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“How are you doing?”: Parental Well-being in Family with Neurodivergent Children: A Systematic Review

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ABSTRACT

Background: Parental well-being is a critical concern for families with neurodivergent children. The term "neurodivergence" will be used in this review as an umbrella term to refer to autism, ADHD, intellectual disabilities, and learning disorders. These conditions impact family dynamics, increasing stress levels and affecting emotional well-being. This review aims to summarize recent findings on the psychological challenges and coping strategies of parents in these families.

Methods: A systematic review was conducted using PRISMA guidelines. PsycINFO, Scopus, and Web of Science databases were searched for studies published between 2014 and 2024, focusing on parental stress, coping, and well-being. 22 articles on autism, 4 articles on ADHD, 2 articles on intellectual disability and 1 article on specific learning disorders were analysed.

Results: A total of 29 studies were reviewed. Findings indicate that parents of neurodivergent children experience elevated stress, especially those with autistic children. Social support and tailored interventions were identified as crucial factors for improving parental well-being.

Conclusions: Parents of neurodivergent children face significant emotional challenges. Targeted support and strategies for coping are necessary to enhance their mental health and overall quality of life.

Keywords: Parental well-being; Neurodivergent children; Systematic review

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Introduction

Parenting is a complex phenomenon that has interested numerous scholars over time. One of the earliest definitions of this concept describes parenting as a set of behaviours, attitudes and practices implemented by parents to promote physical, emotional and social development in their children (Baumrind, 1966). Subsequently, the notion of parenting was further deepened by identifying different parenting styles that influence children's well-being and adjustment, such as authoritarian, permissive and authoritative styles (Maccoby & Martin, 1983). Later, parenting has also been analysed in relation to the challenges and demands of the modern world, such as stress management, work-life balance, and support provided to children with special needs, highlighting the importance of effective coping strategies and appropriate emotional support (Bornstein, 2012; Luthar, 2015). More recently, the term “parenting” was used to define what parents do in terms of raising, supporting, and socializing children (Nomaguchi and Milkie, 2023). Neurodivergence is an extremely multifaceted topic that has been the subject of interest for several scholars over the years. An early definition is the one formulated by Singer in 1999, according to which neurodivergence is a set of natural neurological variations, including autism, attention deficit hyperactivity disorder (ADHD) and dyslexia. Subsequently, the definition of neurodivergence has been broadened to legitimise neurocognitive diversity as an integral part of the human experience, emphasising the need for inclusion to promote the well-being and autonomy of neurodivergent people (Armstrong, 2010). By reconceptualizing neurodiversity as an integral aspect of biodiversity, proponents underscore the imperative of cultivating an ecological society—one that ensures the preservation of neurological minorities through the deliberate construction of ecological niches, thereby accommodating diverse cognitive profiles (Chapman and Botha, 2023). Related to the term “neurodivergence” is that of “neurodiversity”, understood as the natural variety of human neurological functioning, thus including both neurodivergent and neurotypical persons (Bertilsson Rosqvist, Chown, and Stenning, 2020). In a recent literature review (McLennan et al., 2025), the authors analysed 46 studies concerning the definitions and conceptualisations of the term “neurodiversity” and came up with 1 central category, named “Neurodiversity is human diversity”, and 7 key categories to describe this concept. The 7 categories identified by McLennan and colleagues (2025) were: social justice movement;

inseparable aspect of identity; positive notion of difference based on strengths; diversity or difference, not disorder; support should assist, not normalise; the neurodiversity paradigm is aligned with the social model of disability; neurodiversity as a lens through which to understand autism and other neurodivergences. These 7 categories reflect the variability and disagreement among scholars in the definition of the term neurodiversity itself (McLennan et al., 2025). Recent studies have highlighted the importance and necessity of providing adequate support to parents of neurodivergent children to help them manage the emotional burden that this type of parenting entails while also fostering resilience and effective coping strategies (Luthar & Zelazo, 2003). Turnbull (1997) and Kyzar and colleagues (2012) have shown how families who receive adequate social support and have access to therapeutic resources tend to experience a significant improvement in their well-being. This evidence reinforces the idea that an inclusive approach of personalised family support strategies is needed to support not only the well-being of neurodivergent children, but also that of their parents. More recently, Faden, Merdad and Faden (2023) conducted a study whose findings underscore the importance of developing or enhancing support programs and targeted interventions aimed at improving parental well-being, alleviating stress, and fostering stronger, more responsive social support networks for families of children with neurodevelopmental disorders. In summary, investigating the parental well-being of parents with neurodivergent children is crucial not only for the well-being of the children, but also for that of the adults who care for them, thus ensuring a better quality of life for the whole family. This review aims to bring together, systematise and compare studies that have investigated the well-being of parents with neurodivergent children over the past ten years.

Method

For the present review, a literature search was conducted following the guidelines of the PRISMA Statement (Moher et al., 2009). The study was conducted on the PsycINFO, Scopus and Web of Science databases. The keywords used were the following: ‘psychological impact or psychological effect or emotional impact’, ‘neurodivergent children’, ‘parents or caregivers or mother or father or parent’, all linked by the Boolean operator ‘and’ and with a time interval between 2014 and 2024, the year in which the research was conducted. The literature search was conducted in July 2024. This search did not yield any significant results, which is why it was decided to proceed by conducting more searches with a more specific terminology on neurodivergences, replacing the keyword

‘neurodivergent children’ with ‘diagnosis of autism’, ‘diagnosis of ADHD’, ‘diagnosis of intellectual disability’ and ‘diagnosis of specific learning disorders (see specific search strings on Table 1).

Diagnosis	Search string
Autism	“psychological impact or psychological effect or emotional impact” AND “diagnosis of autism” AND “parents or caregivers or mother or father or parent”
ADHD	“psychological impact or psychological effect or emotional impact” AND “diagnosis of adhd” AND “parents or caregivers or mother or father or parent”
Intellectual disability	“psychological impact or psychological effect or emotional impact” AND “diagnosis of intellectual disability” AND “parents or caregivers or mother or father or parent”
Specific learning disorders	“psychological impact or psychological effect or emotional impact” AND “diagnosis of specific learning disorders” AND “parents or caregivers or mother or father or parent”

Table 1. Search Strings for the study selection process.

Articles found on the various databases were analysed by title and abstract. Inclusion criteria: studies in English language, studies about psychological and emotional impact of parents/caregivers of neurodivergent children, wellbeing and stress of parents/caregivers, studies with neurodivergent children who were already diagnosed at the time of the study. Exclusion criteria: studies in languages different from the English one, studies about psychological and emotional impact of other family members of neurodivergent children or adolescents, well-being and stress of other family members, studies with undiagnosed and/or already adult neurodivergent children, studies in the format of a scoping review or dissertation. In the first search, the following key words were used: ‘psychological impact or emotional impact’, ‘diagnosis of autism’, ‘parents or caregivers or mother or father or parent’. All keywords were linked by the Boolean operator ‘and’. On Psycinfo, filters were added: a time period between 2014 and 2024, the English language and that the source type was an academic publication. 9 results emerged, 5 of which were discarded as inconsistent

with the topic being researched, 1 was eliminated as an error-ridden version of another article. 3 records were considered suitable for the purposes of this search. On Scopus, the search yielded 48 results, which were filtered by year of publication (2014 - 2024), lowering the quota to 39. Of these, 1 was discarded as not written in English. The 'Psychology' filter was then applied for the 'Subject area', to keep only the most consistent records, i.e. 18. 1 of these was eliminated as not belonging to the 'article' category of the 'Document type' filter. Of the 17 articles that remained and were screened, 3 were discarded because they were not consistent with the subject being researched; 1 was discarded because it was consistent with the subject being researched, but limited to the period of the Covid-19 pandemic; 2 were discarded because they were in French, despite the fact that the filter was set up for articles in English only (it is thought that it may have remained, as it had an abstract in English) 3 discarded because they talked about the parental experience of parents with children diagnosed with autism and/or other than autism; 2 discarded because they talked about the experience of siblings, but not of parents; 1 discarded because they talked about parental stress of parents with children at risk of autism spectrum disorder. No duplicates were found. For the purposes of this review, 4 articles were considered. On the Web of Science, the search yielded 224 results. These records were skimmed with the following filters: year of publication 2014 - 2024 (204 results), document type 'article' (183 results), Web of science categories 'developmental psychology', 'psychology', 'education special' (81 results), English language (80 results). Out of the 80 remaining records, 7 were discarded because they were duplicates; 42 were discarded because they were inconsistent with the research topic; 1 was discarded because it dealt with the research topic, but only in the circumstances of the Covid – 19 pandemic; 1 was discarded because it was a review; 7 were discarded because they dealt with the psychological/emotional well-being/quality of life of neurodivergent children and not of their parents; 2 were eliminated because they were about the experience of the siblings but not the parents; 1 was eliminated because it spoke of caregivers of adults with disabilities; 3 were eliminated because they spoke of parental well-being/stress of parents with children diagnosed with both autism and non-autism. For the purposes of this research, 16 records were considered suitable.

In the second search, the following keywords were used: 'psychological impact or psychological effect or emotional impact', 'diagnosis of adhd', 'parents or caregivers or mother or father or parent'. All keywords were linked by the Boolean operator 'and'. On Psycinfo, 9 results emerged, which were filtered by year of publication (2014 - 2024), type

of source (academic publication) and English language. From the application of these filters, only one article remained, which was discarded as it dealt with sleep problems in comorbidity with autism and adhd reported by parents. For the purposes of this review, 0 articles were considered suitable. On Scopus, the search produced 27 results. By narrowing the field to articles published between 2014 and 2024, 15 records remained. These results were all in English. The filters 'Psychology' for 'Subject area' and 'article' for 'Document type' were applied, reducing the screening to 3 results. One of these articles was eliminated as it dealt with sleep problems in adhd children reported by parents. For the purposes of this search, 2 records were considered suitable. On the Web of Science, 104 results were found. Restricting the publication period to the interval 2014 - 2024 resulted in 80 records. Of these, the 76 that were article-type documents were retained. To further delimit and specify the search, the following Web of Science categories were included: 'developmental psychology', 'psychology', 'education special', arriving at 22 results. The addition of the English language filter produced no change. Analysing the remaining records, 1 was discarded because it spoke of the work experience of parents of adhd children, 1 was eliminated because it was duplicate; 15 were excluded because they were not consistent with the research topic; 2 were discarded because they spoke of the emotional problems of the children and not of the parents; 1 article was eliminated because it spoke of sleep problems in comorbidity with autism and adhd reported by the parents. For the purposes of this search, 2 records were considered suitable. In the third search, the following keywords were used: 'psychological impact or psychological effect or emotional impact', 'diagnosis of intellectual disability', 'parents or caregivers or mother or father or parent'. All keywords were linked by the Boolean operator 'and'. On Psycinfo, the search produced 3 results. Filtering by year of publication (2014 - 2024, type of source (academic publication) and English language, 2 articles remained. Of these, 1 was eliminated because it talked about caregivers of adult individuals with intellectual disabilities, 1 was discarded because it talked about how the family can influence the adaptive and maladaptive behaviours of children with intellectual disabilities. For the purposes of this search, 0 articles were considered suitable.

On Scopus, 14 results emerged. Of these, 11 had been published in the period of interest (2014 - 2024) and were in English. Of the 11 remaining records, only 4 fell under the 'Subject area - Psychology' and were article-type documents. Of the 4 articles screened for titles and abstracts, 1 was discarded because it discussed the quality of life of adults with

intellectual disabilities and 1 because it was a duplicate. For the purposes of this search, 2 articles were considered suitable. On the Web of Science, 70 records were found. Delimiting the publication period to 2014 - 2024, 59 articles remained. Of these, the 57 that were 'article' type documents were retained. Applying the Web of science categories 'developmental psychology', 'psychology', 'education special', 17 results remained, all in English. Of these, 6 were duplicates and 1 a review, so they were discarded. 6 articles were eliminated because they were inconsistent with the topic being researched; 1 was excluded because it talked about caregivers of adults with disabilities; 2 were discarded because they talked about the impact of the diagnosis of Down syndrome and/or other diagnoses; 1 was eliminated because it talked about a psycho-educational intervention for adolescents with disabilities and their parents, but not about the emotional wellbeing/discomfort of the parents. For the purposes of this research, 0 results were considered suitable. In the fourth and final search, the following keywords were used: 'psychological impact or psychological effect or emotional impact', 'diagnosis of specific learning disorders', 'parents or caregivers or mother or father or parent'. All keywords were linked by the Boolean operator 'and'. No results were found on Psycinfo. On Scopus, 8 results emerged. After delimiting the search to the years 2014 - 2024, the English language, the Subject area 'Psychology' and the documents of type 'article', 3 records remained. Of these, 1 was discarded because it was not consistent with the subject being researched and 2 were excluded because they investigated the emotional experiences of children with specific learning disorders (SLD) and not the parents. None of the results were considered suitable for review. On Web of Science, the search produced 19 results. Entering 2014 - 2024 as the publication period resulted in 14 results, of which only 11 were article-type documents. The search was then delimited and specified by the Web of science categories 'developmental psychology' and 'psychology' (the category 'education special', used in previous searches was not available), down to 4 results, all in English. Of the 4 remaining records, 2 were discarded because they were inconsistent with the topic being researched and 1 because they were duplicate. Only one article was deemed suitable for this review. To summarise, by searching the three databases Psycinfo, Scopus and Web of Science, the following were deemed suitable for the present work 22 articles on parents/caregivers of children with autism (Figures 1, 2, 3, Table 2), 4 articles on parents/caregivers of children with ADHD (Figures 4, 5, 6, Table 3), 2 articles on parents/caregivers of children with intellectual disability (Figures 7, 8, 9, Table 4), 1 article on parents/caregivers of children with LSD (Figures 10, 11, 12, Table 5), for a

total of 29 articles analysed in order to understand the psychological and emotional impact, well-being and stress of parents of children with neurodivergence.

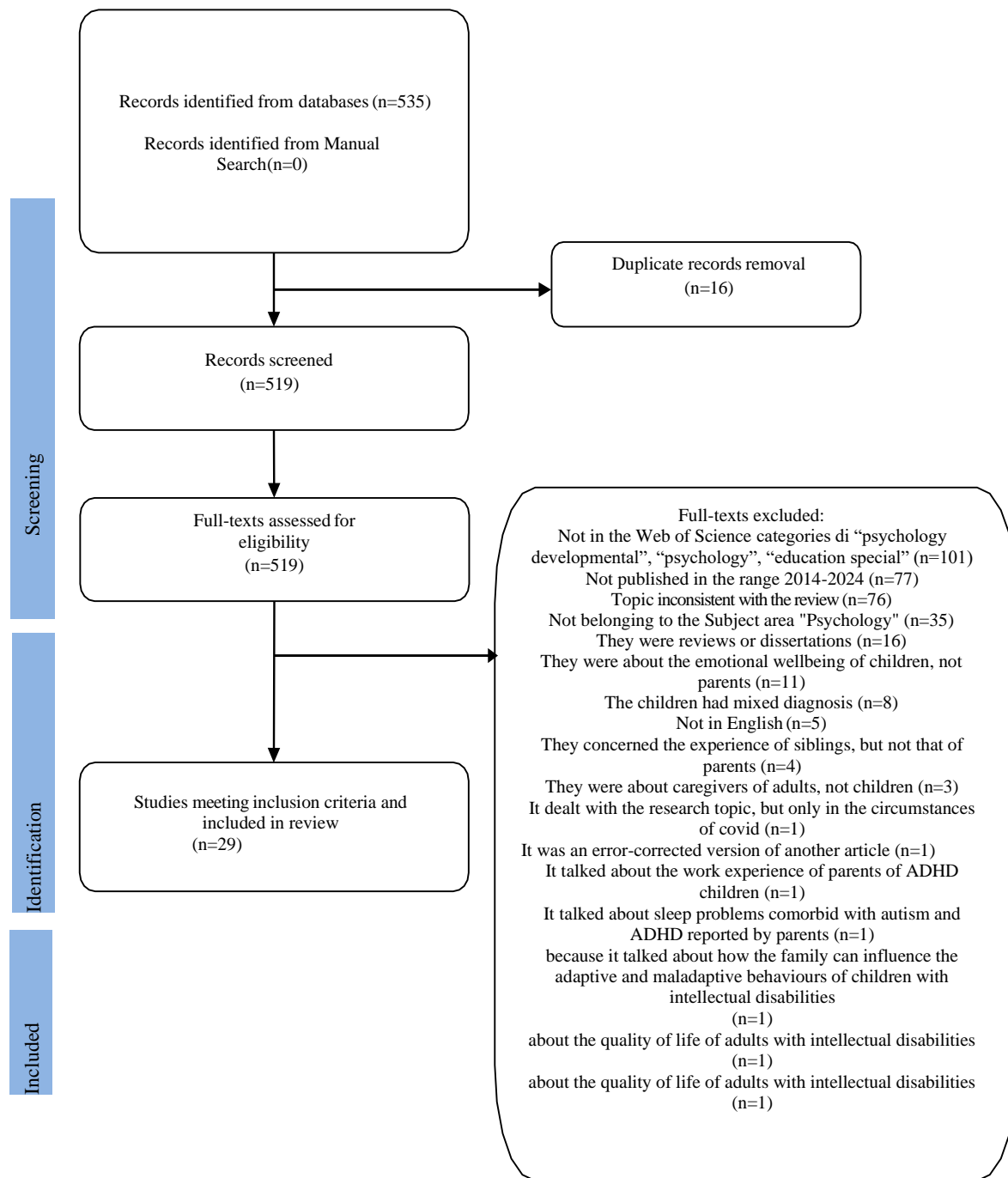


Figure 1. Flow-chart describing the study selection process.

Title, authors, year	Database	Participants	Design	Measures	Results
Parents’ experiences of living with an adolescent diagnosed with an autism spectrum disorder (Mount & Dillon, 2014)	Psycinfo	9 parents of adolescents with autism from a school in the East Midlands (UK)	Qualitative study	Recorded, transcribed, analysed, and coded semi-structured individual interviews using thematic and content analysis to understand	Maintaining a sense of predictability for children was considered a burden for parents. Communication difficulties could lead

					parental stressors.	to outbursts of physical and verbal anger towards parents. Parents reported being mentally and physically tired. Having a diagnosis helped parents work together and accept their children's difficulties.
Death concerns and psychological well-being in mothers of children with autism spectrum disorder (Cox, Eaton, Ekas, & Van Enkevort, 2015)	Scopus	147 mothers, of which 47 with children with autism and 73 with typically developing children	Quantitative experimental design	A word fragment task to measure the accessibility of death-related thoughts (Hayes, Schimel, Arndt, & Faucher, 2010; Schimel et al., 2007) to assess the cognition of death. A 15-item fear of death scale (Conte, Weiner, & Pluchik, 1982) to assess explicit preoccupation with death. II Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988) to measure the mood. The Center for Epidemiologic Studies Depression inventory (CES-D; Devins et al., 1988) to measure depressive symptoms. The State-Trait Anxiety Inventory (STAI; Spielberger et al., 1983) to assess the anxious state.		It was shown that greater accessibility to death-related thoughts was associated with worse psychological health in mothers of children with autism.
Depression in parents of children diagnosed with autism spectrum disorder: A claims-based analysis (Cohrs, & Leslie, 2017)	Web Science	of 42,649 families with one child with autism and 42,649 with typically developing children	Administrative data-driven analytics	The MarketScan® Commercial Claims and Encounters (MarketScan) database, built and maintained by Truven Health.		Mothers and fathers of children with autism were more likely to receive a diagnosis of depression than parents of typically developing children. The odds of depression also increased when there was more than one child with autism in the family and with the age of the child.
Reaction to diagnosis and subsequent health in mothers of children with autism spectrum disorder (Reed, & Osborne, 2019).	Scopus	84 mothers of children with autism	Longitudinal experimental design	The Reaction to Diagnosis Interview (Marvin and Pianta, 1996; Poslawsky et al., 2014) to assess the reaction to the diagnosis. World Health Organization Quality of Life—Brief (WHOQOL-BREF; WHOQOL Group, 1998) to assess		Mothers who had an unresolved reaction to the diagnosis had a worse state of health in terms of perception of physical symptoms at the time of diagnosis and showed a worsening of health levels over the course of a year, compared to mothers who had a resolved reaction to

					<p>participants' perception of their own physique health, psychological health, social relationships and the environment. The General Health Questionnaire -28 (GHI; Goldberg and Hillier, 1979) measures a series of psychiatric and health problems, Immune Functions Questionnaire (IFQ; Reed et al., 2015) assesses the frequency of various symptoms associated with poor immune function. The Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983) is a self-assessment of anxiety and depression levels. The Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2008) is a standardized observation of autism symptoms.</p>	<p>the diagnosis. The results underscore the potential of the diagnostic process to have a negative impact on parental health. This can have negative consequences on the child's prognosis, as well as on the health of the parents.</p>
<p>The role of child problem behaviors in autism spectrum symptoms and parenting stress: A primary school-based study (Siu, Yi, Chan, Chio, Chan, & Mak, 2019).</p>	<p>Web Science</p>	<p>of 177 parents of children with autism and 554 parents of typically developing children</p>	<p>Case-control study</p>	<p>The Childhood Autism Spectrum Test (CAST; Scott et al. 2002) to assess the severity of autistic symptoms by parents; the Strengths and Difficulties Questionnaire (SDQ; Goodman 1997, 2001) to assess externalizing and internalizing behavioural problems and prosocial behaviours; the Parenting Distress subscale of the Parenting Stress Index-Short Form (PSI-SF; Abidin 1995) to assess the level of perceived parental stress.</p>	<p>Although autism spectrum symptoms were positively associated with parental stress, the relationship was mediated by the child's problematic behaviours. The findings suggest that neither the severity of autism spectrum symptoms nor knowledge of the autism diagnosis was a primary source of parenting stress. A hypothetical pathway model of parental stress was tested using structural equation modelling.</p>	
<p>Life after an autism spectrum disorder diagnosis: A comparison of stress and coping profiles of African American and Euro-American caregivers (Williams, Hartmann, Paulson, Raffaele, & Urbano, 2019).</p>	<p>Web Science</p>	<p>of 52 Euro-American families and 51 African-American families</p>	<p>Cross-sectional comparative study</p>	<p>The Parental Perception of the Development of Autism in their Children Questionnaire (GoinKochel et al. 2009) to collect demographic data; the Autism Spectrum Rating Scale (ASRS) Short Form (Goldstein and Naglieri 2010) to assess symptoms</p>	<p>African-American households reported a significantly higher level of stress and used more varied coping strategies than their Euro-American counterparts. Further differences were found between highly and poorly acculturated African-American groups: poorly cultured</p>	

					<p>associated with autism; the Parenting Stress Index, Fourth Edition (PSI-4) Short Form (Abidin 2012) to assess parenting stress; the Autism Parenting Stress Index (APSI; Silva and Schalock, 2012) to assess parenting stress associated with autism characteristics; the Proactive Coping Inventory (PCI) (Greenglass et al. 1999) to assess coping behaviours; the Coping Strategies Inventory-Short Form (CSI-SF; Tobin 2001) to evaluate coping strategies; the Brief RCOPE (Pargament et al., 2000) to evaluate religious behaviours potentially useful as coping strategies; the African American Acculturation Scale-Revised (AAASR; Klonoff and Landrine, 2000) to assess the cultural orientation of African-Americans</p>	<p>African-Americans were more likely to resort to religious coping.</p>
<p>Improving family functioning following diagnosis of ASD: A randomized trial of a parent mentorship program (Moody, Kaiser, Sharp, Kubicek, Rigles, Davis, ... & Rosenberg, 2019).</p>	<p>Web Science</p>	<p>of 33 parents</p>	<p>subjected to the program and 34 parents (from the waiting list) as a control group</p>	<p>Randomized trial</p>	<p>Colorado parent mentoring (CPM) program to provide parents with emotional and informational support immediately after their child's diagnosis, so they could find services that met their family's needs and improve their emotional well-being in the first year after their autism diagnosis.</p>	<p>The intervention improved satisfaction with autism services and prevented rigidity in family functioning. Services used outside of school increased for both groups, but did not reach national recommendations. Participants described the program as highly acceptable and indicated that it improved their emotional well-being.</p>
<p>Psychological characteristics and physiological reactivity to acute stress in mothers of children with autism spectrum disorder (Pattini, Carnevali, Troisi, Matrella, Rollo, Fornari, & Sgoifo, 2019)</p>	<p>Web Science</p>	<p>of 15 mothers of children with autism and 15 mothers of typically developing children</p>		<p>Combination study</p>	<p>Psychometric assessment: Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995) to assess parental stress; STAI (Spielberger & Gorsuch, 1983) to measure the severity of the anxiety trait; the Type D Personality Scale (DS14; Denollet, 2005) to assess the presence of a type D personality. ECG analysis. Salivary cortisol levels were determined by radioimmunoassay.</p>	<p>Mothers of children with autism reported significantly higher levels of parenting stress, anxiety, negative affectivity, social inhibition, and a greater preference for avoidance strategies. Mothers of children with autism showed higher responses in heart rate and cortisol levels during the psychosocial stress test. A positive relationship was found between parental stress levels and the extent of</p>

						cortisol stress response in both groups. The present results indicate an exaggerated physiological reactivity to acute psychosocial stress in mothers of children with autism.
Autism: impact of the diagnosis in the parents (Aguiar & Pondé, 2020)	Psycinfo		21 mothers and 9 fathers of children with autism enrolled in a school for special educational needs in Brazil. 11 mothers and 5 fathers of a university service for the diagnosis of autism	Qualitative study	Narrative approach: semi-structured interviews to understand what parents experience when they receive a diagnosis of their child's autism. Ethnographic observations	The diagnosis of autism is often delayed due to the lack of preparation of doctors. Awareness of one's child's diagnosis has a negative emotional impact on parents, which can be mitigated through coping strategies and communication of the diagnosis that offers technical information, emotional support, and hope regarding the child's development.
Autism spectrum disorder and complex healthcare needs: The role of healthcare experiences (Parker, & Killian, 2020).	Web Science	of	1711 Parents of children with autism	Qualitative study	The severity of autism was measured with the 17th National Survey of Children's Health. Health experiences were measured with a system in which health professionals evaluate the quality of the patient experience compared to the services received (Zablotsky et al., 2014). Parenting stress and parental health were measured with a survey.	Care coordination mediated the relationship between the complexity of autism and parenting. However, family-centred care has significantly predicted that parental stress and health they were not mediators of the relationship between the complexity of autism and parenthood. Shared decision-making was a mediator of parental health, but not of parental stress.
Parenting experiences of fathers of children with autism spectrum disorder with or without intellectual disability (Rafferty, Tidman, & Ekas, 2020)	Web Science	of	12 fathers with children with autism and 16 fathers with children with autism and intellectual disability	Qualitative study	Online questionnaire and telephone interview analysed with the phenomenological approach.	Five main themes emerged. One of the themes that emerged concerned pre-birth expectations, while the remaining themes were related to the post-diagnosis period: adaptations, experiences, co-parenting and the quality of the father-child relationship. Both fathers of a child with autism and those of a child with autism/intellectual disability reported on all topics.
The family adjustment measure: Identifying	Web Science	of	362 parents of children and	Qualitative study	The Family Adjustment Measure	The results suggest that the psychometric

<p>stress in parents of youth with autism (McKee, Liu, Truong, Meinert, Daire, & Mire, 2020)</p>	<p>adolescents with autism</p>	<p>(FAM; Daire et al. 2014) allows the evaluation of the parents' account on four aspects of family adjustment: Parental Distress, Social Support, Family Support and Positive Coping; the Parenting Stress Index-Fourth Edition Short Form (PSI-4-SF; Abidin 2012) was used to estimate FAM threshold scores for the group of parents of children; the Stress Index for Parents of Adolescents (SIPA; Sheras et al. 1998) was used to estimate FAM threshold scores for the adolescent parent group.</p>	<p>properties (i.e., reliability of internal consistency, concurrent validity) of FAM are robust for use with families of children and adolescents with autism. Specifically, for parents of children with autism, the FAM provides an accurate prediction of clinically significant stress. The FAM offers indicators of households that may be at risk of poor resilience.</p>		
<p>Experiences and impact of having children with autism spectrum disorder on the lives of their Korean-American mothers (Kim S., Kim H, Kim J., Nichols & Kang, 2021)</p>	<p>Psycinfo</p>	<p>5 Korean-American Mothers of Children with Autism</p>	<p>Qualitative study</p>	<p>Semi-structured interviews, follow-up telephone interviews, unstructured direct observations and documents</p>	<p>The analysis identified four key themes: 1. Emotional distress: Mothers face economic, language, and immigration-related difficulties as primary caregivers. 2. Family relationships: Marital relationships vary, and neurotypical siblings learn acceptance, while mothers feel guilty for neglecting them. Some family members find it difficult to accept the diagnosis. 3. Lifestyle: Mothers undergo career changes and maintain a connection to religion, with some conversions. 4. Education: Mothers prioritize private therapies over school.</p>
<p>Preliminary results of the effects of a psychoeducational program on stress and quality of life among French parents of a child with autism (Cappe, Downes, Albert-Benaroya, Ech-Chouikh, De Gaulmyn, Luperto, ... & Sankey, 2021).</p>	<p>Web Science</p>	<p>of 20 parents of children with autism took part in the short version of the program (SV group), 15 parents of children with autism took part in the full version of the program (CV group)</p>	<p>Preliminary experimental study</p>	<p>The Appraisal of Life Events Scale validated in French by Cappe et al (2017) (ALES; Ferguson et al., 1999) to assess the perceived stress of parenting a child with autism; the e Parenting Stress Index (ISP-FB, Abidin, 1995; Bigras et al., 1996) in the short version in French to assess parental stress; the Quality of Life Scale for Parents of a Child with ASD</p>	<p>Parents in the CV group appeared to be significantly less stressed, and significant improvement was observed in some areas of their quality of life (relationship with the child, psychological well-being, and personal fulfilment). No significant effects were observed in the SV group. Both groups enjoyed the program very much.</p>

				(EQVPTSA) to assess the impact of autism on different areas of a parent's daily life; the Parent Evaluation Inventory (IEP) of Kazdin et al. (1992) to assess whether parents perceived that they had made progress by participating in the program and to have parents rate the appropriateness and interest of the program itself; the workshop evaluation grid (Gagnon in 1998) to have parents evaluate the workshops.	
Couples' experiences of parenting a child after an autism diagnosis: A qualitative study (Downes, Lichtlé, Lamore, Orève, & Cappe, 2021)	Web Science	of 10 couples of Parents with a Child Diagnosed with Autism	Qualitative study	Interview analysed with thematic content analysis, according to the guidelines of Braun and Clarke (2006)	Overall, the quality of couple relationships before having a baby affected their relationship after diagnosis. In general, parents had complementary roles in coparenting, while differing opinions on how to raise the child tended to strain their relationship.
Dyadic coping and coparenting among couples after their child's recent autism diagnosis (Downes, Geoffray, Isnard, Lemonnier, Orève, & Cappe, 2022)	Scopus	70 couples of parents made up of mothers and fathers of children with autism	Cross-sectional study with a quantitative approach	Parents filled out the questionnaires individually. A questionnaire to collect socio-demographic information (Cappe (2009). The Appraisal of Life Events scale (ALES-vf; Ferguson et al., 1999) to assess stress. The Dyadic Coping Inventory (DCI; Bodenmann, 2008) to assess dyadic coping. The Parenting Alliance Inventory (PAI; Abidin, 1992; Abidin & Brunner, 1995). The Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston, 1977) to measure the sense of competence perceived in one's parental role.	Parents who felt more competent and supported by their partner worked better as a team to raise their child with autism. Fathers invested more in the coparenting relationship when mothers felt more supported by fathers. Mothers have invested in the coparenting relationship more when the fathers felt more competent in their parental role
Parenting stress within mother-father dyads raising a young child with autism spectrum disorder (Patel, Rivard, Mello, & Morin, 2022).	Web Science	of 258 mother-father dyads and their child with autism	Comparative study	The Childhood Autism Rating Scale (CARS; Schopler et al., 1988) to measure the severity of children's autism symptoms; the third edition of the Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995)	Partial correlations revealed that, at the time of diagnosis, after controlling for the children's age and the severity of autism symptoms, the stress of mothers and fathers was positively and significantly associated with each

					other, suggesting a two-way relationship between the psychological adjustment of partners. Cross-lagged analyses demonstrated different longitudinal and transactional connections, depending on the size of the stress examined.
Marginalisation, autism and school exclusion: caregivers' perspectives (Martin-Denham, 2022)	Web Science	of 5 Caregivers of Children with Autism	Interpretative phenomenological analysis	Interviews analysed with Interpretative phenomenological analysis (IPA; King et al., 2019)	The results show that the responsibility fell on caregivers to request effective support from schools. The lack of timely diagnosis and effective school support is detrimental to the emotional and physical health of both children and caregivers.
Family functioning and emotional aspects of children with autism spectrum disorder in southern Brazil (Flenik, Bara, & Cordeiro, 2023).	Web Science	of 21 families with children with autism	Qualitative study	The Family Environment Scale (FES; Moos and Moos 1994) to assess the family environment; the Strength and Difficulties Questionnaire (SDQ; Goodman, 1999) to assess internalizing and externalizing aspects of behaviour and symptoms; the Questionnaire on Resources and Stress – Short Form (QRS-F; Jean Holroyd; 1974) to identify the stressors experienced by the family.	Families reported concern for their child's future. 71% of parents reported giving up on their dreams and plans to care for their child with autism. Communication difficulties have been a recurring theme for many families, as has a decrease in social relationships.
A qualitative study on perspective of parental stress and lower marital quality among parents of children with autism spectrum disorder (Rizvi, & Batool, 2024).	Scopus	15 mothers and 13 fathers of children with autism	Qualitative study	Thematic analysis was used to analyse the data, and five stages of stress and six main themes emerged from the data (child management and diagnosis, treatment and financial challenges, social suffering, emotional and psychological pain, marital discord, and coping mechanism).	In the present study, parents of children with autism reported lack of orientation, high-cost demands, lack of awareness, family pressure, high level of stress, and stigmatization. Parents reported marital discord including conflict, disharmony, lack of communication, and lack of support from their spouse.
Differences in caregiver and child factors within families of autistic youth across birth order groups (Boland,	Web Science	of Three groups of caregivers 1) 34 caregivers with the firstborn with autism; 2) 43 caregivers with a child with	Comparative and cross-sectional study	Questionnaire to collect demographic and diagnosis data; the Depression, Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995) to	Despite comparable assessments of family resources and autism severity, significant differences emerged based on birth order. Having one or more

Barry, & Lindsey, 2024).	autism, but not a firstborn; 3) 78 caregivers with only one child with autism	assess caregiver stress; the Family Resource Scale (FRS; Dunst & Leet, 1987) to assess family resources; the Multidimensional Survey of Perceived Social Support (MSPSS; Zimet et al., 1988) to assess perceived social support; the Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston & Wandersman, 1978; Johnston & Mash, 1989) to assess the sense of parental competence; the Survey of Knowledge of Autism Spectrum Disorder (ASK-ASD; Hansen, 2015) to assess knowledge of autism; the Behavior Assessment System for Children-Parent Rating Scale-Third Edition-Preschool and Child Versions (BASC-3; Reynolds & Kamphaus, 2015) to assess the internalizing and externalizing symptoms of children; the Children's Social Behavior Questionnaire (CSBQ; Hartman et al., 2006) to assess the severity of autism symptoms.	children without autism before having a child with autism can increase feelings of satisfaction and competence as a parent. Parents with only one child with autism also reported higher ratings of competence, had significantly less knowledge about autism, and demonstrated a significant negative correlation between effectiveness and knowledge.	
Brief report: Investigating temporal factors in the context of parenting an autistic child (Meads, Shepherd, Landon, & Goedeke, 2024)	Web Science of 291 parents of children with autism	Secondary analysis of cross-sectional data	The Autism Impact Measure (AIM; Kanne et al., 2014) to have parents assess the severity of autism symptoms; the Autism Parenting Stress Index (APSI; Silva & Schalock 2012) as a self-report tool of parental stress; General Health Questionnaire (GHQ-28) as a self-report tool of parental health.	The age of the child and the parents was related to the main symptoms of autism, parental stress, and psychological well-being, while the age gap between parent and child was not. Diagnostic delay was positively associated only with parental depression and negatively associated with the child's communication problems. The results indicate that time variables may be predictive of parental well-being and autism symptoms in children.
Pillar Mothers: Perspective on the Adaptation Process of Mothers of Autistic Children (Périard-	Web Science of 17 Mothers of Children with Autism	Qualitative study	The Childhood Autism Rating Scale, 2nd edition (CARS2) (Schopler et al., 2010) to assess autism	The findings highlight the complexity of the maternal adjustment process in the context of autism, which

Larivée, Godbout, Bégin, St-Laurent, de Serres-Lafontaine, De Pauw, & Bussi eres, 2024)

characteristics is a semi-structured interview, based on existing research, consisting of seven questions and insights into mothers' perceptions regarding their adjustment and the successes and challenges encountered as mothers of an autistic child. a thematic analysis (Braun & Clarke, 2006) using a mixed inductive and deductive coding tree (Miles et al., 2020) to analyse the interviews. Subsequently, a cross-case analysis was carried out to highlight themes and sub-themes.

begins before the child's diagnosis. Stressors, facilitators, and outcomes have been described as overlapping in the psychological, social, professional, marital, and parenting domains. The accumulation of stressors has been identified as the main source of stress for mothers of autistic children and almost impossible to reduce. The participants explained that they had difficulty accessing effective facilitators. Although adjustment outcomes vary between mothers and life domains, indicators of distress were identified for all participants.

Table 2. Selected articles for autism

Title, authors, year	Database	Participants	Design	Measures	Results
Evaluation of a psychoeducation programme for parents of children and adolescents with ADHD: Immediate and long-term effects using a blind randomized controlled trial (Ferrin, Moreno-Granados, Salcedo-Marin, Ruiz-Veguilla, M., Perez-Ayala, & Taylor, 2014)	Web of Science	44 families with ADHD children received an intervention based on a psychoeducation program (experimental group); 37 families with ADHD children received parenting counselling and support intervention (control group)	A Blinded Randomized Controlled Trial	Schedule for Affective Disorders and Schizophrenia for school age children (KSADS-PL) for diagnoses; Attention deficit hyperactivity disorder-Index, the Spanish version of the Conners' Parent Rating Scale Revised 27-items version (CPRS-R:S) used as the primary outcome of the study; Strengths and Difficulties Questionnaire (SDQ) to assess emotional symptoms and problem behaviours; Clinical Global Impression Scale (CGI) for severity and improvement of global symptoms; Parenting stress index (PSI; Abidin, 1995); EuroQoL FiveDimension Questionnaire (EQ-5D) for quality of life; PedsQLTM Family Impact Module to assess the impact on the	Compared to the control group, in the experimental group the ADHD index and cognitive/inattention levels were significantly reduced after the intervention. An improvement in the pro-social domain was also observed after 1 year of follow-up. No significant differences in quality of life or family stress were found compared to the control group.

<p>Does parent stress predict the quality of life of children with a diagnosis of ADHD? A comparison of parent and child perspectives (Galloway, Newman, Miller, & Yuill, 2019)</p>	<p>Web of Science</p>	<p>45 dyads</p>	<p>parent-child</p>	<p>Cross-sectional study</p>	<p>family. Demographic questionnaire; Child self-report and parent proxy report (KIDSCREEN-27; Ravens-Sieberer et al., 2007) to assess the subjective health and well-being of children and adolescents; Strengths and Weaknesses of ADHD Symptoms and Normal Behaviour Rating Scale (SWAN; Hay, Bennett, Levy, Sergeant, & Swanson, 2007) to assess inattentive, impulsive, hyperactive behaviours; Perceived Stress Scale (PSS; parent self-report; S. Cohen et al., 1983) to assess stress and how experiences are perceived as unpredictable.</p>	<p>Parents who gave lower scores to their child's quality of life, compared to the child's self-assigned scores, had higher stress levels. Parenting stress was a predictor of the child's quality of life.</p>
<p>Health-related quality of life in mothers of children with attention deficit hyperactivity disorder in Taiwan: The roles of child, parent, and family characteristics (Liang, Lee, Kelsen, Chen, .2021)</p>	<p>Scopus</p>	<p>257 children with ADHD and their mothers, 324 typically developing children and their mothers</p>	<p>Report, part of a comparative study</p>	<p>Children's variables: Swanson, Nolan, and Pelham rating scale version IV (SNAP-IV) used by parents and teachers to assess ADHD symptoms; Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) to assess children's behaviours, emotional problems, and skills; Childhood Autism Spectrum Test (CAST) report compiled by parents to understand the level of autistic traits of the child. Parenting variables: World Health Organization Quality of Life - BREF (WHOQOL-BREF) to assess the subjective perception of one's quality of life; Adult ADHD Self-report Scale (ASRS) to report symptoms of hyperactivity-impulsivity and inattention; Chinese version of The</p>	<p>Mothers of children with ADHD reported significantly worse health-related quality of life (HRQOL) in all four domains than those of typically developing children. Multiple regressions revealed that the consistently HRQOL-related factors of mothers of children with ADHD and those with typical development were maternal depression and perceived family support, after controlling for several family, parenting, and child variables. HRQOL of mothers of children with ADHD and those with typical development was more closely linked to personal and family factors rather than to ADHD symptoms assessed by mother or teacher, the clinical diagnosis of ADHD,</p>	

					Centre for Epidemiologic Studies Depression Scale (CESD-C; Cheung & Bagley, 1998; Chien & Cheng, 1985; Radloff, 1977; Ross & Mirowsky, 1984) to assess depressive symptoms and interpersonal problems. Family variables: Family Adaptation, Partnership, Growth, Affection, Resolve (The Family APGAR; Good, 1979) to assess levels of satisfaction with family support and communication	or the child's psychopathology.
Mothers' stress and behavioral and emotional problems in children with ADHD. Mediation of coping strategies (Berenguer, Rosello, & Miranda, 2021)	Scopus	35 mothers of children with ADHD and 37 mothers of typically developing children	Cross sectional design	Parental Stress Questionnaire-Short Form (The Parental Stress Index-PSI-SF; Abidin, 1995; Spanish Adaptation by Diaz Herrero, Brito de la Nuez, Lopez Pina, Perez-Lopez & Martinez-Fuentes, 2010) to assess mothers' stress; Coping Orientation to Problems Experienced (Brief COPE, Carver, 1997; Spanish adaptation by Moran, Landero & Gonzalez, 2010) to evaluate coping strategies; Strengths and Difficulties Questionnaire (SDQ-Cas; Goodman, 1997 Spanish adaptation by Rodriguez-Hernandez et al., 2012) self-report questionnaire completed by parents and teachers to assess prosocial and problematic behaviours in children and adolescents.	Comparative analyses showed that mothers' stress and their children's behavioural/emotional problems were significantly higher in the group with ADHD than in the group without ADHD. Correlation analyses revealed different correlation patterns in the two groups, with behavioural/emotional problems significantly associated with parenting stress and cognitive disengagement and restructuring coping strategies reported by mothers of children with ADHD. Furthermore, according to the mediation analysis, the disengagement coping strategy was found to be a significant mediator in the relationship between behavioural/emotional problems and mothers' stress.	

Table 3. Selected articles for ADHD

Title, authors, year	Database	Participants	Design	Measures	Results
Caregiving burden among informal caregivers of people with disability (Sit,	Scopus	234 informal caregivers of families with individuals with	Cross-sectional correlational study	Depression, Anxiety, and Stress Scale (DASS-21; Lovibond &	CBI and PD were associated with depression, anxiety, and stress. While

<p>Huang, Chang, Chau, & Hall, 2020)</p>	<p>intellectual or mental disabilities in Macau (China)</p>	<p>Lovibond, 1995) to assess the severity of depressive, anxious, and stress symptoms; the perceived difficulty (PD; Hastings and Taunt, 2002; Mak and Ho, 2007) by the caregiver was measured across 15 tasks (e.g., dressing); Chinese version of the Caregiver Burden Inventory (CBI; Chou, Jiann-Chyun, & Chu, 2002) to measure caregiver burden; a Chinese version of the Chinese Coping Scale (CCS; Hwang (1977; Shek and Mak, 1987; Shek and Cheung, 1990). Demographic characteristics of caregivers and people with disabilities.</p>	<p>internal coping buffered the effect of PD on depression and anxiety, external coping exacerbated the effect of PD on anxiety and the effect of CBI on depression and anxiety.</p>	
<p>Development and Preliminary Validation of the Accommodations & Impact Scale for Developmental Disabilities (Udhmani, Miller, & Lecavalier, 2024)</p>	<p>407 caregivers of young people with disabilities</p>	<p>Survey design</p>	<p>Accommodation & Impact Scale for DD (AISDD; Udhmani, Miller, & Lecavalier, 2024) measures the daily adaptations and effects of raising a child with an intellectual disability; Caregiver Strain Questionnaire (Brannan et al., 1997) to assess stressful situations in caregivers' lives; and Parenting Daily Hassles Scale (PDH; Crnic & Greenberg, 1990) to assess the small daily tensions experienced by caregivers during routine daily caregiving activities or during interactions; Adaptive Behavior Assessment System—Third edition (ABAS-3; Harrison & Oakland, 2015) measures adaptive abilities throughout the caregiver's lifespan; Nisonger Child Behavior Rating Form (NCBRF; Aman et</p>	<p>The AISDD is a one-dimensional scale consisting of 19 items with excellent internal consistency (ordinal alpha = .93) and test-retest reliability (ICC = .95). Scores were normally distributed and age-sensitive, diagnosis, adaptive functioning, problematic behaviours. These results support the use of AISDD as a valid and reliable tool for measuring adaptations among caregivers of individuals with disabilities.</p>

al., 1996) evaluates the behaviours of children with intellectual disabilities; demographic questionnaire.

Table 4. Selected articles for intellectual disability

Title, authors, year	Database	Participants	Design	Measures	Results
Perception of families of children with specific learning disorder: An exploratory study (Sahu, Bhargava, Sagar, & Mehta, 2018)	Web of Science	5 focus groups each composed of 30 parents of children with SLD	Descriptive qualitative study	Semi-structured demographic interview: FGD format guide created for the present study to investigate parents' concerns	Parents showed a lack of conceptual knowledge regarding the symptoms of Specific Learning Disorder (SLD) and the appropriate guidelines to address their child's problem. They have expressed negative attitudes and reactions towards their child's diagnosis of ASD, such as rejection, denial, overprotection and loss of hope. Most parents also perceived that their role as caregivers involved a physical, personal, social, financial, and emotional burden.

Table 5. Selected articles for specific learning disorders

Since the number of articles found for each neurodivergence examined is very uneven, it is reasonable to assume that, in the analysis of the results of the different studies, there may be biases related to the overrepresentation of the experience of parents of children with autism, compared to the underrepresentation of the experience of parents with children with different diagnoses. No quality or risk bias assessment tools were applied to the included studies.

Results

From the analysis of the 29 articles assessed as suitable for this review, it was possible to outline both some quantitative data and some qualitative data. In some papers statistical analysis, such as ANOVA, ANCOVA, Pearson's correlation, Structural Equation Modeling (SEM) and Mediation Analysis, Chi square test (X^2), Regression (Logistic and Linear), Student's t-test, ROC analysis (Receiver Operating Characteristic), Cronbach's alpha were present. With regard to qualitative data, a number of recurring themes in various articles and in different diagnostic groups. Specifically, four themes were found to be common to more than one neurodivergent category: impact on family functioning and family factors (with a specific focus on parental stress and coping strategies), access to appropriate services, level of well-being, support and awareness.

Other issues, however, seem to be peculiar to parents and caregivers of children with specific diagnoses. In particular, among parents of children with autism, themes emerged concerning parenting experiences and reaction to the diagnosis, the latter of which was also relevant for parents of children with a specific learning disorder.

From the articles on intellectual disability, the burden of the caregivers was found to be salient, whereas for parents of children with a specific learning disorder, the burden of the caregiver in physical, personal, financial, social and emotional terms appeared to be relevant.

Statistical analysis

Autism

The study by Cox et al. (2015) used the ANCOVA with an alpha level of .05 to examine the effect of parenting status (parents of children with autism vs. parents of typically developing children) on measures of psychological well-being. It found a significant effect of parenting status on negative affect, depression and anxiety, with mothers of children with autism reporting poorer health. None of the covariates (age, ethnicity, marital status and household income) were significant ($p > .05$). Cohrs and Leslie (2017) found that parental depression was significantly more common in families with a child with ASD (20.2%) than in those without (8.5%) ($p < .0001$). Mothers were more frequently diagnosed with depression than fathers (11.6% vs. 5.6%), but both mothers (16.9%) and fathers (7.8%) of children with ASD were more than twice as likely to have depression compared to parents without an

ASD child ($p < .0001$). Logistic regression analysis revealed that having a child with ASD nearly tripled the odds of parental depression (OR 2.77, 95% CI 2.66–2.89), even after controlling for demographic factors. Among parents of children with ASD, the child's sex was not significantly linked to parental depression (OR 1.00, 95% CI 0.94–1.06). However, parents with multiple children with ASD had a 1.4 times higher risk of depression (OR 1.42, 95% CI 1.26–1.59), and the likelihood of parental depression increased as the child with ASD aged. In Reed and Osborne's (2019) study, the following differences were found between mothers who had a resolved reaction of their child's diagnosis compared to those who had an unresolved reaction: anxiety (HADS_A, 8.06 vs 11.06), depression (HADS_D, 6.81 vs 10.21), social relationships (WHO, 12.56 vs 9.83), environment (WHO, 13.90 vs 12.59), physical (WHO, 14.70 vs 11.14), somatic (GHQ, 2.11 vs 2.68), immune (IFQ, 16.31 vs 26.25). In the study by Siu et al. (2019), in parents of typically developing (TD) children, the Childhood autism spectrum test (CAST) scores, child problem behaviours, and parenting stress showed low to moderate correlations ($0.27 \leq |r| \leq 0.55$). In the ASD group, no significant correlations were found between CAST and conduct problems, hyperactivity and emotional problems, externalizing behaviours and peer problems, or emotional problems and prosocial behaviours. Hierarchical regression analyses showed that all predictors in the final models were significantly correlated with parenting stress across both ASD and TD groups. A separate regression analysis examined the impact of ASD diagnosis on parenting stress, revealing that after controlling for demographic factors, ASD diagnosis accounted for an additional 3.9% of the variance ($B = 4.20$, $p < .001$). In the study by Williams et al. (2019), the group centroids indicate that low-acculturation African Americans (Centroid = 1.02) report experiencing higher stress levels and using a greater variety of coping strategies overall compared to high-acculturation African Americans (Centroid = 0.80) and Euro-Americans (Centroid = -0.91). Similarly, the group centroids showed a pattern in which low-acculturation African Americans (Centroid = 1.23) reported higher stress and greater use of coping strategies than high-acculturation African Americans (Centroid = 1.03) and Euro-Americans (Centroid = -1.07). The study by Moody et al. (2019) found significant differences in quality of life, family functioning, and use of services between the group of parents participating in a mentorship program (active) and the group of parents on the waiting list. With regard to quality of life, satisfaction with disability services increased significantly in the active group at follow-up ($p=0.005$), regardless of the child's SRS score. In the waitlist group, on the other hand, satisfaction decreased as the SRS score increased ($p=0.04$). In family functioning, the waitlist group showed a significant increase in family

rigidity after six months ($p=0.02$), while the active group did not experience any changes. The importance attributed to family interaction showed a marginally insignificant trend in the waitlist group ($p=0.08$). Service use was low in both groups, but an average increase of 1.97 hours was found in extra-curricular services after six months ($p=0.02$). None of the groups received the recommended 25 hours per week of behavioural services. In the study by Pattini et al. (2019), mothers of children with ASD (M-ASD) reported significantly higher levels of parental stress (38.4 ± 1.2 vs. 23.0 ± 1.5 ; $t = 8.07$, $p < .05$, $d = 2.93$) and trait anxiety (49.5 ± 2.1 vs. 33.8 ± 1.9 ; $t = 5.57$, $p < .05$, $d = 2.02$) than mothers of children with typical development (M-TD). Furthermore, M-ASDs showed significantly higher scores on the DS-14 scales for negative affectivity (12.6 ± 0.7 vs. 8.4 ± 1.3 ; $t = 2.94$, $p < .05$, $d = 1.04$) and social inhibition (12.1 ± 1.1 vs. 5.4 ± 0.9 ; $t = 4.71$, $p < .05$, $d = 1.72$). The incidence of Type D personality was significantly higher in M-ASDs (11/15) than in M-TDs (2/15) ($\chi^2 = 11.0$, $p < .05$, $d = 1.52$). With regard to coping strategies, M-ASDs scored higher on the subscales of avoidance ($t = 3.85$, $p < .05$, $d = 1.42$), task orientation ($t = 2.35$, $p < .05$, $d = .87$) and transcendent orientation ($t = 2.47$, $p < .05$, $d = .91$). A significant positive correlation was found between trait anxiety and negative affectivity ($r = .61$, $p < .05$). The two-way ANOVA showed a significant group effect on heart rate ($F = 5.61$, $p < .05$), with M-ASDs having higher values in all recording periods. Finally, the overall cortisol response to PST (AUCb) was greater in M-ASDs than in M-TDs ($t = 2.03$, $p = .053$, $d = .63$). Cappe et al. (2021) tested the effectiveness of a psychoeducational program, proposing it to a full version group (CV) and a short version (SV) group. To measure the evolution over time (T0, T1, T2) within each group, analysis of variance for repeated measures (ANOVA) was used. CV group: For perceived stress measured with the ALES-vf, a significant evolution was observed in the "threat" ($F = 4.96$, $p = .01$) and "challenge" ($F = 3.59$, $p = .04$) subscale. Post-hoc tests indicated a significant decrease in the perception of the "threat" from T0 to T1. For parenting stress measured with the ISP-FB, there was a significant decrease in the total score ($F = 4.15$, $p = .03$) and in the "dysfunctional interaction" subscale ($F = 3.56$, $p = .04$). Post-hoc tests showed a significant decrease in total score and dysfunctional interaction from T0 to T2. For quality of life measured with the EQVPTSA, no significant change in total score was observed ($F = 2.09$, $p = .14$). However, significant evolutions were found in the subscales: "Relationship with the child with ASD" ($F = 10.33$, $p = .000$), with a significant improvement from T0 to T2 (post-hoc test) "Psychological well-being" ($F = 4.21$, $p = .03$). "Personal fulfilment" ($F = 6.36$, $p = .005$). SV group: No statistically significant evolutions were found in measures of stress (ALES-vf and ISP-FB) and quality of life

(EQVPTSA) in the SV group (all values of $p > .05$ for ANOVA for repeated measures. Downes et al. (2022) showed that the mean scores for dyadic coping were within the normal range, with no significant differences between mothers and fathers ($t = 0.75, p < 0.47$). Both partners showed similar levels of sense of competence ($t = 0.95, p < 0.34$). The only variable where mothers scored significantly higher than fathers was the perception of stress as a threat ($t = 2.55, p < 0.01$). On average, parents reported similarly high coparenting scores ($t = -0.85, p < 0.40$). Patel et al. (2022) measured stress in parents of children with autism in three different times. Descriptive statistics indicated that, on average, mothers experienced clinically significant stress levels at all three timepoints (Time 1, Time 2, and Time 3), with scores exceeding the 90 thresholds. Paired-samples t-tests showed that mothers consistently reported significantly higher stress than fathers at each timepoint ($p < .001$ at Time 1, $p = .019$ at Time 2, and $p = .034$ at Time 3). However, one-way repeated-measures ANOVAs revealed that while children's autism symptom severity significantly changed between Time 1 and Time 3 ($p = .023$), stress levels in both mothers and fathers remained statistically stable across the three timepoints. Pearson's correlation analyses found a strong association between mothers' and fathers' total stress ($r = .55, p < .001$). Additionally, both parents' stress levels were significantly and positively correlated with child autism symptom severity (mothers: $r = .22, p < .001$; fathers: $r = .28, p < .001$). The study conducted by Boland, Barry and Lindsey (2024) examined three birth order groups of caregivers of children with ASD using a one-way ANOVA. No significant differences were found in caregiver distress, family resources, ASD severity, or externalizing behaviours. However, the Non-First-Born group reported higher satisfaction, while the First-Born group had lower efficacy. The Only-Child group showed higher social support, lower ASD knowledge, and more internalizing behaviours. The study by Meads et al. (2024) found that, on average, ASD symptoms emerged at 1.76 years ($SD = 1.49$), while diagnosis occurred at 4.92 years ($SD = 2.92$), resulting in a mean diagnostic delay of 3.16 years. Regression analyses showed that as children aged, communication deficits decreased while odd behaviours increased. Parenting stress from ASD core symptoms rose with child age, whereas stress from problem behaviours declined. Parental anxiety decreased over time, but self-reported depression increased. Further analyses indicated that communication deficits were negatively correlated with both the age at which parents first noticed ASD symptoms and the age of formal diagnosis, though with a small effect size.

ADHD

The psychoeducational programme, implemented by Ferrin et al. (2014), led to a significant reduction in ADHD symptoms in the treated group compared to the control, with a decrease in the ADHD Index (Mann-Whitney $U = 3.47$; $p = 0.001$) and in cognitive/attention levels (Mann-Whitney $U = 3.34$; $p = 0.001$), as measured by the Conners' Parent Rating Scale Revised 27-items version (CPRS-R:S), with a moderate to large effect size (η^2 partial = 0.096). At long-term, after one year of follow-up, the psychoeducational group showed a significant improvement in pro-social behaviour compared to the control group (Mann-Whitney $U = -2.37$; $p = 0.018$), with a small to medium effect size ($\eta^2 = 0.047$). The repeated-measures ANOVA showed a significant interaction between treatment and time for the ADHD Index ($F(2,72) = 3.41$; $p = 0.038$) and the cognitive domain ($F(2,72) = 3.52$; $p = 0.035$), with medium to large effects (η^2 partial = 0.090) and a power of 70%. However, no significant effects were observed in total Strengths and Difficulties Questionnaire (SDQ) score, parental stress (PSI), quality of life (EuroQoL) and teacher ratings (CTRS-R:S and SDQ). Finally, the global clinical severity index (CGI) showed a significant effect of time ($F(2, 60) = 5.04$; $p < 0.01$, 80% power), but without significant interaction between time and group. In the study by Galloway et al. (2016), the analysis compared quality of life (QoL) ratings between parents and children with ADHD by means of paired-samples t-tests, finding a significant difference between parent-rated ($M = 41.5$) and child self-reported QoL ($M = 45.8$), $t(44) = 4.16$, $p < .001$. Independent-samples tests showed that parents who perceived their child's QoL more negatively reported significantly higher levels of stress ($M = 22.1$ vs. $M = 17.3$, $t(39) = 2.17$, $p < .05$). However, there were no significant differences in QoL and stress scores between children with ADHD alone and those with comorbidities (autism or learning disability). Pearson's coefficient of correlation showed that parental stress was correlated with the discrepancy between parent and child QoL ratings ($r(44) = .44$, $p < .01$), and was negatively associated with both parent-rated ($r(44) = -.63$, $p < .01$) and child self-reported QoL ($r(44) = -.32$, $p < .05$). Hierarchical multiple regression analysis revealed that parental stress was a significant predictor of parent-rated QoL ($\Delta R^2 = .22$, $F = 11.98$, $p < .001$), but not of children's self-reported QoL ($\Delta R^2 = .06$, $F = 1.74$, $p = .17$). In the study by Liang et al. (2021), mothers of children with ADHD reported significantly lower quality of life (HRQOL) in all dimensions (physical, psychological, social and environmental) than mothers of children with typical development ($p < .001$, $d = 0.38 \sim 0.55$). Furthermore, they perceived themselves to be less respected or accepted than mothers of typically developing children ($\chi^2(4) = 23.63$, $p < .001$), whereas no significant differences

emerged in accessibility to preferred foods. Maternal HRQOL was significantly correlated with sleep, behavioural (e.g. inattention, hyperactivity, opposition, aggression) and emotional (anxiety, depression) problems of the children, as well as with maternal (education level, depressive symptoms and hyperactivity) and family (family support and income) factors. Regression analyses showed that children's inattention symptoms ($\beta = .30 \sim .21, p < .01$) and autistic traits ($\beta = .23 \sim .16, p < .01$) were associated with all dimensions of maternal HRQOL. In addition, family income and children's sleep problems influenced the physical dimension of HRQOL, while the psychological dimension was related to parental education level and maternal inattention symptoms. When maternal factors were considered, the effect of child clinical characteristics decreased, with maternal depressive symptoms being the main negative predictor of HRQOL in all domains ($\beta = .19 \sim .36, p < .001$), along with family support ($\beta = .17 \sim .27, p < .001$). Overall, maternal HRQOL was more influenced by maternal and family factors than by the child's diagnosis or psychopathology. In the study by Berenguer, Rosello and Miranda (2021), mothers of children with ADHD reported significantly higher levels of stress than mothers of children with typical development (TD), as confirmed by MANCOVA analysis ($\Lambda = 0.74, F(3,66) = 7.37, p < 0.01$) and post hoc ANOVAs, e.g. for Parental Distress ($F(1, 68) = 7.06, p < 0.05$). Children with ADHD manifested more behavioural and emotional problems than TD children ($\Lambda = 0.36, F(4,65) = 28.43, p < 0.01$), with significant differences in all subscales of the Strengths and difficulties Questionnaire (SDQ), such as for Hyperactivity ($F(1, 68) = 106.77, p < 0.001$). Partial correlations showed distinct patterns in the two groups: in the ADHD group, Parental Distress correlated positively with Disengagement ($r = 0.49; p < 0.01$), whereas Dysfunctional Interaction correlated positively with Disengagement ($r = 0.59; p < 0.01$) and negatively with Cognitive Reframing ($r = -0.38; p < 0.05$). Multiple regression analysis indicated that the total SDQ score ($b = 0.38, p = 0.012$), Disengagement ($b = 0.32, p = 0.028$) and Cognitive Reframing ($b = -0.27, p = 0.043$) were significant predictors of parental stress, explaining 44% of the variance ($R^2 = 0.44$).

Intellectual disability

In the Multiple Regression Analysis, where b was the regression coefficients, Sit et al. (2020) found that the Care burden (CBI) was positively associated with depression ($b = .60, p < .001$), anxiety ($b = .53, p < .001$) and stress ($b = .64, p < .001$). The internal coping was negatively associated with depression ($b = -.13, p < .05$). The external coping was positively associated with anxiety ($b = .18, p < .001$) and stress ($b = .12, p < .05$).

Significant interactions were found between: external coping and care load increased depression ($b = .13, p < .05$) and anxiety ($b = .20, p < .001$); internal coping and perceived difficulty reduced depression ($b = -.17, p < .05$) and anxiety ($b = -.14, p < .05$); external coping and perceived difficulty increased anxiety ($b = .17, p < .05$). Being a male caregiver was negatively associated with caregiver burden ($b = -.25, p < .001$). The article by Udhmani, Miller and Lecavalier (2024) presents the development and preliminary validation of the Accommodations & Impact Scale for Developmental Disabilities (AISDD). The internal consistency of the 19-item scale was excellent with an ordinal alpha coefficient of 0.93. Test-retest reliability (range 10 to 21 days) on the AISDD total score was also excellent ($ICC = 0.95$). Convergent validity was supported by strong Pearson's correlations between the AISDD and the Parenting Daily Hassles Scale (PDH) ($r = 0.77$ for sum of frequency and $r = 0.69$ for sum of intensity) and the Caregiver Strain Questionnaire (CSQ) ($r = 0.77$ for global score). Pearson correlations were calculated to examine the association between AISDD scores and subject characteristics. A small negative correlation was found between the child's age and the AISDD total score ($r = -0.19$).

Qualitative Data

Impact on family functioning and family factors

The study by Moody et al. (2019) tested the effectiveness of a mentorship programme for parents of newly diagnosed children with autism. It was found that parents who took part in the programme reported improved family functioning, decreased parenting stress and increased satisfaction in their parenting role. The study by Downes et al. (2021) investigated the experience of couples with a child with autism. This diagnosis has a significant impact on the couple's relationship, increasing stress. The research also highlighted that communication, seeking resources outside the family and mutual support can help couples. Finally, it was highlighted that couples who shared more parenting commitments and collaborated had more positive experiences in coping with the diagnosis and caring for their child with autism. In a subsequent study by Downes and colleagues (2022), it was found that couples who adopted shared coping strategies were better able to coparent. Patel et al. (2022) focused on mother-father dyads of children with autism, highlighting gender differences between the two parents. Although they both experience stress, the mothers suffer more. Research by Flenik, Bara and Cordeiro (2023) showed that families with autistic children had low levels of cohesion, expressiveness and independence, as well as

low levels of conflict. These families actively participated in intellectual and religious activities, while experiencing difficulties in home organisation. Furthermore, it was revealed that 71% of the parents reported giving up their dreams and plans to care for their child with autism. In particular, working mothers reported spending less time on recreational activities and more time socialising, although many continue to find it difficult to participate in social activities due to caring responsibilities. The results of the study by Périard-Larivée and colleagues (2024) underline the complexity of mothers' adjustment in the context of autism, a process that begins even before the child is diagnosed. Stressors, facilitating factors and adaptation outcomes have been described as closely linked in the different domains of mothers' lives, including psychological, social, professional, marital and parenting. Stress accumulation emerged as the main source of difficulties, making it almost impossible to reduce its impact. Mothers reported difficulties in finding effective supports to cope with these challenges. Despite differences in the adaptation of the different mothers, signs of distress were found in all participants. Sit et al. (2020) using the Chinese version of the Caregiver Burden Inventory (CBI; Chou, Jiann-Chyun, & Chu, 2002) and the assessment of perceived difficulty in caring for a person with a disability, showed how being a caregiver impacts people in terms of stress, depression, and anxiety. Udhmani, Miller and Lecavalier (2024) developed the Accommodation & Impact Scale for DD (AISDD), a rating scale to measure the impact of disability on families, highlighting how changes to daily routines can affect family life. The results support the use of the AISDD as a valid and reliable tool to measure adaptations among caregivers of individuals with intellectual disabilities. Concerning parents of children with a specific learning disorder, difficulty in adapting to their child's difficulties was found due to not knowing the diagnosis (Sahu et al., 2018). In addition, mothers reported spending a lot of time helping their children with schoolwork, while fathers tended to be away from home for longer due to work. As a result, parents saw less quality time to spend together. This led to arguments between the spouses both in terms of disagreement on child-rearing and in terms of marital conflicts.

Stress

Some contributions wanted to investigate more specifically one of the dimensions that have the greatest impact on family functioning: stress. The study by Siu and colleagues (2019) shows that problematic behaviour is one of the main reasons why autism symptoms lead to increased stress in parents. The more acute the children's symptoms, the greater the stress levels of the parents. The management of problematic behaviour can be a determining factor

in relieving parental stress. Furthermore, teachers should be an integral and active part of interventions to help children with autism and support families. The authors' findings seem to suggest that interventions aimed at reducing problematic behaviour in children may lead to a reduction in parental stress. Williams and colleagues (2019) investigated the issue of parental stress from a cultural differences' perspective, comparing European-American and African-American families with children with autism. African-American parents show higher levels of stress than European-American parents. They also implement more coping strategies. The study revealed a further differentiation within the group of African-American parents. Specifically, it was observed that African-American families with a lower level of education deployed more coping strategies related to religious beliefs than African-American families with a higher level of education. Pattini et al. (2019) focused their research on psychological characteristics and physiological reactivity to acute stress in mothers of children with autism. Such mothers reported experiencing significantly higher levels of parenting-related stress, anxiety, negative emotions, and social inhibition, as well as a greater preference for avoidance strategies. They also showed a more pronounced increase in heart rate and cortisol levels during the psychosocial stress test than other mothers. A positive correlation was observed between the level of parental stress and the intensity of the cortisol response in both groups of mothers. These results suggest an excessive physiological response to acute psychosocial stress in mothers of children with autism. Research by McKee and colleagues (2020) evaluated the ability of the Family Adjustment Measure (FAM; Daire et al. 2014) to identify clinically significant stress in parents of young people with autism. The FAM was shown to be effective in its intended purpose, offering indicators as to which families may be at risk for poor resilience. The study by Downes and colleagues (2022) highlights how dyadic coping, i.e. how parents cope with stress together after their child's autism diagnosis, affects the quality of coparenting, along with perceived competence in their parenting role. Rizvi and Batool (2024) investigated the relationship between parental stress and the quality of coparenting in couples of parents with children with autism. What the authors found was that raising a child with autism generates high levels of stress in parents. The bidirectional relationship between stress and poor quality of the marital relationship was highlighted. In fact, stress negatively influences the quality of the marriage and at the same time poor marital satisfaction aggravates parenting stress. Boland, Barry and Lindsey (2024) investigated the issue of parental stress by considering the birth order of children with autism. Caregivers of first-born autistic children reported higher levels of stress than caregivers of children born later. This could be attributed to the

initial challenges and uncertainty faced during the first parenting experience of an autistic child. Meads and colleagues (2024) conducted a study that found that the stress level of parents with children with autism varies over time, with peaks associated with specific moments in the child's development, such as diagnosis, the start of school, and adolescence (a time of greater autonomy and higher social demands). However, as the years pass, many parents develop more effective coping strategies, leading to a gradual reduction in stress. Two studies (Galloway et al., 2019; Berenguer, Rosello and Miranda, 2021) examined how parental stress can affect children with ADHD. Specifically, Galloway et al. (2019) questioned whether parental stress could predict the quality of life of children with ADHD and found as parental stress increased, it also tended to decrease the child's quality of life. Furthermore, parents who gave lower scores to their child's quality of life, compared to the child's self-assigned scores, had higher levels of stress. Berenguer Rosello and Miranda (2021), on the other hand, showed that higher levels of maternal stress were associated with a higher frequency of problem behaviour in children with ADHD. Appropriate coping strategies can reduce the impact that maternal stress has on the behaviour of children with ADHD. The study by Sit and colleagues (2020) found that internal coping strategies can mitigate the effect of the Perceived Difficulty Scale (PD; Hastings and Taunt, 2002; Mak and Ho, 2007) on caregivers' depression and anxiety in caring for family members with disabilities, whereas external coping (i.e. asking others for help) exacerbated the effect of the Perceived Difficulty Scale and the Caregiving Burden Inventory (CBI; Chou et al., 2002) on depression and anxiety. A summary on the finds about impact on family functioning and family factors can be found in Table 6.

Title, author, year	Study design	Participants	Results
Improving family functioning following diagnosis of ASD: A randomized trial of a parent mentorship program (Moody, Kaiser, Sharp, Kubicek, Rigles, Davis, ... & Rosenberg, 2019)	Randomized trial	33 parents subjected to the program and 34 parents (from the waiting list) as a control group	Parents who took part in the programme reported improved family functioning, decreased parenting stress and increased satisfaction in their parenting role
Couples' experiences of parenting a child after an autism diagnosis: A qualitative study (Downes, Lichtlé, Lamore, Orève, & Cappe, 2021)	Qualitative study	10 couples of Parents with a Child Diagnosed with Autism	The diagnosis significantly increases stress within the relationship. However, effective communication, seeking external resources, and mutual support can help couples manage these

			challenges. Additionally, couples who shared parenting responsibilities and collaborated more closely reported a more positive experience in coping with the diagnosis and caring for their child
Parenting stress within mother-father dyads raising a young child with autism spectrum disorder (Patel, Rivard, Mello, & Morin, 2022)	Comparative study	258 mother-father dyads and their child with autism	Although both mothers and fathers experience stress, the mothers suffer more
Family functioning and emotional aspects of children with autism spectrum disorder in southern Brazil (Flenik, Bara, & Cordeiro, 2023)	Qualitative study	21 families with children with autism	Families with autistic children exhibited low levels of cohesion, expressiveness, and independence, along with low conflict levels. These families actively engaged in intellectual and religious activities but faced challenges in home organization. Additionally, 71% of parents reported sacrificing their dreams and plans to care for their child. Working mothers, in particular, spent less time on recreational activities and more on socializing, though many still struggled to participate in social events due to caregiving responsibilities
Pillar Mothers: Perspective on the Adaptation Process of Mothers of Autistic Children (Périard-Larivée, Godbout, Bégin, St-Laurent, de Serres-Lafontaine, De Pauw, & Bussièrès, 2024)	Qualitative study	17 Mothers of Children with Autism	The authors highlighted the complexity of mothers' adjustment to autism, a process that begins even before diagnosis. Stressors, facilitating factors, and adaptation outcomes were found to be deeply interconnected across psychological, social, professional, marital, and parenting domains. Stress accumulation emerged as the primary challenge,

				making it nearly impossible to mitigate its impact. Mothers reported difficulties in finding effective support to cope with these challenges. Despite variations in individual adaptation, all participants showed signs of distress
Development and Preliminary Validation of the Accommodations & Impact Scale for Developmental Disabilities (Udhnani, Miller, & Lecavalier, 2024)	Survey design		407 caregivers of young people with disabilities	The authors developed the Accommodation & Impact Scale for DD (AISDD), a tool to assess the impact of disability on families and changes in daily routines. The study confirmed AISDD as a valid and reliable measure of caregiver adaptations in families of individuals with intellectual disabilities
Perception of families of children with specific learning disorder: An exploratory study (Sahu, Bhargava, Sagar, & Mehta, 2018)	Descriptive study	qualitative	5 focus groups each composed of 30 parents of children with SLD	The authors found that parents of children with specific learning disorders struggled to adapt, particularly due to a lack of awareness about the diagnosis. Mothers spent significant time assisting with schoolwork, while fathers were often away for work, reducing quality time as a couple. This imbalance led to conflicts between spouses, both regarding parenting decisions and marital relationships
Studies with results about impact on family functioning and family factors with a specific focus on stress				
The role of child problem behaviors in autism spectrum symptoms and parenting stress: A primary school-based study (Siu, Yi, Chan, Chio, Chan, & Mak, 2019)	Case-control study		177 parents of children with autism and 554 parents of typically developing children	The authors found that problematic behavior is a key factor in the stress experienced by parents of children with autism. Higher symptom severity correlates with increased parental stress, making behavior management crucial for relief. The study emphasizes the importance

			of teachers as active participants in interventions, suggesting that reducing problematic behavior in children could help lower parental stress levels
Life after an autism spectrum disorder diagnosis: A comparison of stress and coping profiles of African American and Euro-American caregivers (Williams, Hartmann, Paulson, Raffaele, & Urbano, 2019)	Cross-sectional comparative study	52 Euro-American families and 51 African-American families	The study examined parental stress from a cultural perspective, comparing European-American and African-American families of children with autism. African-American parents reported higher stress levels and used more coping strategies. The study also found that within the African-American group, families with lower education levels relied more on religious-based coping strategies than those with higher education levels
Psychological characteristics and physiological reactivity to acute stress in mothers of children with autism spectrum disorder (Pattini, Carnevali, Troisi, Matrella, Rollo, Fornari, & Sgoifo, 2019)	Combination study	15 mothers of children with autism and 15 mothers of typically developing children	The study investigated the psychological traits and physiological reactivity to acute stress in mothers of children with autism. These mothers reported higher levels of parenting-related stress, anxiety, negative emotions, social inhibition, and a preference for avoidance strategies. They also exhibited a stronger physiological response to stress, with increased heart rate and cortisol levels during a psychosocial stress test. A positive correlation was found between parental stress levels and cortisol response intensity in both groups of mothers, suggesting an excessive physiological reaction to acute stress in mothers of children with autism

The family adjustment measure: Identifying stress in parents of youth with autism (McKee, Liu, Truong, Meinert, Daire, & Mire, 2020)	Cross-validation study	362 parents of children and adolescents with autism	The authors evaluated the effectiveness of the Family Adjustment Measure (FAM; Daire et al., 2014) in identifying clinically significant stress in parents of young people with autism. The study confirmed that the FAM is a useful tool for this purpose, providing indicators to identify families at risk of poor resilience
Dyadic coping and coparenting among couples after their child's recent autism diagnosis (Downes, Geoffray, Isnard, Lemonnier, Orève, & Cappe, 2022)	Cross-sectional study with a quantitative approach	70 couples of parents made up of mothers and fathers of children with autism	The study examined the impact of dyadic coping—how parents manage stress together after their child's autism diagnosis—on coparenting quality and perceived parenting competence. The study found that effective dyadic coping positively influences both factors
A qualitative study on perspective of parental stress and lower marital quality among parents of children with autism spectrum disorder (Rizvi, & Batool, 2024)	Qualitative study	15 mothers and 13 fathers of children with autism	Their findings indicate that parenting a child with autism leads to high stress levels. A bidirectional relationship was observed, where stress negatively impacts marital quality, and in turn, poor marital satisfaction exacerbates parenting stress
Differences in caregiver and child factors within families of autistic youth across birth order groups (Boland, Barry, & Lindsey, 2024)	Comparative and cross-sectional study	Three groups of caregivers 1) 34 caregivers with the firstborn with autism; 2) 43 caregivers with a child with autism, but not a firstborn; 3) 78 caregivers with only one child with autism	Caregivers of first-born autistic children reported higher stress levels than those of later-born autistic children, likely due to the initial challenges and uncertainty of parenting an autistic child for the first time
Brief report: Investigating temporal factors in the context of parenting an autistic child (Meads, Shepherd, Landon, & Goedeke, 2024)	Secondary analysis of cross-sectional data	291 parents of children with autism	The author's found that parental stress levels in families with autistic children fluctuate over time, peaking at key developmental stages such as diagnosis, school entry,

			and adolescence. However, over the years, many parents develop more effective coping strategies, leading to a gradual decrease in stress.
Does parent stress predict the quality of life of children with a diagnosis of ADHD? A comparison of parent and child perspectives (Galloway, Newman, Miller, & Yuill, 2019)	Cross-sectional study	45 parent-child dyads	The study found that higher parental stress levels were associated with a lower quality of life for the child with ADHD. Additionally, parents who rated their child's quality of life lower than the child's self-assessment experienced higher stress levels
Mothers' stress and behavioral and emotional problems in children with ADHD. Mediation of coping strategies (Berenguer, Rosello, & Miranda, 2021)	Cross sectional design	35 mothers of children with ADHD and 37 mothers of typically developing children	Higher levels of maternal stress were associated with a higher frequency of problem behaviour in children with ADHD. Appropriate coping strategies can reduce the impact that maternal stress has on the behaviour of children with ADHD
Caregiving burden among informal caregivers of people with disability (Sit, Huang, Chang, Chau, & Hall, 2020)		234 informal caregivers of families with individuals with intellectual or mental disabilities in Macau (China)	The study revealed that being a caregiver significantly contributes to stress, depression, and anxiety. Internal coping strategies can mitigate the effect of the Perceived Difficulty Scale on caregivers' depression and anxiety in caring for family members with disabilities, whereas external coping exacerbated the effect of the Perceived Difficulty Scale and the Caregiving Burden Inventory

Table 6. Studies with results about impact on family functioning and family factors

Availability and quality of services

The study by Parker and Killian (2020) focuses on the difficulties and obstacles that families with children with autism face in the context of health services. One of the most relevant themes that emerged is the lack of understanding and preparation of health professionals. Families report difficulties in accessing services, ineffective communication with doctors and inadequate support for the needs of their family members with autism. These types of situations lead to increased stress in caregivers. The study also draws attention to the need to provide autism-specific training for healthcare professionals. In Martin-Denham's (2022) analysis, many parents reported a lack of understanding, knowledge and support for their children with autism, which led to marginalisation and exclusion in the school context. This isolation not only had negative consequences for the children, but also influenced the caregivers, who felt abandoned by the school. The results of the study highlight the need for appropriate autism training for school staff so that they are prepared to offer the parents of these children the support and assistance they need. The study by Meads and colleagues (2024) found that the type and effectiveness of support tends to change over time as the child grows, with more practical support needed in the early stages and emotional support more necessary during the child's adolescence. Waiting time for diagnosis and access to necessary services is a major source of frustration and anxiety for parents. Parents participating in Sahu and colleagues' (2018) research reported delays in identifying the diagnosis of ASD for their children and a lack of support and guidance from teachers and counsellors on strategies to support their children's learning. A summary on the finds about availability and quality of services can be found in Table 7.

Title, authors, year	Study design	Participants	Results
Autism spectrum disorder and complex healthcare needs: The role of healthcare experiences (Parker, & Killian, 2020)	Qualitative study	1711 Parents of children with autism	A key issue identified was the lack of understanding and preparation among healthcare professionals. Families reported difficulties in accessing services, poor communication with doctors, and insufficient support for their autistic children's needs. These obstacles contributed to increased caregiver stress. The study emphasizes the importance of providing

			autism-specific training for healthcare providers
Marginalisation, autism and school exclusion: caregivers' perspectives (Martin-Denham, 2022)	Interpretative phenomenological analysis	5 Caregivers of Children with Autism	Many parents reported a lack of understanding, knowledge, and support for their autistic children within the school system, leading to marginalisation and exclusion. This isolation affected not only the children but also their caregivers, who felt abandoned by the school. The study highlights the urgent need for proper autism training for school staff to ensure they can provide appropriate support to both children and their parents
Brief report: Investigating temporal factors in the context of parenting an autistic child (Meads, Shepherd, Landon, & Goedeke, 2024)	Secondary analysis of cross-sectional data	291 parents of children with autism	The nature and effectiveness of support shift over time: practical help is more important in early childhood, while emotional support becomes more crucial during adolescence. Additionally, long waiting times for diagnosis and access to services were major sources of frustration and anxiety for parents
Perception of families of children with specific learning disorder: An exploratory study (Sahu, Bhargava, Sagar, & Mehta, 2018)	Descriptive qualitative study	5 focus groups each composed of 30 parents of children with SLD	Parents reported delays in receiving an ASD diagnosis for their children, as well as a lack of support and guidance from teachers and counsellors regarding effective learning strategies for their children

Table 7. Studies with results about availability and quality of services.

Level of wellbeing

Cox and colleagues (2015) conducted research on death-related thoughts in mothers of children with autism. The authors found that such mothers had worse psychological health.

In addition, they showed greater accessibility to thoughts of death than mothers of typically developing children but did not differ in explicit concerns about mortality. Greater accessibility to the thought of death in mothers of children with autism was associated with worse mental health. On the topic of mental health, the study by Cohrs and Leslie (2017) investigated the likelihood of receiving a diagnosis of depression in parents with typically developing children or children with autism. What emerged was that parents of children with autism were more likely to develop depression than those with typically developing children. Furthermore, the likelihood of receiving a depression diagnosis was greater with increasing age of the child with autism and the number of children with autism in the family. Cappe et al. (2021) tested the impact of a psycho-educational programme on stress and quality of life in parents with children with autism. Two versions of the programme were formulated, a full version (CV) and a short-form version (SV). Participants in the CV group appeared to be significantly less stressed and a significant improvement was observed in certain areas of their quality of life, specifically the relationship with their child, psychological well-being and personal fulfilment. No significant effects were observed in the parents of the SV group. Both groups highly appreciated the programme. Boland, Barry and Lindsey (2024) conducted research in which they considered the role of the birth order of autistic children and found that caregivers of first-born autistic children were more likely to report feelings of isolation and lack of support, whereas those with autistic children born later had better access to resources and support networks, probably due to their experience with their first child. The study by Liang and colleagues (2021) examines the influence that child, parent and family characteristics have on the health-related quality of life of mothers of children with ADHD. Evidence suggests that stress and complexities in managing one's child negatively impact all four domains (physical, psychological, social, environmental) of mothers' quality of life. Having social support and good family relationships seem to significantly improve mothers' well-being. Sit et al. (2020) by means of the Chinese version of the Caregiver Burden Inventory (CBI; Chou, Jiann-Chyun, & Chu, 2002) and the assessment of the perceived difficulty in caring for a person with a disability, showed how being a caregiver impacts people in terms of stress, depression and anxiety. Furthermore, the authors showed that being female was associated with a higher perceived burden in caring for a family member with a disability. Finally, a higher caregiving burden, a monthly household income of less than 5,000 Macao Pataca (MOP), more people in the household, and the use of external coping strategies were positively associated with anxiety. Sahu and colleagues (2018) pointed out that caregiver load is divided into five types of loads for

parents of children with ASD. The first was a physical type of load, i.e. having to spend more time than commonly needed to get their child to do a task as well as fatigue and poor quantity and quality of sleep. The second load was a personal one, i.e. parents stated that they had to invest more time in their child's learning, especially mothers. As a result, parents had fewer opportunities to spend quality time together, which discouraged and irritated mothers, leading to conflicts in both child-rearing and marriage. The third load was the social load: parents stated that they did not have the opportunity to engage in socialising due to the time taken up by their children's academic activities. The fourth load was financial: parents expressed that they had to resort to tutors or private centres to support their children's learning. Finally, the fifth load was related to emotions. Parents reported thinking more negatively and losing interest in activities they used to consider enjoyable. Feelings of anxiety and repressed negative emotions were also reported. A summary on the finds about level of wellbeing can be found in Table 8.

Title, authors, year	Study design	Participants	Results
Death concerns and psychological well-being in mothers of children with autism spectrum disorder (Cox, Eaton, Ekas, & Van Enkevort, 2015)	Quantitative experimental design	147 mothers, of which 47 with children with autism and 73 with typically developing children	Mothers of children with ASD had poorer psychological health compared to those of typically developing children. They also showed greater accessibility to death-related thoughts, although not higher explicit concerns about mortality. This increased accessibility was linked to worse mental health outcomes
Depression in parents of children diagnosed with autism spectrum disorder: A claims-based analysis (Cohrs, & Leslie, 2017)	Administrative data-driven analytics	42,649 families with one child with autism and 42,649 with typically developing children	Parents of children with autism were more likely to be diagnosed with depression. This likelihood increased with the child's age and the number of children with autism in the family
Preliminary results of the effects of a psychoeducational program on stress and quality of life among french parents of an child with autism (Cappe, Downes, Albert-Benaroya, Ech-Chouikh, De Gaulmyn, Luperto, ... & Sankey, 2021)	Preliminary experimental study	20 parents of children with autism took part in the short version of the program (SV group), 15 parents of children with autism took part in the full version of the program (CV group)	Two versions of a psycho-educational programme on stress and quality of life in parents of children with autism were tested: a comprehensive version (CV) and a short version (SV). Parents in the CV group showed significantly lower stress levels and

			improvements in areas such as their relationship with their child, psychological well-being, and personal fulfilment. No significant improvements were found in the SV group, although both groups expressed high satisfaction with the programme.
Differences in caregiver and child factors within families of autistic youth across birth order groups (Boland, Barry, & Lindsey, 2024)	Comparative and cross-sectional study	Three groups of caregivers 1) 34 caregivers with the firstborn with autism; 2) 43 caregivers with a child with autism, but not a firstborn; 3) 78 caregivers with only one child with autism	Caregivers of first-born autistic children were more likely to experience feelings of isolation and a lack of support. In contrast, those with later-born autistic children reported better access to resources and support networks, likely benefiting from the experience gained with their first child
Health-related quality of life in mothers of children with attention deficit hyperactivity disorder in Taiwan: The roles of child, parent, and family characteristics(Liang, Lee, Kelsen, Chen, 2021)	Report, part of a comparative study	257 children with ADHD and their mothers, 324 typically developing children and their mothers	The findings indicate that stress and difficulties in managing a child negatively impact all four domains of the quality of life (physical, psychological, social, environmental) of mothers' quality of life. However, social support and positive family relationships appear to significantly enhance mothers' well-being
Caregiving burden among informal caregivers of people with disability (Sit, Huang, Chang, Chau, & Hall, 2020)	Cross-sectional correlational study	234 informal caregivers of families with individuals with intellectual or mental disabilities in Macau (China)	Being female was linked to a higher perceived burden in caregiving. Additionally, a greater caregiving burden, a monthly household income below 5,000 Macao Pataca (MOP), more people in the household, and the use of external coping strategies were all positively associated with anxiety
Perception of families of children with specific learning disorder: An exploratory study (Sahu, Bhargava, Sagar, & Mehta, 2018)	Descriptive qualitative study	5 focus groups each composed of 30 parents of children with SLD	The study identified five types of caregiver load experienced by parents of children with ASD. The first was a physical load, involving more time and effort to get their child to complete tasks, along with fatigue and poor sleep. The second was a personal load,

where parents, particularly mothers, had to dedicate extra time to their child's learning, reducing quality family time and leading to conflicts in child-rearing and marriage. The third was a social load, as parents felt they had less opportunity for socializing due to their children's academic demands. The fourth was a financial load, with parents spending on tutors or private centers for their child's education. The fifth was an emotional load, where parents experienced negative thoughts, loss of interest in previously enjoyable activities, anxiety, and repressed negative emotions

Table 8. Studies with results about level of wellbeing.

Parental experiences

Mount and Dillon (2014) investigated parents' experiences of living with an adolescent child with autism. The parents interviewed stated that maintaining a sense of predictability for their child was burdensome. Communication difficulties could lead adolescents to have physical and verbal outbursts of anger towards their parents. Parents reported being mentally and physically tired. Despite this, having a diagnosis helped the parents to cooperate and accept their child's diagnosis. Rafferty, Tidman and Ekas (2020) investigated the parental experience of fathers of autistic children with and without intellectual disabilities. From their analysis, five main themes emerged. The first theme concerned pre-birth expectations, in which fathers discussed what kind of parent they would like to be and their involvement in raising and caring for their child. The remaining four themes were about post-diagnosis moments. The second theme concerned adjustments the fathers had to make after the diagnosis. These adjustments concerned aspects of daily life, but also expectations. Some fathers struggled to accept the diagnosis. The third theme concerned experiences in raising a child with autism. Many fathers revealed positive aspects of parenting and that they had become more empathetic. The fourth theme was about co-parenting, fathers spoke about the fact that they compare themselves with the other parent to make decisions about services for

their child. In addition, some fathers revealed that they perform certain tasks in caring for their child, while their wives engage in other care tasks. Finally, the fifth theme concerned the quality of the father-child relationship. All fathers stated that they had a good relationship with their child. Many were proud of the progress and skills their children had acquired. However, some fathers also reported that they sometimes had difficulties in the relationship, as the children did not always seem to reciprocate their feelings towards their fathers. The study by Kim and colleagues (2021) explores the motherhood experiences of Korean-American women, mothers of children with autism. The analysis identified four main themes. The first theme of interest was emotional distress: the mothers faced economic, language and immigration-related difficulties as primary caregivers. A second theme of interest was family relationships, specifically marital relationships varied, and neurotypical siblings learned acceptance, while mothers had the perception of neglecting them and felt guilty. Some family members had difficulty accepting the diagnosis. A third relevant point was the lifestyle of the mothers, who underwent career changes, but tended to maintain a connection with religion, although some mothers converted to different religions from those practised prior to their children's diagnosis. The fourth point worthy of attention concerned education: mothers prioritised private therapy over school. The study by Boland, Barry and Lindsey (2024) highlighted how the parental experience changes according to the birth order of children with autism. Specifically, birth order influenced the type and intensity of educational and therapeutic interventions. Autistic first-borns were more likely to receive early intensive interventions than autistic siblings born later. Meads and colleagues (2024) reported that parents of autistic children reported having an altered perception of time, perceiving time as 'accelerated' during times of crisis and 'slowed down' during waiting periods for services or diagnosis. Also related to the concept of time, the theme of 'stolen time' emerged, in which parents feel that the needs of their autistic child limit the time they can devote to other activities or relationships, including time for themselves or their other children. Parents also tend to make predictions for the future based on past experiences, which can lead to feelings of anxiety or hope. The ability to adjust and revise time expectations was identified as a key factor in parents' long-term well-being. Finally, the study examined how parents manage expectations, trying to balance planning for the future of their autistic child with the need to remain flexible in the face of uncertainty. A summary on the finds about parental experiences can be found in Table 9.

Title, authors, year	Study design	Participants	Results
Parents’ experiences of living with an adolescent diagnosed with an autism spectrum disorder (Mount & Dillon, 2014)	Qualitative study	9 parents of adolescents with autism from a school in the East Midlands (UK)	The parents reported that maintaining a sense of predictability for their child was challenging. Communication difficulties often led to physical and verbal outbursts of anger from the adolescents towards their parents. As a result, parents felt both mentally and physically exhausted. However, having a diagnosis helped parents cooperate and accept their child's condition
Parenting experiences of fathers of children with autism spectrum disorder with or without intellectual disability (Rafferty, Tidman, & Ekas, 2020)	Qualitative study	12 fathers with children with autism and 16 fathers with children with autism and intellectual disability	The analysis revealed five main themes. The first theme was pre-birth expectations, where fathers discussed their hopes for parenthood and their involvement in raising their child. The next four themes focused on post-diagnosis experiences. The second theme dealt with adjustments fathers had to make after the diagnosis, including changes in daily life and expectations, with some fathers struggling to accept the diagnosis. The third theme highlighted the experiences of raising a child with autism, with many fathers reporting positive aspects of parenting and increased empathy. The fourth theme involved co-parenting, where fathers discussed comparing themselves to their partner and sharing caregiving tasks. The final theme was the father-child relationship. All fathers reported a strong bond with their child and pride in their

				child's progress, though some noted occasional difficulties due to their child not always reciprocating feelings
Experiences and impact of having children with autism spectrum disorder on the lives of their Korean-American mothers (Kim S., Kim H, Kim J., Nichols & Kang, 2021)	Qualitative study	5	Korean-American Mothers of Children with Autism	Four main themes were identified. The first was emotional distress, as mothers faced economic, language, and immigration challenges while being primary caregivers. The second theme focused on family relationships, with marital dynamics varying, neurotypical siblings learning acceptance, and mothers feeling guilty for neglecting them. Some family members struggled to accept the diagnosis. The third theme concerned the mothers' lifestyle, with many undergoing career changes but maintaining a connection to religion, and some even converting to new religions after their child's diagnosis. The fourth theme was education, where mothers prioritized private therapy over school for their child
Differences in caregiver and child factors within families of autistic youth across birth order groups (Boland, Barry, & Lindsey, 2024)	Comparative and cross-sectional study	Three groups of caregivers	1) 34 caregivers with the firstborn with autism; 2) 43 caregivers with a child with autism, but not a firstborn; 3) 78 caregivers with only one child with autism	Birth order influenced the type and intensity of educational and therapeutic interventions, with first-born autistic children more likely to receive early intensive interventions compared to later-born siblings
Brief report: Investigating temporal factors in the context of parenting an autistic child (Meads, Shepherd, Landon, & Goedeke, 2024)	Secondary analysis of cross-sectional data	291	parents of children with autism	The study found that parents of autistic children often experience an altered perception of time, feeling it as "accelerated" during crises and "slowed down" during waiting periods for services or diagnoses. The

theme of "stolen time" emerged, where parents feel their child's needs limit the time available for other activities or relationships, including personal time or time with other children. Parents also tend to predict the future based on past experiences, leading to feelings of anxiety or hope. The study identified the ability to adjust and revise time expectations as crucial for parents' long-term well-being. Additionally, it examined how parents manage expectations by balancing planning for their child's future with the need for flexibility in the face of uncertainty

Table 9. Studies with results about parental experiences.

Reaction to diagnosis

Reed and Osborne (2019) studied how mothers' reaction to their children's autism diagnosis may influence maternal health status. The authors divided the mothers into two groups: those with a 'resolved' reaction to the diagnosis and those with an 'unresolved' reaction. It is clear from the results that the second group had a worse health status both in terms of perceived physical symptoms and self-reported illnesses at the time of diagnosis. The researchers also showed that worse health levels were present for over a year in mothers with an unresolved experience towards their child's diagnosis. In contrast, a 'resolved' reaction was correlated with psychological well-being at the time of diagnosis. Aguiar and Pondé (2020) studied the impact of an autism diagnosis on parents, revealing differences between mothers and fathers. Most mothers expressed feelings of despair, sadness and anguish upon hearing the news of the diagnosis. Some mothers showed signs of the emotional impact of the moment, while others simply asked questions about possible treatments and special needs schools. None of the fathers, on the other hand, showed great signs of emotion when the diagnosis was communicated, but the majority nevertheless described the moment as sad, difficult, and a shock. Among the mothers, but not among the fathers, the issue of how the diagnosis was communicated emerged. In particular, the manner of communicating the diagnosis was

considered inadequate in cases where the practitioner was pretentious, gave little explanation and focused on the negative aspects. Inadequate communication, on the other hand, the practitioner was able to soften the more negative aspects related to the diagnosis, provided information and was able to accommodate the mothers' pain with sensitivity. The study by Boland, Barry and Lindsey (2024) showed that the reaction to and acceptance of the diagnosis could vary according to the birth order of children with autism. Parents of first-born autistic children often had higher expectations and found it more difficult to adapt to the diagnosis, whereas parents of children born later had more realistic expectations and adapted more quickly. Sahu and colleagues (2018) described that parents of children with SLD reacted to their children's diagnosis in three ways: denial, excessive denial and involvement, and loss of hope. Those who reacted with denial believed that their child's poor academic performance was caused by teachers, the school system or the child's problematic behaviour. The reaction of denial was related to the lack of knowledge of the disorder. Finally, some parents tried to help their children as much as possible, in some cases even giving up work to devote themselves to their child's learning. However, this investment did not always lead to the desired results for the parents, generating a loss of hope and concern about their child's possible future career. A summary on the finds about reaction to diagnosis can be found in Table 10.

Title, authors, year	Study design	Participants	Results
Reaction to diagnosis and subsequent health in mothers of children with autism spectrum disorder (Reed, & Osborne, 2019)	Longitudinal experimental design	84 mothers of children with autism	The researchers divided mothers into two groups: those with a "resolved" reaction to their children's diagnosis and those with an "unresolved" reaction. The study found that mothers with an unresolved reaction had worse health, both in terms of perceived physical symptoms and self-reported illnesses at the time of diagnosis. These negative health effects persisted for over a year. In contrast, mothers with a resolved reaction experienced better psychological well-being at the time of diagnosis

<p>Autism: impact of the diagnosis in the parents (Aguiar & Pondé, 2020)</p>	<p>Qualitative study</p>	<p>21 mothers and 9 fathers of children with autism enrolled in a school for special educational needs in Brazil. 11 mothers and 5 fathers of a university service for the diagnosis of autism</p>	<p>Most mothers felt despair, sadness, and anguish upon hearing the diagnosis. Some showed emotional reactions, while others focused on questions about treatments and special needs schools. In contrast, fathers did not show strong emotional reactions but described the moment as sad, difficult, and shocking. The way the diagnosis was communicated was a significant issue for mothers, but not for fathers. Mothers felt the communication was inadequate when the practitioner was dismissive, gave little explanation, and focused on negative aspects. However, when the practitioner was more sensitive, provided information, and softened the negative aspects, it helped accommodate the mothers' pain</p>
<p>Differences in caregiver and child factors within families of autistic youth across birth order groups (Boland, Barry, & Lindsey, 2024)</p>	<p>Comparative and cross-sectional study</p>	<p>Three groups of caregivers 1) 34 caregivers with the firstborn with autism; 2) 43 caregivers with a child with autism, but not a firstborn; 3) 78 caregivers with only one child with autism</p>	<p>Parents' reactions to and acceptance of an autism diagnosis varied based on the birth order of their children. Parents of first-born autistic children often had higher expectations and struggled more with adapting to the diagnosis, while parents of later-born children had more realistic expectations and adapted more quickly</p>
<p>Perception of families of children with specific learning disorder: An exploratory study (Sahu, Bhargava, Sagar, & Mehta, 2018)</p>	<p>Descriptive qualitative study</p>	<p>5 focus groups each composed of 30 parents of children with SLD</p>	<p>The study described three common reactions of parents to their children's SLD diagnosis: denial, excessive denial and involvement, and loss of hope. Parents who reacted with denial blamed their child's poor academic performance on teachers, the school system, or the child's behaviour, often due to a lack of knowledge about the disorder. Some parents, in an attempt to help their children,</p>

became excessively involved, even sacrificing work to focus on their child's learning. However, this intense investment did not always yield the desired results, leading to feelings of hopelessness and concern about their child's future

Table 10. Studies with results about reaction to diagnosis.

Caregiver burden

From the findings of Sit and colleagues (2020) on the caregiver experience for a family member with a disability, it was revealed that the Chinese version of the Caregiving Burden Inventory (CBI; Chou, Jiann-Chyun, & Chu, 2002) and the Perceived Difficulty Scale (PD; Hastings and Taunt, 2002; Mak and Ho, 2007) are associated with depression, stress and anxiety in caregivers. Furthermore, the authors showed that being female was associated with a higher perceived burden in caring for a family member with a disability. Finally, a higher caregiving burden, a monthly household income of less than 5,000 Macao Pataca (MOP), more people in the household, and the use of external coping strategies were positively associated with anxiety. Sahu and colleagues (2018) pointed out that caregiver load is divided into five types of loads for parents of children with SLD. The first was a physical load, i.e. having to spend more time than is commonly needed to get their child to do a task as well as fatigue and poor quantity and quality of sleep. The second load was a personal one, i.e. parents stated that they had to invest more time in their child's learning, especially mothers. As a result, parents had fewer opportunities to spend quality time together, which discouraged and irritated mothers, leading to conflicts in both child-rearing and marriage. The third load was the social load: parents stated that they did not have the opportunity to engage in socialising due to the time taken up by their children's academic activities. The fourth load was financial: parents expressed that they had to resort to tutors or private centres to support their children's learning. Finally, the fifth load was related to emotions. Parents reported thinking more negatively and losing interest in activities they used to consider enjoyable. Feelings of anxiety and repressed negative emotions were also reported. A summary on the finds about caregiver burden can be found in Table 11.

Title, authors, year	Study design	Participants	Results
Caregiving burden among informal caregivers of people with disability (Sit, Huang, Chang, Chau, & Hall, 2020)	Cross-sectional correlational study	234 informal caregivers of families with individuals with intellectual or mental disabilities in Macau (China)	The authors found that the Chinese versions of the Caregiving Burden Inventory (CBI) and the Perceived Difficulty Scale (PD) were linked to depression, stress, and anxiety in caregivers. The study also revealed that being female was associated with a higher perceived burden in caring for a family member with a disability. Additionally, a higher caregiving burden, a monthly household income of less than 5,000 Macao Pataca (MOP), more people in the household, and the use of external coping strategies were positively associated with anxiety
Perception of families of children with specific learning disorder: An exploratory study (Sahu, Bhargava, Sagar, & Mehta, 2018)	Descriptive qualitative study	5 focus groups each composed of 30 parents of children with SLD	Five types of caregiver load were experienced by parents of children with SLD. The first was a physical load, where parents spent more time than usual helping their child complete tasks, leading to fatigue and poor sleep. The second was a personal load, where parents, especially mothers, had to invest more time in their child's learning, which reduced opportunities for quality family time, causing frustration and conflicts in both child-rearing and marriage. The third was a social load, as parents had limited time for socializing due to their children's academic demands. The fourth was a financial load, with parents needing to hire tutors or use private centers to support their child's education. The fifth was an emotional load, as parents experienced negative thoughts, lost interest in enjoyable activities, and reported feelings of anxiety and repressed negative emotions

Table 11. Studies with results about caregiver burden.

Discussion

The aim of this paper was to summarise the findings regarding parenting in families with neurodivergent children. As it turned out in the search for articles to be included in this review, the definition of “Neurodivergence” is still imprecise, which may be one reason why it is also underused. Compared to other literature reviews, which had focused on single diagnoses (Turnage and Connor, 2022; PV and Kotian, 2022), with this article the authors wanted to propose a more wide-ranging view on the parental well-being of parents with neurodivergent children. The articles examined were collected using the PRISMA Statement methodology (Moher et al., 2009), covering the time span between 2014 and 2024, to have as complete and, at the same time, recent and up-to-date a view as possible. From the survey conducted, a discrete variety of item types and parental aspects studied emerged. In particular, it was observed that some topics were common to several parents with children with different neurodivergences. The theme of the impact on family functioning and family factors is present in families with children with autism (Moody et al., 2019; Downes et al., 2021; Downes et al., 2022; Patel et al., 2022; Flenik, Bara and Cordeiro, 2023; Périard-Larivée et al., 2024), intellectual disability (Udhani, Miller and Lecavalier, 2024) and specific learning disabilities (Sahu et al., 2018). Within the topic area on family functioning, parental stress is a common topic for families with children with autism (Siu et al., 2019; Williams et al., 2019; Pattini et al., 2019; McKee et al., 2020; Downes et al., 2022; Rizvi and Batool, 2024; Boland, Barry and Lindsey, 2024; Meads et al., 2024), with ADHD (Galloway et al., 2019; Berenguer, Rosello and Miranda, 2021), with intellectual disabilities (Sit et al., 2020). The issue of access to and quality of services emerged in articles on parents of children with autism (Parker and Killian, 2020; Martin-Denham, 2022; Meads et al., 2024), with ADHD (Ferrin et al., 2014) and with ASD (Sahu et al., 2018), while that of the level of well-being is present in research on families with children with autism (Cox et al., 2015; Cohrs and Leslie, 2017; Cappe et al., 2021; Boland, Barry and Lindsey, 2024), with ADHD (Liang et al., 2021), with disabilities (Sit et al., 2020) and with DSA (Sahu et al., 2018). Finally, psychoeducation, support and mindfulness interventions have been found to be relevant in articles on families with children with ADHD (Ferrin et al., 2014) and with DSA (Sahu et al., 2018). From the literature, it appears crucial to investigate the well-being and need for support of parents of neurodivergent children (D'Arcy et al., 2024). The results

highlight that such parents experience low levels of well-being and high levels of stress, having overall poor mental health (D'Arcy et al., 2024). Therefore, the need for intervention to adequately support the psychological well-being of these parents is highlighted, to prevent the negative consequences that chronic stress can have on mental health in the long term (Manning et al., 2021). In general, in studies comparing parents of neurodivergent children with parents of typically developing children, it was found that parents of neurodivergent children report lower psychological well-being than parents of typically developing children. In the study by Cox et al. (2015), mothers of autistic children report more death-related concerns than their counterparts with typically developing children. In the study by Cohrs and Leslie (2017), it was found that mothers and fathers of children with autism were more likely to be diagnosed with depression than parents of typically developing children. Siu and colleagues (2019) highlighted how parents of children with autism report higher levels of stress than those with typically developing children. Pattini et al. (2019) highlighted that mothers of children with autism have higher physiological reactivity to stress and higher levels of depression and anxiety than mothers of typically developing children. In the study by Liang and colleagues (2021), it was shown that mothers of children with ADHD reported significantly worse health-related quality of life (HRQOL) than mothers of children with typical development. Berenguer, Rosello and Miranda (2021) compared mothers of children with ADHD and mothers of typically developing children. What emerged was that the mothers' stress and their children's behavioural/emotional problems were significantly higher in the group with ADHD than in the group without ADHD. Despite the variety of diagnoses, experimental designs and samples examined, some form of psychological distress in parents of neurodivergent children emerges from all articles. It is therefore possible to infer the need to think about parenting support interventions tailored to the needs of parents who have to bring up neurodivergent children.

Limitations of the studies

The studies analysed are not without their limitations. The limitations found in the studies concern: the experimental design and the methodology adopted, the type and size of the population sample chosen, bias, the lack of consideration of factors that could have led to different results, the generalisability of the results, the fact that they did not fully demonstrate what the researchers had set out to do, and the lack of results on possible long-term effects. The limitation most commonly encountered concerns the methodology adopted, specifically below are the studies in which this was found. Mount and Dillon (2014)

used qualitative interviews in their research, which, while providing an accurate analysis of personal experiences, did not allow for the establishment of causal relationships and the collection of quantitative data. Aguiar and Pondé (2020) also favoured the qualitative method for their research, but this resulted in not being able to produce generalisable statistics. In the study by Downes and colleagues (2021), longitudinal data were missing due to the cross-sectional nature of the study. Martin-Denham (2022) adopted a qualitative methodology that hinders the possibility of taking objective measures and making statistical generalisations. Rizvi and Batool's (2024) research lack quantitative data due to the qualitative nature of the approach adopted. Cox and colleagues (2015) adopted a cross-sectional approach, so it is difficult to determine whether the observed differences are due to having a child with autism or to other factors. This approach was also chosen by: Siu and colleagues (2019), Galloway and colleagues (2019), Sit and colleagues (2020), Liang and colleagues (2021) and Berenguer, Rosello and Miranda (2021), making it difficult to draw causal relationships. In the study by Parker and Killian (2020), the use of cross-sectional data did not allow the influence of autism and health experiences on parental well-being to be examined. In the studies by Downes and colleagues (2022) and Meads and colleagues (2024), longitudinal data were missing due to the cross-sectional nature of the studies. The limitation of the cross-sectional studies is that they collect data at a single point in time, making it challenging to establish causal relationships between variables. While they can identify associations, they cannot prove causality, which limits the generalization of conclusions to contexts where the relationship between variables remains stable over time. Additionally, if the sample is not representative of the broader population, the conclusions may not apply to all groups. For instance, a cross-sectional study examining the impact of a condition on a small group may not accurately reflect the experiences of others with different characteristics. In the research conducted by Ferrin et al. (2014), the instruments used are observational questionnaires completed by parents and clinicians, not behavioural or cognitive measures. Furthermore, there is a lack of separation of comparisons between the various intervention blocks. Williams et al. (2019) used an online format, which did not allow them to assess whether those who completed the measurements were actually caregivers of a child with autism. Furthermore, the level of acculturation was measured with the African American Acculturation Scale-Revised (AAASR; Klonoff and Landrine, 2000), an instrument from 2000 and thus somewhat dated. Even in the study by Patel and colleagues (2022), an instrument that was not quite fit for purpose was used, i.e. the Childhood Autism Rating Scale (CARS; Schopler et al., 1988) was used to measure the symptoms of autism

instead of more commonly used instruments for this purpose, such as the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999). Furthermore, in the study by Patel et al. (2022) there was a high drop-out rate in the sample. The study by Boland, Barry and Lindsey (2024) investigated the constructs of interest only by means of parent reports, without using additional, more objective instruments. Galloway et al. (2019), Cappe et al. (2021) and Flenik et al. (2023) structured their research without providing for a control group; this lack makes the experimental designs of the studies lose robustness. In the study by Périard-Larivée et al. (2024), given the different meanings of the word ‘adaptation’, several participants had difficulty answering one of the questions on this topic. Furthermore, it was not possible to conduct the interviews in person due to the restrictions for COVID-19, so the experimenters may not have had access to non-verbal information. Sahu et al. (2018) conducted exploratory research, from which no conclusive results can be drawn. A second limitation found in several studies concerns the type of sample. Small samples limit the ability to detect significant effects. This means that observed effects may not be real or significant at the population level. With small samples, individual variability is more pronounced, and the results may reflect specific experiences of a small group rather than general trends. Additionally, a small sample may lack the diversity needed to represent the broader population, leading to conclusions that are not applicable to larger or different groups. Specifically, several studies have limited themselves to investigating samples of populations that are too specific to be able to generalise the results to different populations, while other studies have adopted small samples. Articles that have investigated samples of specific populations will be listed below. Cox and colleagues (2015), Reed and Osborne (2019), Pattini and colleagues (2019) and Périard-Larivée and colleagues (2024) used a sample of mothers only. The themes that emerged from Rafferty, Tidman and Ekas (2020) research may be peculiar to the population examined, namely fathers with children with autism. Sit et al (2020) adopted a specific sample of informal caregivers only. Siu et al. (2019) recruited parents from intervention programmes, so parents who do not participate in such programmes might have been left out. Furthermore, the data collected are primarily based on mothers, as were those from the study by Cappe and colleagues (2021) and Boland, Berry and Lindsey (2024). McKee et al. (2020) collected a sample of families who had already participated in the Simons Simplex Collection (SSC) and who had a high level of education and a higher-than-average annual salary. The participants selected by Udhmani, Miller and Lecavalier (2024) were also not representative for household economic situation and educational level. Cohrs and Leslie (2017) only conducted their research on patients

with employer-paid health insurance. The sample of the study by Downes et al (2021) is heterogeneous, but not heterogeneous enough to also explore cultural differences, different family structures and different socio-economic situations. The study focuses only on parental couples of people who are still in an intimate relationship. Most of the sample consisted of families with male children with autism. Also, in a later study Downes and colleagues (2022) only recruited parent couples in an intimate relationship. The sample of Ferrin et al. (2014) did not include individuals undergoing drug treatment, while Flenik et al. (2023) excluded families with children with mild or severe autism from their sample, focusing only on families with children with mild autism. The following studies had a small sample number: Mount and Dillon (2014), Ferrin et al. (2014), Sahu et al. (2018), Pattini et al. (2019), Galloway et al. (2019), Aguiar and Pondé (2020), Kim et al. (2021), Cappe et al. (2021), Berenguer, Rosello and Miranda (2021), Martin-Denham (2022), Flenik et al. (2023), Udhmani Miller and Lecavalier (2024). Some studies have revealed biases, which will be explained below. In the studies by Cox et al. (2015) and Reed and Osborne (2019), a self-selection bias is present, as the participants are volunteers. In the study by Liang and colleagues (2021), children with ADHD and their mothers were recruited through a paediatric clinic, while families with typically developing children were volunteers, so a selection bias is present.

Siu et al. (2019) collected self-report data from parents (on the severity of autism symptoms and children's problem behaviours). Similarly, in the study by Liang et al. (2021), maternal and children's psychopathology and perceived family support were only measured with reports compiled by mothers. In the study by Berenguer, Rosello and Miranda (2021), information was also collected from mothers. Aguiar and Pondé (2020) based their research on parents' self-reports, which can be influenced by subjective bias. The protocol tested by Kim et al. (2021) was created by the first and second author, so bias in the creation of this instrument cannot be excluded. Downes and colleagues (2021) structured a study involving couple interviews. This mode may have limited the partners to express themselves freely, so the answers could be tainted by bias. The data collected by Sit et al. (2021) might be subject to social desirability bias, i.e. there might be an underestimation of the true prevalence of mental health problems. Data collected through interviews by Rizvi and Batool (2024) could also be subject to social desirability bias. In some studies, there was a limitation of not including certain factors in their survey, which could have had an influence on the results. Reed and Osborne (2019) did not consider the health status of mothers prior

to autism diagnosis. Parker and Killian (2020) did not include any latent constructs or the use of correlated error terms that could have introduced unexplained variances into the model. For Sit et al. (2020), it was not possible to measure family composition or to have information on who refused to participate. Liang et al. (2021) neglected the measurement of variables related to maternal mental health and paternal ADHD symptoms. Furthermore, the mothers' interpersonal problems were assessed with only two questions. Depression levels were not assessed. Berenguer, Rosello and Miranda (2021) did not take socioeconomic factors into account. Downes et al., 2022 did not observe potentially relevant variables such as the family support network, sibling data or children's problematic behaviour. Patel et al. (2022) did not investigate other child characteristics that might have been associated with parental stress. Boland, Barry and Lindsey (2024) considered ethnic differences for information purposes only. The study did not consider collecting data on the neurotype of the parents. Some studies have led to results that are not very generalisable, specifically: Moody et al. (2019), Pattini et al. (2019), Parker and Killian (2020), Rafferty, Tidman and Ekas (2020), McKee et al. (2020), Kim et al. (2021). One reason for low generalisability was that the research was conducted with too specific a sample (Moody et al., 2019; Parker & Killian, 2020; Rafferty, Tidman and Ekas 2020; McKee et al., 2020). A few studies, despite their initial premises, failed to prove all that they set out to do. Pattini et al. (2019) failed to demonstrate whether personality, psychological characteristics and coping strategies mediated the effect of parental stress on individuals' responses to stress. The study by Rafferty, Tidman and Ekas (2020) failed to draw comparative conclusions on the differences between fathers with children with autism and fathers with children with autism and intellectual disability. In the study by Liang et al. (2021), the associations between variables and quality of life of mothers of children with ADHD and with typically developing children were not particularly clinically and practically significant. Finally, in the study by Moody and colleagues (2019), it was revealed that the long-term effects of the mentorship programme were not explored.

Limitations of the review

This review has limitations of its own. In particular, this work had set itself the goal of understanding how the parents of neurodivergent children are doing. However, as the definition of 'neurodivergence' is still very recent and, consequently, little used, it was complex to find articles using this concept as a keyword, which is why the authors preferred to divide the search into several searches, each time changing the diagnostic framework of

interest. This strategy resulted in finding an uneven number of articles for each diagnosis. In fact, the number of articles concerning autism is unbalanced compared to the other diagnoses, in particular that of specific learning disorder, for which only one article was found. Future systematic reviews could benefit from more widespread use of the concept of neurodivergence. In addition, one might consider structuring review with a more balanced number of articles for each diagnosis, to have a more complete picture of parental well-being with respect to the various experiences of neurodivergence. Moreover, could be interesting to include more studies with longitudinal designs to assess long-term parental well-being.

Implications for future practice

Parents of neurodivergent children experience high levels of stress (Williams et al., 2019; Galloway et al., 2019; Berenguer, Rosello and Miranda, 2021; Downes et al., 2022; Rizvi & Batool, 2024), anxiety and depression (Cohrs & Leslie, 2017; Cox et al., 2015). It is, therefore, crucial to create emotional support services to support the mental health of parents of neurodivergent children. These services can also be designed as psycho-educational programmes for the parents themselves, with the aim of increasing knowledge about their children's neurodivergence, thus increasing the quality of life of the family system, as suggested by the studies of Cappe et al. (2021) and Ferrin et al. (2024). In addition, monitoring moments could be envisaged, with the use of instruments such as the Family Adjustment Measure (FAM; Daire et al. 2014) and the Accommodation & Impact Scale for DD (AISDD; Udhmani, Miller and Lecavalier, 2024). Furthermore, it seems to be necessary to also structure interventions to support parents from a couple and co-parenting perspective (Downes et al., 2022), supporting parents in developing shared strategies. A few studies (Parker & Killian, 2020; Martin-Denham, 2022) have shown that parents not infrequently struggle to access services and receive the support they need, both in the health and education spheres. It is therefore important to provide awareness-raising and training for health and school personnel who interface with neurodivergent children and adolescents. A further point of interest is family adaptation to neurodivergence, which can have a significant impact on family functioning (Flenik et al., 2023). It may therefore be important to implement support networks for families with neurodivergent children by creating family groups that can share similar experiences. Finally, some studies (Sahu et al., 2018; Parker and Killian, 2020; Martin-Denham, 2022; Meads et al., 2024) have highlighted the difficulty

in obtaining a diagnosis and in accessing appropriate services. It is, therefore, crucial to expand the network of services and shorten waiting times for access, in order to guarantee the necessary support within a short timeframe, which also enables the implementation of early interventions, both for children and parents. In conclusion, from a clinical practice point of view, more early interventions and psychoeducational programmes for parents of neurodivergent children should be available and easy to access. From a policy recommendation perspective, both public and private services for neurodivergent children and their families should be easily accessible both financially and in terms of timing (e.g. waiting lists that are not excessively long). Finally, from a research point of view, it might be interesting, in a few years' time, to conduct a review to see if and what changes there will have been not only on parental well-being in parents of neurodivergent children, but also in the definition of “neurodivergence” and in terms of support interventions.

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Declaration of Interest statement

Declarations of interest: none.

Authors' contribution

The first author assisted with conceptualization, investigation, methodology, writing-original draft, writing-review and editing; the second author assisted with conceptualization and editing; the third author assisted with conceptualization and study supervision. All authors contributed to and have approved the final manuscript.

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