noting professionals "not thinking that was a legitimate [reason to struggle with breastfeeding]" (Grant et al., 2024). Parents highlighted challenges such as "the intensity of breastfeeding, the unpredictability of baby's feeding patterns and unpleasant sensations from baby sucking" (Grant et al., 2024).

Breastfeeding thus illustrates how standard perinatal practices, when not adapted for autistic parents, can become barriers rather than supports. At the same time, it demonstrates that relatively small changes, such as asking permission, adjusting proximity, using clear and direct communication, and acknowledging sensory needs, can make breastfeeding support both accessible and enabling.

When Support Works: Respect, Clarity, and Autism-Informed Adaptation. Alongside pervasive challenges, participants described instances where professional support was experienced as genuinely helpful, validating, and enabling. These positive accounts shared common elements: respect for autistic differences, recognition of parents as experts, clear and honest communication, and practical, tailored assistance.

Parents spoke positively about professionals who demonstrated autism-specific understanding: feeling "accepted as the experts" in their own and their children's needs (Dugdale et al., 2021), feeling "validate[d]" or reminded "it's just a different way and it's not necessarily the wrong way" (Dugdale et al., 2021). Supportive attitudes were captured succinctly in one participant's request: "I think we need understanding, acceptance, respect, and nurturing towards us. Don't view us as broken and less, but different. It's a neurological difference . . . Basically, don't assume we are all terrible mothers. It is demeaning" (Wilson & Andrassy, 2022).

When breastfeeding support was autism-informed and respectful, parents described a markedly more positive and effective experience. One parent contrasted two lactation consultants: "I wasn't comfortable with the first lactation consultant. She was sitting too close to me on a couch and made me nervous. Second lactation consultant . . . asked permission to help, helped from in front of me . . . This worked better for me" (Gardner et al., 2016). Others described "really excellent and hands on support," "a great source of information and comfort," and that they "would not have been able to breast feed without this support" (Grant et al., 2024). Community groups and breastfeeding counselors were described as reassuring, informative, and something that kept parents going, although some found "the social aspect of the groups difficult so I didn't attend consistently" (Grant et al., 2024). Mothers felt there was a need for more general breastfeeding training and support and articulated recommendations, such as "using clear and direct communication and making breastfeeding support more accessible" (Grant et al., 2024). One participant shared additional advice, "Being aware of the sensory issues and having plenty of clear, honest advice. I don't want to have things sugarcoated. Tell me if it might hurt, be clear and honest. I am less likely to give up if I know what to expect" (Grant et al., 2024).

Practical, ongoing support was particularly valued. One parent stated: "I would not have been able to breastfeed without this support. She came to my home regularly to help and give advice. I could call her whenever. She was a great source of information and comfort" (Grant et al., 2024). Others described "really excellent and hands on support" and "lots of general support and positioning advice" (Grant et al., 2024), as well as breastfeeding groups with "a breastfeeding councillor and peer support people . . . that's been really useful" (Hampton et al., 2022) and "reassuring" and "informative" groups that "kept me going" (Grant et al., 2024).

Participants also directly articulated how to improve parenting support: a need for staff "having plenty of clear, honest advice," "Being aware of the sensory issues", and using "clear and direct communication" (Grant et al., 2024). Many called for professionals, including midwives, health visitors, and GPs, to have training in "how autism presents" (Dugdale et al., 2021), and for professionals to refrain from judging parents by their autism label (Hwang & Heslop, 2023).

These accounts demonstrate that when professionals approach autistic parents with openness rather than judgment, adapt their communication and physical interactions, and provide consistent practical support, services can become genuinely enabling. Under these conditions, support is experienced not as surveillance or correction, but as a partnership that strengthens parents' capacity to engage in the occupation of parenting.

Discussion

This qualitative meta-synthesis identified five interrelated themes that reflect how autistic parents experience formal parenting support services. Across the studies included, parents described pervasive barriers grounded in stigma, systemic rigidity, and the general absence of autism-informed approaches. While many actively sought support to fulfill their parenting roles, available services were frequently misaligned with their sensory, communication, and practical needs, and in some cases, were perceived as distressing or risky, rather than helpful. Notably, parents also described moments when respectful, individualized, and partnership-based interactions enabled meaningful engagement and reinforced their confidence in parenting. Taken together, these findings reveal a consistent pattern of marginalization and unmet need, underscoring the need for services to transition from deficit-oriented models toward affirming, rights-based, and neurodiversity-aligned systems of support.

These findings extend prior reviews of autistic parenting by centering interactions with formal support systems. Consistent with previous work, challenges appear to arise less from parenting itself and more from how autistic parents are understood and supported within systems (Lockington & Gullon-Scott, 2025; Thom-Jones et al., 2024, 2025). However, the extent to which these patterns reflect the experiences of autistic parents across diverse racial, cultural, and gender identities remains insufficiently understood, as the included studies featured limited racial diversity and included fathers in only one study; a pattern also observed in a prior reviews of autistic parenting (Thom-Jones et al., 2024), highlighting important gaps in the evidence base and directions for future research.

A central theme in this synthesis was the presence of assumptions and judgments from professionals, which often undermined parents' credibility and obscured their actual needs and concerns. Many parents were judged against neurotypical standards of parenting, leading to dismissal, misinterpretation of parenting approaches, or outright denial of support. These experiences are consistent with the concept of epistemic injustice, the dismissal of an individual's account due to bias against their identity, which has been documented in healthcare encounters involving autistic individuals (Corden et al., 2022). In this context, such injustice can carry particularly high stakes when it influences decisions about parenting competence and service eligibility. Similar patterns of dismissal and professional mistrust have been reported in prior research with autistic parents (Lockington & Gullon-Scott, 2025; Thom-Jones et al., 2025).

In tandem with these judgments, parents reported that they had overlooked and unmet needs, even when they had proactively sought help. Requests for practical assistance were often minimized, misdirected, or ignored, leaving

parents to manage complex family and health demands without adequate support. Similar patterns are evident among parents with chronic disease who frequently reported unmet parenting needs, limited access to services, and fragmented care (McGrath et al., 2025). These reports align with prior findings highlighting the lack of access to appropriate support and provision of unsuitable services for autistic parents (Thom-Jones et al., 2025). Importantly, the perceived scrutiny of parenting practices contributed not only to frustration but also to help-seeking avoidance, with some parents withholding concerns or delaying engagement with services to reduce the risk of being judged, misunderstood, or viewed as unsafe caregivers. This may mean that support is accessed only at the point of crisis rather than as proactive prevention, which echoes findings in the broader disability literature, where fears of surveillance, mislabeling, and potential child welfare involvement shape how and when parents engage with services and reflect critiques that services often fail to recognize the legitimacy of parenting needs among disabled adults (Albert & Powell, 2021; Pituch et al., 2022, 2024; Swain & Cameron, 2003).

A critical issue within this synthesis was the apparent lack of autism-informed service design, particularly the absence of individualized adjustments for sensory, cognitive, and communication needs. Breastfeeding is a concentrated and meaningful example of this misalignment. While breastfeeding was one of the most common areas for parenting support, parents described sensory overwhelm, non-consensual touch, difficulty advocating for their needs during feeding support, and environments that intensified distress rather than relieved it. These findings demonstrate how seemingly routine aspects of parental support can become inaccessible when their design assumes neurotypical sensory and communication preferences. This aligns with critiques in the neurodiversity literature, which argue that interventions grounded in neuronormative expectations often fail to account for autistic individuals' lived experiences and values (Den Houting, 2019; Kapp, 2020). To address these persistent gaps, future research should adopt participatory action research approaches that involve autistic parents as collaborators in all phases of the research process (Keating, 2021). Doing so would not only enhance the relevance and accessibility of findings but also validate the expertise of autistic individuals in shaping services that profoundly impact their lives. In general, qualitative research has highlighted major barriers to healthcare for autistic adults, echoing concerns noted in this meta-synthesis surrounding the lack of autism knowledge, services, and consideration of autism-specific needs in treatment (Dückert et al., 2023). A systematic review found that healthcare professionals report only moderate levels of knowledge and self-efficacy regarding autism (Corden et al., 2022), indicating a need for improved training for both students and healthcare professionals.

A further insight from this synthesis is the substantial emotional and practical labor that autistic parents expend in accessing or attempting to access support. Self-reliance was often framed as necessary rather than preferred—an adaptation to systems perceived as unresponsive or potentially punitive. These findings suggest that when healthcare and support systems delegate the responsibility for coordination, communication, and translation of needs back to families, they inadvertently reproduce inequity: Services become most accessible to those already skilled in advocacy and least accessible to those who may benefit the most. This pattern of external barriers alongside internalized strain is also reflected in prior work on autistic parents' experiences (Thom-Jones et al., 2025).

Collectively, these findings suggest a need to re-evaluate how parenting support services are conceptualized, delivered, and evaluated for autistic parents. Services must move beyond deficit-based models and adopt inclusive, accessible, and responsive approaches that reflect the diversity of parenting experiences. This includes providing autism-specific training to professionals (Doherty et al., 2021), involving autistic parents in service co-design, and ensuring accommodations are built into all stages of service delivery. Future research should prioritize the inclusion of racially, culturally, and socioeconomically diverse parents, as well as fathers and non-traditional family structures, to better reflect the heterogeneity of autistic parenting experiences and inform more equitable support systems. A rights-based, neurodiversity-affirming framework is essential to creating systems that recognize autistic parents not as exceptions, but as integral members of the parenting population. Recent work has also emphasized that many of the accommodations autistic individuals need, such as alternative waiting environments or additional time to process and communicate, are feasible and low-cost yet inconsistently implemented across health and social service systems (Mason et al., 2021).

In addition to structural redesign, the findings highlight the importance of relational dimensions of practice, which may be just as important as procedural or environmental accommodations. Autistic parents described positive experiences when care was delivered by consistent providers, with predictable processes and communication that was direct, consent-based, and grounded in respect for parents' expertise in their own lives. A parent-centric approach (McGrath et al., 2024), one that recognizes parenting itself as a meaningful occupation and supports parents' goals, values, and routines, further emphasizes the need to view autistic parents as active agents rather than recipients of prescriptive guidance. Embedding such interactional approaches offers an opportunity to foster psychological safety, increase self-efficacy, and facilitate earlier engagement with support, moving from crisis-driven responses toward proactive partnership. These insights demonstrate that autism-informed care is not limited to specialized programs but encompasses everyday relational practices that

validate lived experiences, reduce uncertainty, and foster trust. Integrating these relational competencies alongside systemic accommodations provides a pathway to transform services from models of surveillance and correction to ones rooted in collaboration, support, dignity, and shared expertise.

Limitations

First, although a comprehensive search strategy was employed, relevant studies may have been missed due to inconsistent terminology and the diffuse nature of the literature on autistic parenting and support services. Second, many included studies did not focus exclusively on parenting support, and relevant data were often limited to specific excerpts or themes. In addition, the prominence of breastfeeding within the findings may reflect the distribution of the existing literature, which has focused heavily on pregnancy and perinatal experiences among autistic parents, rather than its relative importance across domains of parenting support. Finally, the synthesis reflects the perspectives of parents represented in the existing literature, which consists mostly of White mothers, potentially underrepresenting the voices of those who are racially, culturally, or socioeconomically diverse, thereby limiting the transferability of the findings. Autistic fathers were only represented in one of the included studies (Hwang & Heslop, 2023), limiting our understanding of their experiences accessing parenting support.

Conclusion

Autistic parents in this meta-synthesis described navigating parenting support systems that were frequently shaped by stigma, neurotypical norms, and rigid service structures, resulting in experiences of judgment, dismissal, and unmet needs. At the same time, they also articulated clear examples of what meaningful support can look like: relationships characterized by respect, clear and direct communication, consent-based interaction, practical assistance, and recognition of parenting as a central occupation in their lives. Together, these findings call for a shift from deficit-focused, risk-oriented approaches toward rights-based, neurodiversity-affirming, and parent-centric models of support. Such a shift requires autism-specific training for professionals, structural and sensory accommodations, continuity and predictability in care, and genuine involvement of autistic parents in the design, delivery, and evaluation of services.

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Ethical Considerations

This systematic review and meta-synthesis of published research does not require ethics approval.

Author Contributions

John V. Rider: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing.
Anne Honey: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Supervision; Validation; Visualization; Writing – review & editing.
Abigail E. LaVerdure: Formal analysis; Writing – original draft; Writing – review & editing.
Veronica O'Mara: Data curation; Formal analysis; Project administration; Writing – original draft; Writing – review & editing.
Margaret McGrath: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Supervision; Validation; Writing – review & editing.

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Data Availability Statement

All data analyzed in this systematic review and meta-synthesis are available online through the original publications. In addition, the systematic review protocol and detailed search strategies are available at (https://www.crd.york.ac.uk/PROSPERO/view/CRD42023396592).

Positionality Statement

The authors are occupational therapists, including one occupational therapy student (VO). The majority of authors are female (all except JR), and three are parents (JR, AH, MM). Two authors identify as autistic (AL, VO). All authors have clinical experience working with autistic individuals and are engaged in supporting parents through clinical practice and research, which may inform their interpretation of the findings.

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Appendix 1. Search Strategy

Database: Ovid MEDLINE

1 Parents/ (80048)
2 parent*.mp. (556015)
3 Mothers/ (55240)
4 mother*.mp. (279933)
5 Fathers/ (10883)
6 father*.mp. (53527)
7 Single Parent/ (1237)
8 single parent*.mp. (4321)
9 foster parent*.mp. (601)
10 biological parent*.mp. (1490)
11 expectant father*.mp. (321)
12 expectant mother*.mp. (1488)
13 Adolescent Mothers/ (75)
14 adolescent mother*.mp. (1852)
15 Adolescent Fathers/ (1)
16 adolescent father*.mp. (123)
17 disable* parent*.mp. (49)
18 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 (797373)
19 Chronic Disease/ (280510)
20 chronic illness*.mp. (19676)
21 long term condition*.mp. (2591)
22 chronic condition*.mp. (25210)
23 Diabetes Mellitus, Type 1/ (85427)
24 Diabetes Mellitus, Type 2/ (169079)
25 type 1 diabetes.mp. (50371)
26 type 2 diabetes.mp. (164847)
27 Cystic Fibrosis/ (39691)
28 cystic fibrosis.mp. (57404)
29 Cardiovascular Diseases/ (175462)
30 cardiovascular disease*.mp. (322142)
31 Back Pain/ (18907)
32 back pain*.mp. (73667)
33 Hypertension/ (256651)
34 high blood pressure.mp. (17704)
35 low blood pressure.mp. (1795)
36 Asthma/ (138759)
37 asthma*.mp. (201434)
38 Epilepsy/ (84704)
39 epileps*.mp. (165870)
40 Arthritis/ (37094)
41 arthritis.mp. (249953)
42 Musculoskeletal Diseases/ (14993)
43 Musculoskeletal*.mp. (84714)
44 Osteoarthritis/ (43162)

45 Osteoarthritis.mp. (110113)
46 Arthritis, Rheumatoid/ (109383)
47 Rheumatoid arthritis*.mp. (120719)
48 Spinal Cord Injuries/ (43849)
49 Spin* Cord Injur*.mp. (58457)
50 Low Back Pain/ (26405)
51 low* back pain*.mp. (44300)
52 disabled persons/ or amputees/ or persons with mental disabilities/ or mentally ill persons/ or para-athletes/ or persons with hearing impairments/ or visually impaired persons/ (66806)
53 (disab* or handicap* or mental* retard* or development* disabilit* or intellectual disabilit*or learning disabilit*or learning disorder* or cognitive impair* or amputee*).mp. (520912)
54 exp Hearing Disorders/ (96566)
55 (hearing impair*or hearing loss* or hearing disorder*).mp. (15776)
56 exp Intellectual Disability/ (104904)
57 (Intellectual Disabilit* or intellectual disorder* or Cri-du-Chat Syndrome* or down syndrome* or de lange syndrome* or Mental retardation* or Rubinstein?taybi syndrome* or trisomy 13 syndrome* or WAGR syndrome* or Williams Syndrome* or Prader?willi syndrome* or genetic disorder*).mp. (139865)
58 exp Vision Disorders/ (78858)
59 (Vision disorder* or vision impair* or blind* or low vision* or visual disorder*).mp. (450363)
60 Language Development Disorders/ (7259)
61 (language development disorder* or speech disorder* or communication disorder* or communication disabilt* or mutism or deaf* or sign language or Auslan or auditory processing disorder* or speech delay* or language delay* or semantc pragmatic disorder*).mp. (81314)
62 Brain injur*.mp. (110861)
63 exp "Congenital, Hereditary, and Neonatal Diseases and Abnormalities"/ (1361513)
64 (congenital disorder* or neurological disorder* or genetic disorder*).mp. (62567)
65 exp Autism Spectrum Disorder/ (41741)
66 (autism* or autisitc* or kanner* syndrome*).mp. (61466)
67 exp Brain Damage, Chronic/ (40725)
68 (Chronic brain damage* or Cerebral Palsy).mp. (31822)
69 exp Spinal Dysraphism/ (8914)
70 (Spinal dysraphism or Spina bifida*).mp. (12922)
71 neurodivers*.mp. (304)
72 exp Mental Disorders/ (1425190)
73 (Mental disorder* or psych* disorder* or psych* disab* or motor disorder* or neurocognative disorder* or neurodevelopment disorder* or bipolar disorder* or substance related disorder*).mp. (465997)
74 ((Acoustic or Cognitive* or Communication or Developmental* or Ear* or Eye* or Hearing or Intellectual* or Invisible or Language or Learning or Mental* or Mental Health or Mobil* or Motor or Neurodevelopmental* or Neuro-developmental or Neurological* or Physical* or Psychiatric or Psychological* or Psychosocial* or Sensory or Speech or Vision or Visual*) adj1 (Deficienc* or Delay* or Difficult* or Disabilit* or Disabled or Handicap* or Ill* or Impair* or Loss or Retard*)).ti,ab. (442330)
75 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 (5536609)
76 18 and 75 (228528)
77 Qualitative Research/ (80919)
78 qualitative research*.mp. (99888)
79 qualitative stud*.mp. (67620)
80 action research.mp. (5582)
81 thematic.mp. (59025)
82 qualitative data.mp. (23546)
83 key informant*.mp. (10696)
84 grounded theory.mp. (15098)
85 phenomeno*.mp. (280966)
86 lived experience*.mp. (11346)
87 consumer perspective*.mp. (556)
88 service user perspective*.mp. (165)
89 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 (469907)
90 76 and 89 (8467)