PARENTS' AND GUARDIANS' EXPERIENCES IN ACCESSING AUTISM SPECTRUM DISORDER DIAGNOSTIC SERVICES FOR CHILDREN

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A thesis submitted to the School of Graduate Studies in partial fulfillment of the requirements for the degree of

Doctor of Philosophy (Clinical Epidemiology)

Faculty of Medicine

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February 2025

St. John's Newfoundland and Labrador, Canada

Abstract

Background: Since 1990, there has been a global increase in the incidence of Autism Spectrum Disorder (ASD). As a result, there are additional demands for assessment, diagnostic, and treatment services, already identified as being inadequate in many jurisdictions. Early identification and diagnosis of ASD is a priority because the best chance of improving symptoms occurs through early and intensive interventions. A definitive diagnosis is often a prerequisite for children to access publicly funded healthcare services when available. Yet obtaining a diagnosis in itself can be stressful, frustrating, and time-consuming for many parents. It is important to understand parents' experiences and the barriers they face in the process of accessing autism spectrum disorder diagnostic services for their children.

Aim: To examine parents' experiences in accessing autism spectrum disorder diagnostic services for their children and the barriers they face in that process.

Methods: Qualitative research methodologies were used that included: grounded theory, descriptive exploratory methods, and the Joanna Briggs Institute methodology for systematic reviews of qualitative evidence. Analysis of interview data included constant comparative analysis, reflexive thematic analysis, and systematic data synthesis. A total of 32 parents and caregivers of children and youth diagnosed with ASD participated in in-depth, semi-structured interviews. The systematic review included 36 studies that varied in qualitative research designs with high methodological quality.

Results: Parents' experiences in accessing timely autism spectrum diagnostic services are impacted by factors that include: parents' skills and capacity to advocate on their child's behalf, severity of the disorder, time commitments involved in parenting a child with the disorder, perceived stigma related to their child's diagnosis, delays in accessing diagnosis and supportive

services, lack of information provided to them by healthcare practitioners, lack of availability of diagnostic services, encountering healthcare professionals with a lack of specialized knowledge, experienced confusion surrounding inaccurate or mixed diagnosis relating to co-morbidities, and socioeconomic and cultural disparities.

Conclusions: There is a need to address wait times for services, and provide education and support services to parents and healthcare providers. These support services should focus on improving self-advocacy skills and reducing contextual and systemic barriers to accessing autism spectrum disorder diagnostic services including socioeconomic and cultural disparities. Study findings indicate further recommendations for policy, practice and research.

Key Words: Access, autism spectrum disorder, barriers and facilitators, child advocacy, diagnostic services, parents, qualitative research, socioeconomic status

Lay Summary

Autism Spectrum Disorder is a group of developmental conditions related to development of the brain. The exact cause of this condition is not known. About 1 in 100 children has autism spectrum disorder and the rates are increasing. This condition appears in different forms with varying levels of severity. Each individual with this condition experiences their own unique strengths, symptoms, and challenges. This condition affects how people interact, communicate, learn and behave. Experts agree that the best chance of improving symptoms is early diagnosis and providing early intervention and supportive services. Autism spectrum disorder can be detected in early childhood but many are not diagnosed until later in life. It is important to understand the barriers to early assessment and diagnosis for children with autism spectrum disorder.

The aim of this research was to understand parents' experiences and the challenges they face in accessing autism spectrum diagnostic services for their children. We interviewed 32 parents and caregivers of children diagnosed with this condition in Atlantic Canada. We also conducted a systematic review of 36 qualitative studies to capture a global perspective of parents' and guardians experiences in accessing autism spectrum diagnostic services for their children.

Findings from this research revealed that parents and caregivers faced delays in accessing autism spectrum diagnostic and supportive services for their children. They were challenged by the lack of available autism spectrum disorder assessment and diagnostic services, financial inequalities, cultural differences, and stigma. They experienced confusion when they were provided inaccurate or mixed diagnoses by healthcare providers with a lack of specialized knowledge about autism spectrum disorder.

Parents and caregivers of children with autism spectrum disorder need education, support and guidance during autism spectrum disorder assessment and diagnosis. Strategies need to be developed to reduce wait times for services. Policies need to be developed to address financial inequalities, cultural differences, and stigma. Further research is needed to understand the needs of healthcare providers working with parents and caregivers of children with autism spectrum disorder.

Dedication and Acknowledgements

I dedicate this thesis to the memory of my son, Christopher who will remain in our hearts forever. Christopher was a loving and caring son and a wonderful father to his two daughters, Bianca and Allison.

We acknowledge that the lands on which Memorial University's campuses are situated are in the traditional territories of diverse Indigenous groups, and we acknowledge with respect the diverse histories and cultures of the Beothuk, Mi'kmaq, Innu, and Inuit of this province.

I would like to thank my academic supervisory committee: Dr. Roger Chafe, Dr. Rick Audas, Dr. Diana Gustafson, and Dr. Gerald Mugford for their professionalism, guidance, kindness and support throughout my PhD program. You have all supported me both professionally and personally. I would like to express my sincere appreciation for all your care and encouragement.

I wish to express my appreciation to the participants in the studies who were willing to share their experiences in accessing autism spectrum disorder assessments and diagnostic services for their children and youth. Thank you for your time and support of this meaningful work.

I wish to thank Memorial University and my friends and colleagues in the Faculty of Nursing who have supported me throughout my educational, employment, and life experiences.

I would like to thank Patti, my lifelong friend, who has supported me in all my endeavors and provided encouragement along my life journey.

I am also grateful for the support from my husband, Gerard, my son Trevor and his wife, Julie, Chris' widow, Line and my three grandchildren. Owen (aged 10) is a handsome, kind and talented rising soccer star and inspiring computer enthusiast like his dad, Trevor. Bianca (aged 8)

and Allison (aged 6), Christopher's beautiful daughters are talented upcoming ballerinas who are avid book enthusiasts and creative artists. They are both kind and caring just like their father, now their guardian angel watching over them keeping them safe.

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List of Abbreviations

American Psychiatric Association (APA)

Applied Behavior Analysis (ABA)

Atlantic Canada Children's Effective Service Strategies in Mental Health (ACCESS-MH)

Attention Deficit Hyperactivity Disorder (ADHD)

Autism Diagnostic Observation Schedule (ADOS)

Autism Spectrum Disorder (ASD)

Diagnostic and Statistical Manual of Mental Disorders (DSM)

Healthcare Provider (HCP)

Information Technology (IT)

Joint Attention Symbolic Play Engagement and Regulation (JASPER)

Joanna Briggs Institute (JBI)

Modified Checklist for Autism in Toddlers (M-CHAT)

Modified Checklist for Autism in Toddlers Revised with Follow-up (M-CHAT-R/F)

Newfoundland and Labrador (NL)

Obsessive-Compulsive Disorder (OCD)

Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)

Public Health Agency of Canada (PHAC)

Social (pragmatic) Communication Disorder (SCD)

Socioeconomic Status (SES)

World Health Organization (WHO)

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List of Publications

The following publications have been derived from the work of this thesis:

Smith-Young J, Chafe R, Audas R. “Managing the wait”: parents’ experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with autism spectrum disorder. Health Services Insights. 2020;13:1-10. DOI: 10.1177/1178632920902141.

Smith-Young J, Chafe R, Audas R, Gustafson DL. “I know how to advocate”: parents’ experiences in advocating for their children and youth diagnosed with autism spectrum disorder. Health Services Insights. 2022;15:1-11. DOI: 10.1177/11786329221078803.

Smith-Young J, Murray C, Swab M. Parents’ and guardians’ experiences of barriers and facilitators in accessing autism spectrum disorder diagnostic services for their children: a systematic review protocol of qualitative evidence. JBI Database of Systematic Reviews and Implementation Reports. 2018;16(5):1141-1146. DOI: 10.11124/JBISRIR-2017-003437.

Smith-Young J, Pike A, Chafe R, Swab M. Parents’ and guardians’ experiences of barriers and facilitators in accessing autism spectrum disorder diagnostic services for their children: a qualitative systematic review. JBI Evidence Synthesis 2024;00(0):1-62. DOI: 10.11124/JBIES-23-00332.

Chapter 1: Introduction

Background and Rationale for Thesis

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder defined by impairment in social communication and repetitive and restrictive behaviors that can vary along a continuum of severity.[1] ASD is associated with a wide range of co-occurring developmental, mental and physical health conditions, including intellectual disability, epilepsy, attention-deficit hyperactivity disorder, anxiety, depression, behavioral disturbances and tics, abnormal sleep patterns, motor difficulties, eating and elimination disorders, diabetes, hypertension, obesity, and cardiovascular diseases.[2] Each individual with ASD has a unique life experience with different onset, combinations, severities, and persistence of ASD symptoms and co-occurring conditions. Thus, there is a no one-size-fits-all healthcare approach. The need for other social supports will also vary by the nature of the symptoms and comorbidities. Healthcare providers must be responsive and accessible because early diagnosis is essential for better healthcare outcomes.[1] Treatment for ASD should begin as soon as possible after diagnosis.[2]

Individuals with ASD were once viewed as mentally ill people who were often institutionalized. In 1912, Eugene Bleuler, a Swiss psychiatrist and humanist, was one of the first to use the word autistic; in fact, he incorrectly viewed autism as a form of schizophrenia.[3] In 1943, Leo Kanner, an Austrian-American psychiatrist, physician, and social activist, introduced the term, infantile autism to describe this unique disorder and he described two features that were significant in the diagnosis, extreme isolation and obsession on the preservation of sameness.[3] Kanner was the first to identify the varying degrees of ASD and indicated a spectrum.

Hans Asperger published his research about autistic psychopathy where participants presented with social withdrawal and obsessions with sameness and specific interests. However,

participants in his study demonstrated better social communication skills than those of Kanner. Official recognition of the disorder was not until 1980 when the American Psychiatric Association (APA) included autism in the 3rd edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM).[4] In 2013, DSM-5 provides a comprehensive framework for diagnosing ASD and allows clinicians to diagnose individuals who may have shown early signs but whose symptoms became clearer later, such as during adolescence or adulthood.[5] According to Rosen and associates, the newest edition marks an important shift in the conceptualization of autism from a multi-categorical diagnostic system to a single diagnosis based on multiple dimensions.[4]

ASD is an increasingly prevalent condition.[6] There is no specific biological or genetic test to diagnose ASD. Diagnosis is made by specially trained physicians and psychologists who administer ASD-specific behavioral evaluations.[7] ASD can be detected as early as 12 to 18 months of age and can be diagnosed as early as 14 months.[2] Early diagnosis means more intensive therapy can begin sooner, resulting in better outcomes, i.e., improvements in cognitive, language and adaptive skills.[8-9] However, evidence shows that the time lapse between parents' concerns and diagnosis can be much longer. A recent scoping review reported the time lapse between parents' expressions of first concerns of symptoms of ASD to age of diagnosis ranged from 12 months to 55 months.[10] Furthermore, the global average age at ASD diagnosis from a recent meta-analysis was reportedly between 43 and 60 months.[11] A recent report indicated the wait time for ASD diagnosis reported in British Columbia, Canada was over 80 weeks following referral.[12]

A number of barriers in accessing ASD diagnosis have been identified including stigma,[2,10] transportation issues,[2] dismissive or unskilled health professionals,[10] socioeconomic status,[10] knowledge and awareness,[10] language and cultural values,[10] and ASD service supply

shortage, especially for those living outside urban centres.[10] Facilitators to earlier assessment and diagnosis have been reported such as higher level of parental education and higher socioeconomic status.[13,14] A definitive ASD diagnosis is often a prerequisite for children to access publicly-funded services; yet obtaining a diagnosis in itself can be stressful, frustrating, and time-consuming for many families. Parental advocacy is an active coping strategy for parents of children with ASD, however not all parents have the skills and abilities to effectively advocate for their children. Several contextual factors are recognized that may increase or decrease parental advocacy over time such as financial status, education and skills, time commitment, and level of ASD severity in the child.[15]

Many of the health and educational services needed by children with ASD are publicly-insured so there should be no actual financial barriers in accessing ASD services. However, due to lengthy delays and long waiting lists in accessing publicly-funded ASD services, those families who have the financial means often choose to look for private services as a means of gaining quicker access. It is important to understand the experiences of parents in accessing diagnostic ASD services for children and to identify barriers and facilitators within that process as a means to identify recommendations for policy, practice and research in this area. My thesis contributes to this gap in understanding.

ASD Terminology

The terminology we use influences our conscious and unconscious perceptions of ourselves and the perceptions of others. Language is shaped by our sense of self-identity and the intricate interaction of experiences and environment.[16] It is important to always be respectful and mindful of individual preferences regarding terminology in order to achieve inclusive communication.[17-19]

There is an active debate within the autism community about how best to refer to autistic people. In the medical model of disability, person-first (person with autism) is preferred. The advantage of this model is that it sees the person as not defined by their condition. In contrast, the social model of disability views disability as a neutral or positive characteristic of a person. It places emphasis on the person and their strengths, rather than any perceived disability.[16] From the perspective of advocates of the social model of disability, language grounded in the medical model of disability could be harmful to disabled and autistic people because it may perpetuate and reinforce stigma.[20]

Research efforts are exploring the current terminology preferences of the autistic community. Several studies have recently emerged seeking to ask the autism community what their preferences are. Current results indicate that preferences include the identity-first term, 'autistic person' as well as the person-first term, 'person on the autism spectrum'.[19] A recent study conducted with French-Canadian adults indicated that there was no clear consensus on identity-first or person-first terminology.[21] The researchers suggest using the terminology preferred by the majority of an autistic community.[21] Flowers et al.[22] indicate that the best practice may be to alter language use based on individual preferences when interacting with different autistic communities.

Advocates of both person-first (person with autism) and identity-first (autistic person) language share a common goal of encouraging respectful communication. In this PhD thesis, I have predominantly used person-first language terms consistent with current guidelines for usage in professional settings.[23] The use of person-first terminology was also recommended by the Newfoundland and Labrador Autism Society at the start of the wider ACCESS-MH CIHR project. As the debate about the most appropriate terminology continues, my hope is that my

terminology is considered acceptable and respectful to the autistic community and the participants in this study.

Reflexivity and Philosophical Assumptions

As university graduate students, we each have our own distinct philosophical assumptions that have been fostered during our educational and professional training. Often, we are unaware of these assumptions until we exercise them in our scholarly activities and throughout the research process from conception of an idea, developing research questions, choosing a research methodology, collecting and analyzing data to writing manuscripts and sharing knowledge. Our philosophical assumptions inform the overall research process. Sometimes they are explicit in our writings, other times they are implicit and deduced by a discerning reader.

According to Creswell, philosophy purports "the use of abstract ideas and beliefs that inform our research".[24(p.16)] Philosophical beliefs are informed based on identification of a researcher's positionality as well as his/her ontological and epistemological perspectives. These serve to clarify the philosophical stance of the researcher within the study. *Positionality* can be described as the significant aspects of a researcher's identity such as gender, race, class, and age. According to Bourke, researchers "strive to remain objective, but must be ever mindful of our subjectivities, that is positionality".[25(p.3)] Both researchers and research participants are defined by their location in society within shifting networks of power relations and make assumptions based on their positionality. According to positionality theory, individuals derive meaning from their identities.[25]

The art of examining the research process in the context of my positionality can be described, at least in part, as reflexivity. Reflexivity involves a self-scrutiny on the part of the

researcher. Part of my positionality as a researcher for my proposed study is that I identify as a female (she/her), am of Irish and English descent, grew up in a middle-class family of two parents and one brother in Montreal, Quebec, Canada. Presently, I am married with two sons—my older son recently passed away after a six-month battle with cancer.

Before I entered my nursing career, I worked as an Early Childhood Educator in an elementary school in Montreal, Quebec. I had experience working with children with ASD in that position. I pursued my education at Memorial University in Newfoundland and graduated with a BN and then a Master's degree in Nursing. My educational background and my work as a healthcare provider included training in the universal principles of beneficence (do good), non-maleficence (do no harm), respect for autonomy, fairness, truthfulness, and justice. My positionality incorporates those experiences, identities, and principles.

Epistemology is the philosophical study of knowledge and how we can know things. The epistemological perspective is concerned with the way knowledge is acquired and depends on the relationship between the researcher and participant and how the researcher perceives reality.[24] My epistemological stance aligns well with qualitative research because the aim of qualitative research is to generate knowledge grounded in human experiences.[26] According to Creswell, an epistemological assumption in a qualitative study implies, "researchers try to get as close as possible to the participants being studied…and subjective evidence is assembled based on individual views." [24(p.20)] *Ontology* is the philosophical assumption about the nature of reality. A researcher's ontological position often shapes his/her methodological decision-making.[24] Methodology is concerned with the rationale for the processes and methods which the researcher uses in their project.[24]

My ontological and epistemological assumptions include: 1) all of the concepts pertaining to a given phenomenon have not yet been discovered; 2) people's behaviors are shaped by meaning; 3) social realities are negotiated by people; 4) people's interpretations of events shape what happens; 5) people take an active role in responding to problems they encounter in life; 6) researchers are part of the world they study and data they collect; and 7) we are living in a dynamic, ever-changing world.[24] Philosophical assumptions are embedded within interpretative frameworks that qualitative researchers use when they conduct a study.

As a researcher, I situate myself in a constructivism-interpretivism paradigm. The constructivism-interpretivism paradigm assumes a relativist ontology that infers there are multiple realities and a subjectivist epistemology where the knower and respondent co-create understandings in the natural world though a set of methodological procedures.[27] My position is influenced by the works of Lincoln & Guba[28] who claim that reality is socially, culturally, and historically constructed; that is, there are multiple truths and people make their own reality by the meanings and interpretations they give to their experiences.[27] This is the position I align with as a researcher. Since knowledge is created and can be value-laden, my values need to be acknowledged and made explicit in my work. I acknowledge that I am not a parent of a child diagnosed with ASD. I also do not have any personal experience accessing ASD diagnostic services. Once I identify my positionality, ontological and epistemological orientation, I need to ensure methodological congruence.

Methodological congruence

Methodological congruence is the fit or match between the research problem and the question; the fit between the research question and the method; and the fit among the method, the data, and the way the data are handled. Each qualitative method requires a specific way of

thinking about data, and using the appropriate methods that are congruent with that methodology. It is worth noting that methodology and method are not the same. The methodology is the approach taken to the research design as a whole in relation to finding answers to the research question. The methods are the techniques used to collect and analyze data to provide evidence for the knowledge the research constructs.[24]

In order to achieve methodological congruence, I chose three different methodologies to achieve the aims of each research question that would guide me in the methods of collecting and analyzing the data. The verification strategies for establishing reliability and validity as outlined by Morse and Field (1994) were used including attention to congruence between the research question and the methodological components of each study.[29]

Brief History and Philosophical Underpinnings of Grounded Theory

Grounded Theory was first developed in 1967 by two sociologists, Barney Glaser and Anselm Strauss and their 1960s research on dying in hospitals, a topic rarely studied at that time.[30] Glaser and Strauss observed dying patients and how an awareness that they were dying influenced their interactions with relatives and hospital staff. As they constructed their analyses of dying, they developed systematic methodological strategies that social scientists could adopt for studying other topics. Their book, *The Discovery of Grounded Theory* (1967) first articulated these strategies and advocated for developing theories from research grounded in data rather than deducing testable hypotheses from existing theories.[31] The goal of Grounded Theory is to generate a theory that speculates a relationship between various concepts or emergent ideas.[31]

Grounded Theory combines two contrasting and competing traditions in sociology influenced by the different backgrounds of Glaser and Strauss. Glaser came from Columbia University where quantitative methods were a strong influence on him. Glaser's positivist

training resulted in his focus on codifying qualitative methods and generating middle-range theories, narrower in scope than grand theories, useful in linking human behavior and natural processes in observable patterns to make sense of people's actions and experiences in the social world.[31] Strauss came from the University of Chicago with a long history in qualitative research where symbolic interactionist and pragmatist writings had a strong influence on him.[32] Symbolic interactionism emphasizes understanding of the world by interpreting human interaction that occurs through using symbols such as language.[33] Pragmatism emphasizes practical consequences as the primary criteria in determining meaning or truth.[24]

There are now several versions of Grounded Theory including: The Glaserian version[34], the Strausserian version[35-37], and Charmaz' constructivist version of Grounded Theory.[38] Each comes from a different philosophical and research tradition. Glaser disagreed with Strauss & Corbin's version of Grounded Theory that was published in their book, Basics of Qualitative Research and wrote a letter to Strauss stating,

> I request you pull the book (Basics of Qualitative Research). It distorts and misconceives grounded theory, while engaging in a gross neglect of 90% of its important ideas…you wrote a whole different method so why call it 'grounded theory'?...your work is fractured and scattered. [39(p.2)]

As a result of this dispute, Glaser coined the term, Glaserian version[24] that has remained consistent with the earlier version of Grounded Theory that, "is based on the systematic generating of theory from data, that itself is systematically obtained from social research; thus, the Grounded Theory method offers a rigorous, orderly guide to theory development".[40(p.2)] Glaser's position comes very close to traditional positivism, with its assumptions of an objective, external reality where the researcher is a neutral observer who discovers data, focusing on an

absolute truth rejecting interpretations.[40] According to Glaser, "Grounded Theory methodology stands on its own as a way to generate conceptual theory, or as a way of thinking conceptually".[40(p.7)]

The earlier Strauss and Corbin version of Grounded Theory[37] seem to be rooted mainly in symbolic interactionism. Strauss[35] and Strauss and Corbin[36,37] advise giving voice to their respondents, representing them as accurately as possible, recognizing art as well as science in the analytic product and process. The following illustrates Corbin and Strauss' stance on developing theory.

> …sensitivity to what the data are saying and the ability to recognize when our own biases, or those of our participants, are intruding into our analysis. Although some analysts claim to be able to 'bracket' their beliefs and perspectives toward data, we have found that doing so is easier said than done...we never can be completely free of our biases for so many are unconscious...we find it more helpful to acknowledge that these influence our thinking. [36(p. 99)]

Later Corbin expressed agreement with Charmaz' constructionist viewpoint of Grounded Theory that "concepts and theories are constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and lives, both to the researcher and themselves".[41] According to Charmaz' (2014) constructivist grounded theory, "subjectivity and the researcher's involvement in the construction and interpretation of data;" [38(p. 14)] thus, what is understood as real, objective knowledge and truth is based on perspectives that construct an image of reality, not an external, objective, true reality.[38]

For the first study I used a qualitative research design based on the Strausserian version of grounded theory methodology[35-37] and constant comparative analysis. My aim was to develop a process model and understand the core concept about parents' experiences in accessing diagnostic and treatment services for children and adolescents suspected to be on the ASD spectrum or diagnosed with ASD. Grounded Theory is based on the assumptions that: reality can be discovered, explored and understood; there is a multiplicity of perspectives; and people construct realities through ordinary actions.[26] Studies that incorporate a Grounded Theory methodological approach are designed towards conceptual thinking and theory building, rather than empirical testing of a theory.

For the second study, I used qualitative descriptive exploratory methodology[42-44] informed by reflexive thematic analysis. This is the methodology of choice when descriptions and interpretations of experiences are desired.[44] Accordingly, qualitative descriptive studies draw from naturalistic inquiry that is the study of behaviors and experiences in non-experimental contexts.[44] Since I wanted to explore the concept of advocacy in parents and caregivers of children and youth diagnosed with ASD, that was the methodology I chose.

Thematic analysis is a method of analysis used to identify, analyze, organize, describe and report themes found within the data.[45,46] Following the steps in thematic analysis,[45-46] I familiarized myself with the data by reading the transcripts several times, generating initial codes and looking for themes. Lastly, I reviewed and finalized the themes in consensus with my supervisors and wrote up the findings.

The third study is a systematic review of the literature of parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children. The protocol for this review is found in Appendix 1.I. The systematic review was conducted in

accordance with the Joanna Briggs Institute methodology for systematic reviews of qualitative evidence and data synthesis of qualitative findings.[47] This review was guided by *a priori* systematic review protocol.[48]

Rationale for Dissertation Research

Although there is a growing body of literature looking at the overall experiences of parents of children of ASD, there needs to be an understanding of the unique experiences of different subgroups of parents and children and a need to explore global perspectives. Recently, several gaps in current autism research have been identified that include the need to identify underlying obstacles to acquiring timely access to ASD diagnostic and treatment services, the local and global challenges and systemic barriers faced by affected individuals, and a better understanding of parents' experiences during the ASD assessment and diagnostic experience for children.[39] A scoping review also highlighted gaps remaining in terms of "understanding the full breadth of factors that influence the diagnostic experience" of parents of children affected by ASD.[10] This dissertation research is focused on addressing that gap.

Research Objectives

The central aim of this research is to examine parents' experiences in accessing autism spectrum disorder diagnostic services for their children and the barriers they face in that process. The research objectives are:

1. To examine parents' experiences of accessing diagnostic services in one Canadian province.
2. To explore the extent to which families' self-described SES affected access to ASD diagnostic services.

3. To explore advocacy in parents and caregivers of children and youth diagnosed with ASD.
4. To comprehensively identify the best available qualitative evidence about parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children.
5. To develop recommendations based on a systematic review of qualitative evidence to address barriers for parents in accessing ASD diagnostic services.

Program of Research for Dissertation

This section details my substantial contribution to this program of research and clarifies the roles at the level of the individual and that of the team. I am the first author on all manuscripts included in this thesis. This thesis is my independent scholarly work. I provide a co-authorship statement that outlines the contributions of the research team for each manuscript.

During my PhD studies in Clinical Epidemiology, Medicine, an opportunity arose whereby I was able to access interview data from a larger research study that was designed to explore the life journey of parents of children diagnosed with mental health conditions, including ASD. It was apparent from the interview data that was collected that parents of children with ASD struggled to access timely ASD assessment and diagnostic services. I decided then to explore that lens and learn about the strategies parents used to access ASD diagnostic services for their children. Considering my study population, I needed to take my positionality into consideration and attempt to 'bracket' my assumptions. Bracketing in qualitative research can be described as, suspending knowledge by using reflexivity to foster inquisitiveness.[24] Growing up in the Canadian health system of universal healthcare and in my training as a healthcare professional, my positionality includes the belief in the right to free and accessible health care

services. This research intends to better understand why parents seem to struggle in accessing ASD assessment and diagnostic services within the context of our Canadian healthcare system.

Manuscript Format

This thesis is presented in a manuscript format. The three distinct studies, build on each other to give a comprehensive view of parents' and guardians' experiences in accessing ASD diagnostic services for children. The first study that was conducted was an exploration, at the local level, of the process that parents and guardians went through in attempting to access ASD diagnostic services for their children. Managing the wait and parental advocacy appeared central to that process. These findings led me to examine, at a local level, how parental advocacy affected parents' experiences in seeking help, assessment and diagnosis for their children affected by ASD, and how they attempted to remove the barriers they faced within that process. Finally, those results directed me to conduct a systematic review so I could understand the barriers and facilitators that parents encountered in Canada as well as other parts of the world as a means of offering recommendations for policy, practice and research to address the barriers parents and guardians faced in accessing ASD diagnostic services for their children. Figure 1.1 describes the process of integration of the three manuscripts into this thesis. Instead of including a separate methods chapter, the description of methods for each study is presented in the individual chapters.

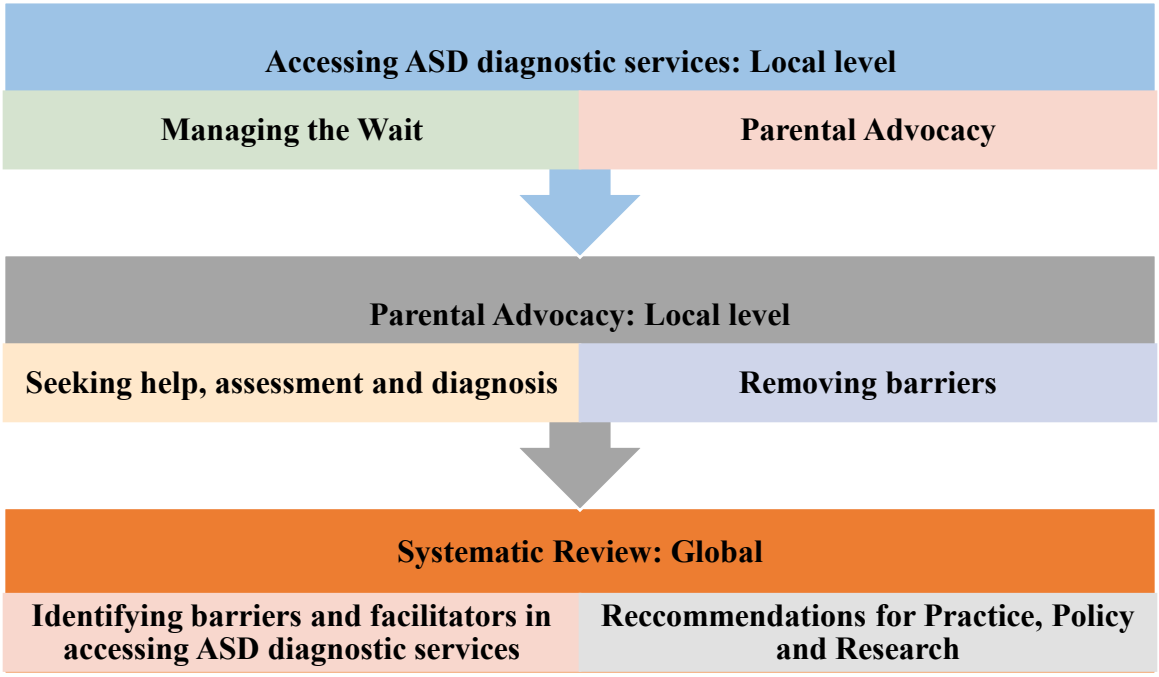

Figure 1.1. Process of Integration

Two of the manuscripts have been published in peer-reviewed journals and the third manuscript has been revised and re-submitted with publication pending.

Chapter 2 is an overview of the literature that provides a background to the three manuscripts that are contained in Chapters 3-5.

Chapter 3 is entitled "Managing the Wait": Parents' experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with ASD." The study aims were to: (1) explore parents' experiences of accessing diagnostic and treatment services over the life course of ASD in one Canadian province and (2) explore the extent to which a family's self-described SES affected their access to services. The presented manuscript was published in *Health Services Insights* on December 21, 2019.[50]

Chapter 4 is entitled "'I know how to advocate': Parents' experiences in advocating for children and youth diagnosed with ASD." This study examined the question, "When, how, and why do parents of children and youth with ASD engage in parental advocacy and what barriers,

if any, do they encounter?" The presented manuscript was published in *Health Services Insights* on January 18, 2022.[51]

Chapter 5 is entitled "Parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children: A qualitative systematic review." The study objectives were to: (1) comprehensively identify the best available evidence about parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children and adolescents; and (2) develop recommendations based on the review for addressing barriers to timely diagnosis and early intervention. The systematic review protocol for this review was published in *JBI Database of Systematic Reviews and Implementation Reports* in 2018.[48] The presented manuscript was accepted for publication on July 22, 2024 with an online version made available pending print publication in JBI Evidence Synthesis 2024; 22(00):1-63.

Chapter 6 provides a general discussion and implications for practice, policy and research. This chapter will first summarize the overview and main findings of the three manuscripts. Strengths and limitations of the research will then be discussed. Next, is a comparison of the research findings to current literature as well as implications for policy, practice, and research. Finally, I will provide concluding remarks.

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Chapter 2 Literature Review

Introduction

In this chapter, I provide relevant background information about the history of ASD, the evolution of ASD diagnostic criteria and the relation to ASD prevalence rates, ASD diagnostic tools and treatments/interventions, parents' perceptions of the ASD diagnostic process, impact of ASD on families, parental advocacy in ASD, a general discussion about autism in Canada and NL, followed by closing remarks. This information will help provide context for the three manuscripts presented in Chapters 3-5.

History of ASD

Early descriptions of children who likely had autism were evidenced in the 1800s in a school for intellectually-disabled.[1] However, earlier reports of children who had run away from their parents were also described as having traits of autism.[2] In 1912, Bleuler, a Swiss psychiatrist was the first to use the term, 'autistic' in describing social withdrawal observed in adults with schizophrenia.[3-5] It was not until 1943 that an Austrian-American child psychologist Leo Kanner presented his classic description of infantile autism.[6]

In a study conducted by Kanner in 1943, children were described as, having strong cognitive ability with concurrent severe social interaction difficulties, limitations in spontaneity, echolalia, pronoun reversal, unusual speech tone, hypersensitivity to stimuli, excellent rote memory, and difficulty processing or adapting to change manifesting in an insistence on sameness.[6] Later on, Kanner perceived only two of these observed features as necessary and sufficient for the diagnosis of autism: extreme isolation and obsession on the preservation of sameness.[6] He also noted that the disorder manifested in extremely varying fashions between individuals, with no two individuals expressing identical developmental strengths and

weaknesses; thus, he described it as an evolving condition throughout the lifespan of the individual.[6]

Following Kanner's definition came a flood of new research. In 1944, Hans Asperger published his work on childhood 'autistic psychopathy'[7]; this work, however, would not become well known until its translation to English in 1991. Asperger also described similar characteristics to Kanner such as social withdrawal, obsession with routine or sameness, and obsessiveness with individualized interests.[7] Kanner emphasized the importance of autism as a developmental disorder; however, Asperger described behaviors that resembled a personality disorder and reported adults exhibiting similar characteristics.[7] Asperger's Syndrome, a term defined by Lorna Wing in 1981, was used to describe those individuals with less severe characteristics of autism.[7] Kanner's suggestion that autism was not associated with other medical conditions later proved to be incorrect.[8-9]

Several important developments occurred in the latter half of the 1960s and the 1970s related to defining and diagnosing autism. Rimland created the first checklist for assessing symptoms suggestive of autism.[10-11] At this time, convergence among researchers suggested that autism was a distinct concept and not an early manifestation of schizophrenia, as noted in earlier works by Bleuler.[3] Prominent educator and psychiatrist, Battelheim (1967), in an attempt to explain the confusion surrounding autism, introduced his 'refrigerator mother' theory.[12] His theory hypothesized that autism in children developed as a response to a dangerous and unloving environment created specifically by the child's mother.[12] This hypothesis was officially discredited with the shift from pure psychological stance to biologically-based psychology. Unfortunately, Bettelheim's original studies introduced a great deal of misunderstanding and confusion surrounding the disorder.

In the late 20th century, there was a shift focusing on discovering genetic, neurological or environmental pathways of autism. Autism was introduced as a genetic-based disorder in 1977.[13] Rutter offered a new definition of autism that included delayed and deviant social and language abilities and restricted interests and repetitive behaviors that started in early childhood.[14] Autism was also noted to be a brain-based disorder due to its association with epilepsy often occurring in adolescence.[15]

There are two internationally-employed and standardized diagnostic tools: the WHO's International Classification of Diseases, 10th edition[16] and the APA's DSM-5.[17] These standardized diagnostic tools provide a better understanding of what ASD is and is not. In the next section, I provide an overview of the evolution of ASD diagnostic criteria according to DSM.

Evolution of ASD Diagnostic Criteria

Eisenberg and Kanner (1956) were the first to propose diagnostic criteria for autism.[18] In 1968, the DSM-II defined autism as a psychiatric condition, a form of childhood schizophrenia, describing individuals with this condition as having a detachment from reality.[19] In this version of the DSM, Early Infantile Autism and Autistic Psychopathy were not included despite Kanner's (1943) and Asperger's (1944/1991) original descriptions of these disorders.[20]

Autistic disorder was not officially recognized as a diagnosis until 1980 with the publication of DSM-III.[21] Autism was then established as a separate diagnosis described as 'pervasive developmental disorder' distinct from schizophrenia.[21] The DSM-III introduced specific criteria for diagnosis that included a lack of interest in people, severe communication impairments, and atypical sensory responses such as becoming agitated when exposed to loud noises in environment.[22] For a diagnosis of autistic disorder, DSM-III required individuals to

meet all listed criteria by history and clinical assessment. Later Wing (1981) outlined essential characteristics of Asperger's syndrome that included absence of empathy, impaired social interaction, monotonic speech, poor motor skills, obsessive behaviors, and impaired non-verbal skills.[23]

In 1987, a revised version, DSM-III-R was released.[24] This version provided 16 criteria for autistic disorder that were grouped into three broad categories.[24] A diagnosis of autism required that an individual, regardless of age had to exhibit at least eight of the 16 criteria.[24] These criteria had to include two symptoms from the social domain and one each from the communication and restricted activities categories. In this version, the appearance of ASD symptoms by 30 months was dropped as an essential feature; however, the diagnostician could specify onset before or after age three years.[22] According to this version, the diagnosis of autism could be made on the basis of current exam only and knowledge of early history was not required.[22] The name change from infantile autism to autistic disorder emphasized the persistence of the condition. This version expanded the concept and included more cases of autistic disorder than the DSM-II and the rate of 'false positives' increased.[22] Also, problematic with this version is that the diagnostic criteria was more complex and detailed, thus requiring more from the diagnostician.[22]

In 1994, the definition of autism was broadened with the release of DSM-IV.[25] The term, pervasive development disorders was retained that included five subcategories: autistic disorder, Asperger's disorder, Rett's disorder, childhood disintegrative disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), including atypical autism.[25] Retained in DSM-IV was the requirement for early age of symptom onset (before 36 months of age).[25] The diagnostic criteria in DSM-IV presented three domains: marked impairment in social

interaction, delayed and/or deviant language development, and repetitive behaviors or interests.[25] The diagnosis of ASD in DSM-IV required the presence of two symptoms in the social domain and at least one symptom in each of the communication and repetitive behavior domains.[25] Language delay was not required for a diagnosis of Asperger's disorder. The wider definition of ASD described in DSM-IV (autistic disorder, Asperger's disorder, and PDDNOS) had a large impact on ASD reported prevalence.[26] In the DSM-IV classification, the category of PDDNOS included 5 different subtypes of autism: autistic disorder (considered to be on the more severe end of the autism spectrum), Asperger's disorder (considered to be on the less severe end of the autism spectrum), childhood disintegrative disorder (characterized by severe developmental reversals and regressions), PDDNOS (or atypical autism, a diagnosis given when a developmental disorder didn't quite meet the criteria for autism, and Rett syndrome (affecting movement and communication, primarily in girls).[27]

The breakdown of autism subtypes echoed the research hypothesis at the time that autism is rooted in genetics, and that each category would ultimately be linked to a set of specific problems and treatments; however, it became clear that finding genetic underpinnings and corresponding treatments for 5 conditions specified in the DSM-IV would not be feasible. There was consensus that differences in social and cognitive abilities between subgroups are better defined in terms of a continuum, rather than separate subtypes. As a result, DSM-5 replaced 4 of these subtypes (autistic disorder, Asperger's disorder, childhood disintegrative disorder, and PDDNOS) with one central diagnosis, autism spectrum disorder (ASD) with Rett syndrome no longer included.[27]

In 2013, the term ASD was officially introduced in DSM-5 and the term PDD was replaced with ASD. In this version, Asperger's Disorder, Childhood Disintegrative Disorder, and

PDDNOS were included under the overarching category of ASD and Rett's disorder was removed from the DSM-5 ASD category.[17] In this version, ASD is characterized by two domains: social-communication and restricted-repetitive purviews.[17] There are three symptom groups indicated under the social-communication domain and four symptom groups indicated under the restricted-repetitive domain. The proposed DSM-5 ASD classification does not specifically require the presence of a minimum number of symptoms under the social-communication domain but at least two symptom criteria under restricted-repetitive domain are required to obtain an ASD diagnosis.[17] A new, related diagnosis, social (pragmatic) communication disorder (SCD) is included in DSM-5 and ASD must be ruled out before making a diagnosis of SCD.[17] To qualify for a SCD diagnosis, symptoms must be present in early childhood but may not manifest until social expectations exceed limited capabilities.[22] The DSM-5 version was aimed at addressing concerns about over-diagnosis and variability in diagnostic practices. Some researchers have questioned whether DSM-5 criteria will alter ASD prevalence rates.[28]

ASD Prevalence

The global ASD prevalence rate increased by 39.3% between 1990 and 2019 with an estimated 28.3 million cases of ASD reported worldwide in 2019.[29] Approximately, 1 in every 100 children are diagnosed with ASD worldwide.[30] However, the true prevalence rate may be much higher. A recent report indicated the overall prevalence rate in 2020 was 1 in 36 among children aged 8 years in 11 states in the US.[31] A recent systematic review conducted in 2022 revealed several etiological factors that appear to influence ASD prevalence rates.[30] These factors include sociodemographic status and regional differences related to availability and/or access to services, increased ASD diagnosis in populations that were initially underdiagnosed,

and an increase in prevalence rates over time in certain countries. For example, France reported prevalence rates were higher among children born in 2003 compared to those born in 1997; and Australia reported prevalence rates higher for children born four years apart (1999/2000 versus 2003/2004).[30]

In recent years, the international community witnessed increased public awareness and public health response for ASD including the significant improvements in early identification of the condition that in part, accounts for higher prevalence rates over time.[30] Epidemiological estimates have been increasing worldwide, especially in previously under-represented regions such as Africa and Middle East countries.[30] The evolving nature of the clinical definition of autism, as reflected in the revised versions of DSM, over the years also influences prevalence rates. As evidenced in the findings of a systematic review, there did not appear to be any direct causal associations between SES and variation in ASD prevalence rates but rather, the review reflected differences in availability and affordability of health services in certain countries.[30] Hence, there is a need for improved understanding and targeted policies to address health disparities.

It is apparent that ASD has steadily increased in reported prevalence over the last decade, leading to growing pressure on diagnosticians and healthcare systems to provide timely and accurate diagnosis. Healthcare professionals are challenged by making ASD diagnoses related to the complexities of assessment. Several qualitative studies of HCPs caring for children with ASD have been conducted that revealed barriers for HCPs in conducting ASD diagnostic assessments including inadequate training, challenges disclosing the diagnosis to families, and concerns about how to assist families navigate ASD resources in a fragmented health and social care system.[32,33]

Next, I discuss some of the ASD diagnostic tools and treatments/interventions that are available for ASD.

ASD Diagnostic Tools and Treatments/Interventions

There are currently no reliable biomarkers for diagnosing ASD.[34] History taking, observations and using screening tools that measure social and cognitive abilities are ways in which ASD is usually diagnosed.[34] There is a lack of universal screening instruments, however, many countries have programs in place to identify young children with ASD (between 18 and 30 months) using M-CHAT (Modified Checklist for Autism in Toddlers) or other similar screening tools.[35] The sensitivity of these screening tools has been questioned because they often fail to identify most children with ASD before their parents have already reported concerns or delays in development.[36]

The M-CHAT is intended to screen children aged between 16 and 30 months and contains 23 'yes/no' items that span various developmental domains that also involves an interview with parents or guardians.[37] This checklist relies on the parent's report of the child's behaviors and skills rather than the observations of a HCP.[37] Since 2009, the M-CHAT-revised with follow-up (M-CHAT-R/F) includes 10 'yes/no' items and a component for a HCP to review with a follow-up interview for those identified with ASD.[38] This tool is available internationally in several different languages and is also available electronically.

A reliable and widely used tool is the Autism Diagnostic Observation Schedule (ADOS) that is a 45-minute observation conducted by a HCP to diagnose ASD from 12 months to adulthood.[35] Other screening tools such as, the Social Responsiveness Scale, the Social Communication Questionnaire and the Childhood Autism Rating Scale can also be used to assess symptoms of ASD in children.[34] DSM-5 allows for dual diagnoses of ASD and other

comorbidities such as ADHD, anxiety, depression, aggression or genetic disorders such as Fragile X syndrome, an inherited form of intellectual and development disability caused by a mutation in the FRMI gene located on the X chromosome.[39]

Treatments/interventions depend on ASD severity and co-morbidities, which can include behavioral training, pharmacological use, and dietary supplement.[34] Behavior-oriented interventions are a series of programs that target ASD behaviors and develop social and cognitive skills. To date, no single or combination of treatments have been able to reverse ASD completely.[34] Whether and to what extent ASD can or should be treated is a controversial topic, especially considering the heterogeneity of ASD in children. Some therapies include Applied Behavioral Assessment (ABA) therapy, pharmacology, and diet.[34] Educational and behavioral interventions play a central role in addressing communication, social skills, play, academic skills, and inappropriate behaviors.[34] Individualized treatments are recommended due to the diverse nature of ASD. There is consensus on the importance of providing early therapy immediately after diagnosis or with suspected diagnosis and the training and involvement of parents and family members are important.[34]

ABA therapy is one of the widely used evidence-based treatment approaches.[40] The main goal is providing skills in a progressive and systematic manner through reinforcement to target ASD behaviors. ABA has demonstrated improvements in language and academic skills.[41,42] One ABA intervention is Early Intensive Behavioral Intervention that is used for children younger than three years old.[34] Yu et al.[43] performed a meta-analysis of ABA-based studies. Results showed that although there were no significant effects for the outcomes of general symptoms of ASD, receptive language, adaptive behavior, daily living skills, verbal and non-verbal IQ, restricted and repetitive behavior, motor and cognition, ABA-based interventions were effective

on the outcomes of socialization, communication, and expressive language.[43] Likewise, a recent systematic review indicated that behavioral interventions appear to have moderate positive effects on social emotional or challenging behavior outcomes that may improve social communication in interactions with caregivers.[44]

Naturalistic developmental behavioral interventions, such as joint attention, symbolic play, engagement and regulation (JASPER) are other approaches for young children with or suspected of having ASD.[45] JASPER involves a few sessions (30-60 minutes) per week for one to three months.[45] Interventions are generally delivered in children's day-to-day environments and/or during play, often by those who interact frequently with the child such as parents and/or early childhood educators. They have been shown to be effective in improving social communication, language, cognition and play skills.[46,47]

Pharmaceuticals such as aripiprazole and risperidone, antipsychotic medications, are sometimes prescribed for children with ASD.[34] While the Food and Drug Administration has approved these drugs for use in ASD, they have not been developed specifically for the disorder.[48] Hirsch and Pringshelm[49] conducted a Cochrane review and reported on the safety and efficacy of aripiprazole. Results suggest that although the short-term use of this drug may improve irritability, hyperactivity, and repetitive movements in children and adolescents with ASD, weight gain and neurological side effects such as involuntary movements of the face and jaw can occur.[49] The reviewers recommend that children and adolescents taking this drug should be re-evaluated periodically to monitor improvements in ASD symptoms and side effects.[49] Similarly, a systematic review and meta-analysis conducted in 2021 revealed that although risperidone can be effective for the treatment of lethargy and inadequate speech, concerns arise

about side effects such as weight gain, and increased waist circumference.[50] The reviewers recommend that a need for evaluation of the risk-benefit ratio for this drug.[50]

Vitamins B6, C, magnesium, and Omega-3 fatty acids may be linked with improvements in the behavior of children with ASD.[51-54] Sensory integration therapy, auditory integration, music therapy, and animal-based therapies, such as horseback riding and dolphin therapy, are other interventions that are used for children with ASD.[34] Significant progress has been made with improved therapeutic interventions to treat ASD, however, there are still limitations in the success of these therapies.

Parents' Perceptions of the ASD Diagnostic Process

ASD is a 'spectrum' disorder with those affected demonstrating different cognitive, language, social, and behavioral abilities.[55] The diagnostic process typically begins when a parent (or caregiver) notices atypical development or concerning behaviors in their child. These concerns often lead parents to seek out professional opinions on the nature of these concerns, including attempting to find a diagnosis. Best practice standards dictate a comprehensive and developmental assessment of the child that often involves a multidisciplinary team: pediatrician, psychologist, speech-language pathologist, occupational therapist, and other related health professionals with specific training and experience to evaluate the child's skills and abilities across a variety of domains.[22]

The ASD assessment and diagnostic process can be very stressful for parents. A recent systematic review was conducted to examine factors related to parental (dis)satisfaction with the ASD assessment and diagnostic process.[56] Findings from the review revealed several factors related to (dis)satisfaction during pre-assessment, assessment, and diagnosis phases of the process.[56] During pre-assessment parents reported greater satisfaction when their initial concerns

for their child's development were accepted by their family doctor that led to referral to a diagnostic team of HCPs in a timely and seamless manner.[56] Once referral was initiated, parents expressed satisfaction when they were provided information about the diagnostic process and time commitment required.[56] Parents who self-reported as having higher levels of education and above average family income reported significantly greater satisfaction that presumably facilitated their ability to access available and timely healthcare services for their child.[56] On the other hand, when parents' concerns for their child's development were minimized or not appreciated by HCPs, they reported dissatisfaction.[56] Dissatisfaction was also reported when parents had to return to HCPs many times before their concerns were taken seriously and/or when they felt blamed for their child's behaviors.[56] When parents experienced difficulty in obtaining a referral to an ASD diagnostic clinic, they also reported dissatisfaction.[56]

During the assessment phase, parents reported more satisfaction when their child was diagnosed early and when the diagnostic process was timely, efficient, comprehensive, collaborative, and HCPs were perceived as specialists in ASD assessment.[56] Parents also expressed satisfaction when they received a definitive diagnosis.[56] Conversely, during this phase parents reported they were dissatisfied when they perceived their HCPs as not specializing in ASD thus, perceiving them as being disconnected from understanding of ASD, especially when their child presented with greater behavioral difficulties during the assessment phase.[56] Parents expressed frustration when they perceived the HCP as being unprofessional or uncaring and reported being dissatisfied with the length of time their child remained on a wait list for ASD diagnostic assessment.[56] Parents were also reportedly dissatisfied when they visited medical clinics multiple times before their concerns were taken seriously.[56]

A recent scoping review[57] showed that wait times for diagnostic assessment have been a persistent concern among parents and caregivers, with many families reporting their journey to diagnosis lasting multiple years. In this review, parents also perceived cultural barriers and stigma as contributors to delays in their decision to access diagnosis.[57] Once a child receives an ASD diagnosis, there can be a significant impact on families.

Impact of ASD on Families

It is important to consider family functioning when providing care for autistic children and their families. Research findings indicate that general family functioning was found to be more problematic in families of children with ASD than in families with typically developing children.[58-62] Parents of children with ASD experience higher levels of parenting stress than parents of typically developing children.[62-65] The child's cognitive impairment, disturbed mood or irritability, hyperactivity, noncompliance, language deficits, imposed limits on family activities, inappropriate eating, and social difficulties have been reported as stressors experienced by family members.[66] Parents of children with ASD often attribute most of their child's misbehavior to ASD symptoms, rather than their child's personality or temperament.[67]

Increase in parenting stress, conflict, and child behavior problems can contribute to a higher rate of divorce for parents of children with ASD compared to families of children with typically developing children.[68-70] Divorce rates of families with children with ASD are almost twice as high as in other families.[70] Even for parents who remain married, having a child with ASD is associated with decreased marital satisfaction than other families.[68,71] Marital satisfaction also appears to impact sibling relationships within the family system.[72] Mothers of children with ASD are reported to have increased parenting stress compared to fathers;[73-77] however, mothers reportedly demonstrate increased levels of parental involvement with children affected by

ASD.[77] Mothers of children with developmental disabilities such as ASD reported working approximately eight fewer weeks per year than mothers of children with other mental health difficulties.[78]

Other resource demands on families of children with ASD include time pressures, financial burden, greater investment in healthcare, constant efforts at advocacy, employment challenges, and educational challenges.[79-82] Lavelle and colleagues[83] reported the total economic burden of childhood ASD using three national data sets. According to their report, additional costs associated with caring for children with ASD amounted to > $17,000 per child annually that was associated with healthcare, education, ASD-related therapies, family-coordinated services, and caregiver time.[83] More recently, Rothwell and associates[84] examined household income trajectories of children with and without neuro-disabilities that included those diagnosed with ASD. They found that families of children with neuro-disability had consistently lower household income compared to families of children without neuro-disabilities after controlling for child and family socio-demographic characteristics.[84]

Direct out-of-pocket costs to manage neuro-disabilities such as ASD place financial demands on parents that may include speech and language therapists, occupational therapists, special activities and therapies directly related to an ASD diagnosis.[84] In Canada, the cost for caring for a 10-year old child with ASD who had severe impairments and whose parents were no longer able to parent and provide care to that child was reportedly more expensive than raising a neurotypical child.[85] Among a sample of mothers of children with ASD or intellectual disability, over two-thirds worked less in formal paid employment than other mothers or stopped working altogether to provide care for their child.[86] Parents of children with ASD are also reported to have

higher levels of fatigue and greater physical health impairment than parents of typically developing children.[87,88]

However, while the demands of raising a child with ASD are significant, parents do report a variety of positive experiences that include enjoyment of their child's individual personality traits and watching their child develop and be successful.[89-91] Support from friends and family also have a positive impact on family functioning.[92] Several researchers have found that parenting stress is impacted by the type of coping strategies used by parents;[77,93-95] thus, it is important to understand the role of parental advocacy in raising a child with ASD.

Parental Advocacy

It is well documented that parents of children with ASD experience high levels of parenting stress and their stress levels are often higher than parents of typically developing children or those with other developmental disorders.[94-98] Parental advocacy has been described as an important coping mechanism for parents of children with ASD.[99-101] Parents reportedly value advocacy as a way of focusing on something that is within their capacity to control the situation compared with uncertainty related to their child's ASD diagnosis.[99] Boshoff and colleagues (2018) define advocacy as:

> a set of complex and multifaceted behaviors that include the aspects of obtaining support or a service; promoting the child/family's welfare, well-being, and rights; raising issues and facilitating change; being a voice for their child; advocating for their individual child and on behalf of a broader group to which their child belongs; and educating family/friends/others about the child's condition.[102(p.148)]

Whether parents decide to engage in advocacy efforts may be influenced by their self-efficacy or belief about their own abilities to effectively advocate for their children.[103,104] Self-

efficacy has been described as the perceived belief in one's own ability to succeed and exert control over one's environment.[103] Parents' advocacy efforts are aimed at obtaining healthcare supports and services as well as educational services for their children with ASD.[105] Professionals need to support parents in their advocacy role, however, many report that they feel dismissed by HCPs and blamed for their children's inappropriate behaviors that can impact parental advocacy.[105]

Systemic issues can be barriers to parental advocacy. The cost of ASD assessment, diagnostic and treatment services can deter parents from attempting to seek help at all.[105] Travel time and costs to receive ASD services and supports are a barrier, especially for those living in rural areas.[105] Loss of wages when parents need to leave work to bring their child to appointments can be an additional deterrent to parental advocacy efforts.[105] Parents describe needing to be "vigilant" and confront barriers to ensure their child receives timely and appropriate services.[106(p.1079)] Parents express how they take matters "into their own hands" in taking action by advocating on behalf of their children.[107(p.226)]

For some parents, advocacy becomes a more formal role such as, community advocacy whereby parents join advocacy groups for children with ASD or other disabilities.[108] Reportedly, parents of higher socioeconomic status expend "inordinate amounts of time, effort and resources in order to effectively negotiate the special education system."[109(p.479)] Although parents of lower socioeconomic status also engage in advocacy efforts, they are often limited by lack of financial resources and have less ability to change work schedules to spend the time necessary on their advocacy efforts.[109] Many organizations, websites, and support groups encourage and offer training for parental advocacy.[110-112] Parents' advocacy efforts can provide a sense of social benefit for not only their own children with ASD but for all families affected by ASD.[106]

ASD in Newfoundland and Labrador, Canada

Approximately 1 in 57 individuals in NL are living with ASD, according to the 2018 Public Health Agency of Canada (PHAC) Report on the National ASD surveillance system.[113] The Government of NL introduced a 3-year Action Plan (2019-2022), The Way Forward, focusing on providing better services, greater efficiency, and better outcomes for individuals living with ASD.[114] Implementation of the plan will occur in three phases: Short-term actions completed by March 2020; medium-term actions to be completed by March 2021; and long-term actions to be completed by March 2022.[114] This Plan was the result of consultations with individuals living with ASD, family members, health and education professionals, community providers, government agencies, and researchers in ASD.[114] It was designed to enhance existing treatments, supports, and services for individuals living with ASD and their families by integrating a holistic and person-centered approach to ASD service delivery and is grounded in best evidence available for the identification and diagnosis of ASD, including available services and supports.[114]

Implementation of the plan includes: 1) increasing public awareness of ASD, 2) improving educational programming, interventions and services to support individuals and families living with ASD, 3) reducing wait times for ASD diagnosis, 4) implementing new standardized assessment tools, 5) opening more diagnostic clinics, and 5) increasing the availability of a toolkit for individuals and families that will provide information about ASD upon diagnosis.[111] The government of NL has also adopted JASPER, an ASD therapy that has shown positive results in children up to the age of eight years.[45,114]

In 2023, the Government of Canada officially launched its National Autism Strategy, a framework aimed at improving the diagnosis, treatment, and support of autistic Canadians.[115]

Canada's National Autism Strategy will cover access to services, healthcare, education, and employment.[115] With a growing number of autistic children transitioning to adulthood or other autistic adults ageing, this strategy will expand the scope of support for people over 18 years old who often age out of provincial programs.[115] The goal of the National Autism Strategy is to promote understanding, acceptance, and inclusion for individuals living with ASD.[115]

Furthermore, on March 30, 2023 the Government of Canada passed Bill S-203, the Federal Framework on ASD Act.[115] This Act outlines the establishment of a National Autism Network and commitment for the development of a federal framework designed to support individuals with ASD and their families.[115] Actions of Bill S-203 include identifying measures to provide timely and equitable access to diagnosis, financial support, improved research, and national acceptance campaigns to enhance understanding and acceptance of autism.[115]

Closing Remarks

The aim of this dissertation is five-fold: 1) to examine parents' experiences in accessing autism spectrum disorder diagnostic services for their children in NL; 2) to explore the extent to which families' self-described SES affected access to ASD diagnostic service; 3) to explore advocacy in parents and caregivers of children and youth diagnosed with ASD; 4) to comprehensively identify the best available qualitative evidence about parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children; and 5) to develop recommendations based on a systematic review of qualitative evidence to address barriers for parents in accessing ASD diagnostic services.

The remaining chapters of this dissertation present completed research to address the five aims of this dissertation including two published research studies, one published research protocol and a systematic review under review for pending publication: 1) 'Managing the Wait':

parents experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with ASD; 2) "I know how to advocate": Parents' experiences in advocating for children and youth diagnosed with ASD; and 3) "Parents' and guardians' experiences of barriers and facilitators in access ASD diagnostic services for their children: A qualitative systematic review. The 4th manuscript is a published protocol for the qualitative systematic review (See Appendix 1.I.). Results from these studies provide an improved understanding of the barriers and facilitators in accessing ASD diagnostic services; thus, contributing to and lending support to the work of others in this field as well as providing important implications for practice, policy and research in this area of study.

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Chapter 3 (Manuscript 1)

Introduction and Overview

After exploring the literature there were still important gaps in knowledge about experiences families affected by ASD have in accessing diagnostic and treatment services, especially in the province of Newfoundland and Labrador, Canada and it was deemed important to explore this issue further. For this manuscript, a qualitative design informed by grounded theory methodology was used to explore parents' experiences of accessing diagnostic and treatment services over the life course of ASD and investigate the extent to which a family's self-described socioeconomic status affected their access to services. This study was designed to expand the conceptual understanding of those experiences as well as to provide direction on how to improve services for clients and families affected by ASD.

Co-authorship Statements

- Joanne Smith-Young developed the research design, supervised by Dr. Roger Chafe and Dr. Rick Audas.
- Joanne Smith-Young drafted the manuscript.
- Joanne Smith-Young, Dr. Roger Chafe, and Dr. Rick Audas edited and critically appraised the manuscript.
- Joanne Smith-Young, Dr. Roger Chafe, and Dr. Rick Audas read and approved the final manuscript.

This research draws on a data set that was part of a wider needs assessment for autism services for the Newfoundland and Labrador Autism Society.[33]

"Managing the Wait": Parents' Experiences in Accessing Diagnostic and Treatment Services for Children and Adolescents Diagnosed With Autism Spectrum Disorder

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A version of this article appears in Health Services Insights Open, 2020,

https://doi.org/10.1177/1178632920902141

Abstract

Background: Parents of children and adolescents diagnosed with autism spectrum disorder (ASD) report delays in accessing timely diagnostic and treatment services for their children. Research has generally focused on parents' experiences in caring for a child diagnosed with ASD. This study describes the process of how parents access ASD services for their children and adolescents.

Method: This study used a qualitative research design that was informed by grounded theory methodology. We used constant comparative analysis to develop a process model and a core concept.

Results: Seventeen parents of children and adolescents diagnosed with ASD were interviewed. Our process model included 3 main phases: Watchful waiting (noticing suspected behaviors, and

searching for assessment and diagnosis); Informed waiting (receiving the diagnosis, facing challenges in accessing treatment services, and realizing the impact of an ASD diagnosis); and Contemplative waiting (pondering the future, reflecting on the past, and making recommendations). “Managing the Wait” was identified as the core category central to parents’ experience of this process. This process was found to be impacted by socioeconomic status, parents’ skills and capacity to advocate on their child’s behalf, and severity of their child’s ASD. **Conclusions**: Our findings illustrate the many barriers families face during their journey in accessing ASD services. Our results illustrate the need to address wait times for services, and provide education and support services for parents as a means of improving their self-advocacy skills, especially for parents of children and adolescents with severe disability.

Keywords: Access, autism spectrum disorder, children, health care services, qualitative, socioeconomic status

Background

Autism Spectrum Disorder (ASD) raises a number of unique challenges in terms of clients accessing treatment and support services. It is a complicated condition that requires a variety of services that change over time. Often services are provided through a range of government departments and providers that frequently require integration and collaboration between health care, education, employment, and social support sectors.[1,2] There are recently reported significant increases in prevalence and a global prevalence rate of 1 in 160 children, with many countries having higher rates; as a result, there are additional demands for ASD services, which were already identified as being inadequate in most countries.[1]

Early identification of ASD has been deemed a priority because the best chance for improving symptoms occurs through early and intensive interventions.[1,3-5] Parents play a key role in facilitating any access to services because most clients are minors when they are diagnosed. A definitive ASD diagnosis is often a prerequisite for children to access publicly funded services;[6] yet, obtaining a diagnosis in itself can be stressful, frustrating, and time-consuming for many families.[7-11] Confirming a diagnosis can involve visits to numerous health care professionals to rule out other possible conditions.[12] Although the recommended maximum wait time between initial referral and ASD diagnosis is 5 months,[13] the average time between parents' initial concerns with their child's development and diagnosis is generally between two and four years.[14,15] Once diagnosed, families then have to arrange for services across a wide range of providers and settings, including those in the education system. Wait times in accessing these types of services is a key issue faced by families.[16] As clients get older, there can also be abrupt changes in services as children pass the age requirements of specific programs or require different types of services more appropriate for their stage of life and development.

DePape and Lindsay[17] explored parents' experiences in caring for a child with ASD across various countries and 6 main areas of parental experiences were identified: prediagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward; reportedly, there were negative implications for parents during all of these stages. Similarly, a metasynthesis of qualitative studies explored parenting a child younger than 12 years of age diagnosed with autism and found that parents faced many challenges that changed over time.[18] The lived experience of parents who had a child with autism was also investigated and "Living in a world of our own" emerged as the essence of that experience wherein parents described living in a world of isolation.[19]

Another key aspect in accessing services is the financial impact. Raising a child with ASD was found to be associated with more profound employment and financial burdens for parents compared with children with other types of disabilities and that more than half of families of a child with ASD indicated their employment had been disrupted by autism-related child care difficulties in the past year.[20] In Canada, many of the health and educational services needed by clients with ASD are publicly insured, so that there should be no actual financial barriers in accessing these services. Yet due to lengthy delays, those who have the financial means may choose to look for private services as a means of acquiring quicker access paid out-of-pocket.[21] As a result, this situation raises the possibility of a 2-tiered health care system that is based on a family's socioeconomic status (SES). In fact, evidence has shown that parents who report higher income and education levels express increased satisfaction with the diagnostic process and report fewer barriers.[3,11,12,22,23] Economic hardship has been reported by families who make the choice to pay for private services who cannot really afford to do so.[16] Other financial challenges for families include restrictive insurance coverage, the need to take time off

from work to care for their child, and lack of available transportation to take children to appointments.[24] Yet the exact impact that SES has on the overall process of accessing services is unclear. Research has shown that parents who identify as a visible minority, have lower economic status, and live in a rural setting receive a delayed ASD diagnosis for their children.[23,25,26] However, other researchers found that neighborhood income did not affect the age of ASD diagnosis for children.[27]

Our study explores parents' experiences of accessing diagnostic and treatment services over the life course of ASD in one Canadian province. We also explore the extent to which a family's self-described SES affected their access to services. There are still important gaps in our knowledge about experiences families affected by ASD have in accessing diagnostic and treatment services. It is our hope that this study will expand the conceptual understanding of those experiences as well as to provide direction on how to improve services for clients and families affected by ASD.

Method

Design and data collection

We used a qualitative research design guided by grounded theory methodology.[28-31] The assumptions on which grounded theory is based is symbolic interactionism wherein human behavior and the roles that individuals play are negotiated and renegotiated in a process of interactions that change over time that is the most appropriate approach when looking at psychosocial processes.[32] Grounded theory is built on compared concepts and constant comparison through which similar data are grouped and conceptually labeled during open coding.[28-31] Afterward, concepts are categorized and linked and organized by relationship in a process called axial coding. Finally, when conditions and dimensions are developed through an

interpretive process called selective coding, a theory emerges.[28-31] Grounded theory methodology was seen as particularly useful in this study, in which the focus of inquiry is to discover the strategies parents use over time in dealing with accessing diagnostic and treatment services for their children and adolescents affected by ASD.

We used purposive sampling, selecting participants who could provide data relevant to our study aims. Participants were parents of children diagnosed with ASD who had experience accessing ASD diagnostic and treatment services for their children in the province of Newfoundland and Labrador (NL). Two research assistants under the supervision of the third author conducted interviews as part of a wider needs assessment for autism services for the provincial Autism Society.[32] The interviewers were both a male and a female in their early 20s, who often conducted the interviews together. Neither of them had a child with ASD. Our analysis of the data did not reveal any significant issues relating to the gap in experience between the interviewers and the parents who were interviewed. Parents were invited to participate in a semi-structured interview. Each consenting participant provided written informed consent prior to being interviewed. Parents were asked questions to explore their overall experiences in accessing diagnostic and treatment services for their children through the life course of their condition.

Interviews began with parents describing when they first noticed suspected ASD behaviors and their experience in accessing diagnostic and treatment services for their children. As the interviews continued, more focused questions were asked (i.e., what, if any, impact the ASD diagnosis had on their families and/or financial situations). Finally, parents were asked to reflect on their overall experiences and offer suggestions to improve services for other parents. Interviews were audio-recorded and transcribed verbatim. Confidentiality was assured by

removing all identifiers from the interviews during transcription and using numeric codes to identify participants. Ethics approval was granted by the Memorial University of Newfoundland's Human Investigation Committee.

Data management and analysis

We conducted our analysis in 3 stages: first, coding interview transcripts and establishing preliminary themes through frequent comparisons; second, recoding the data using the preliminary themes and identifying the ones used more frequently; and third, organizing resulting themes into overarching categories; finally, we identified a core category to which all the categories were related that best fit the pattern of behaviors parents used that captured what was happening within the data.[28-31] At each stage of analysis, the first author conducted the initial coding followed by the second and third authors who reviewed the coding, queried interpretations, and challenged assumptions. Trustworthiness was achieved through peer review and involvement of the 3 authors having different areas of expertise throughout the analysis. The 3 authors have extensive experience in analyzing qualitative data. The core category and ensuing categories are presented in the findings with quotes to illustrate each phase of the process.

Results

Seventeen parents that included mothers (n = 13) and fathers (n = 4) of 17 children and adolescents with ASD aged 3 to 19 years (M = 10.5 years, SD = 5.8) participated in a semi-structured interview lasting approximately 1 hour. All children and adolescents were reported by parents as being verbal and diagnoses of ASD were confirmed through parent reports (see Table 1 for further demographic information).

Table 3.1. Demographic information of children/adolescents.

Age category	**N**	**Sex of child**	
		Male	**Female**
Children (aged 1-10 years)	8	7	1
Early adolescence (aged 11-14 years)	4	3	1
Middle adolescence (aged 15-17 years)	1	1	0
Late adolescence (aged 18-21 years)	4	4	0
Total	17	15	2

We recognized waiting as a key feature in parents' experiences and found that managing the wait included 3 main phases over the life course of the condition. The process began as parents initially waited to find out whether or not concerning behaviors they were noticing in their children were permanent or transient. They were subsequently required to wait in the public health system for appointments with health care professionals, usually with a family doctor and subsequently a pediatrician to have their child assessed and diagnosed. They would then face additional waiting to access intervention and treatment services for their children with other health professionals including speech therapists, occupational therapists, and physiotherapists. As they received information about ASD, they began to realize the impact this condition might have on the future that left them once again waiting to see what would happen, looking forward to what services their children might need in the future. Finally, they would reflect on their experiences when their child was first diagnosed, what they found lacking in the system, and make recommendations that would hopefully improve other parents' experiences and better prepare them in managing the wait. "Managing the wait" was identified as the core strategy parents used throughout the entire process (Figure 1).

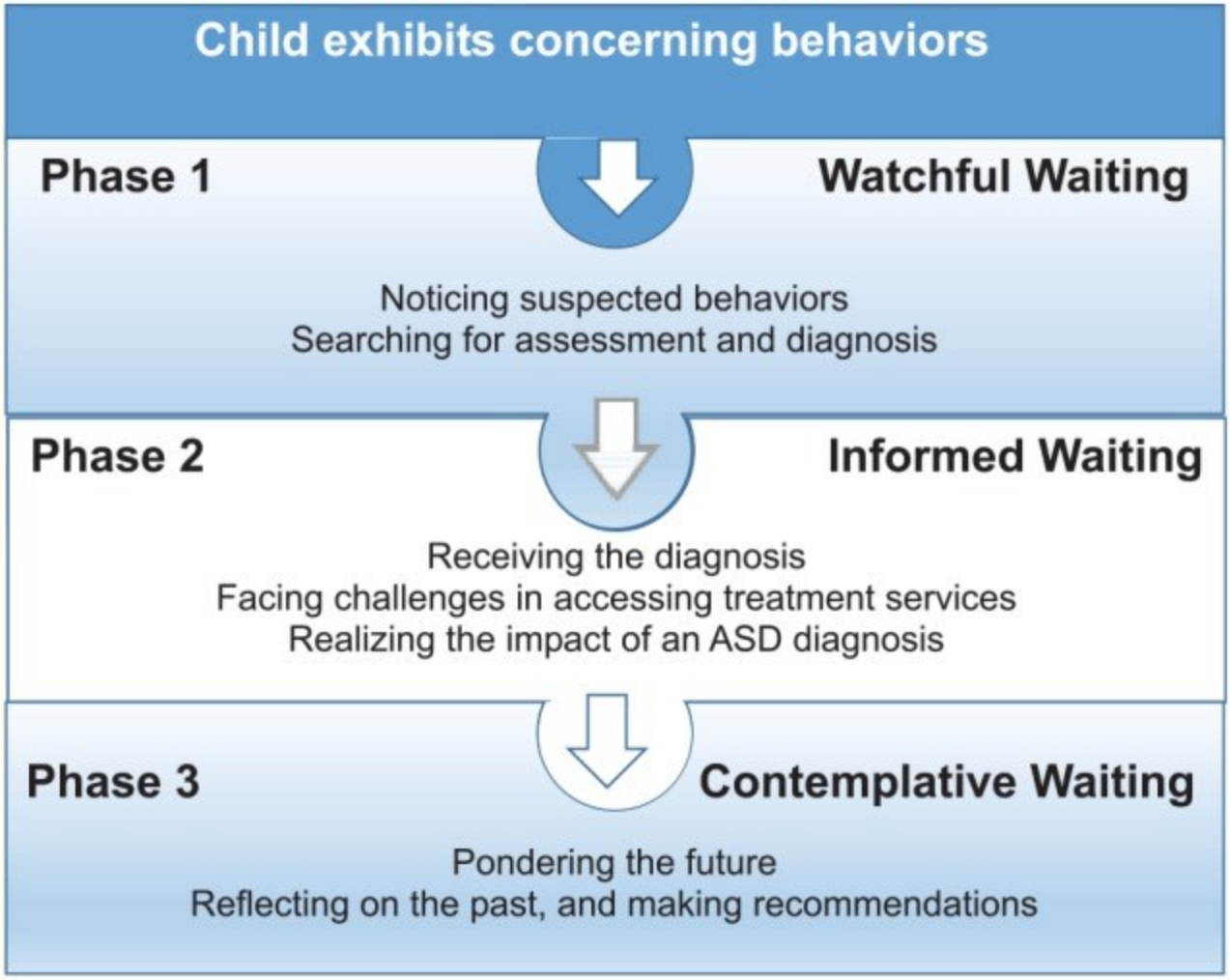

Figure 3.1. Process model of "Managing the Wait."

Watchful waiting

In the first phase of "Watchful waiting," the definition of waiting can be described as, "remaining stationary in readiness or expectation."[34] In this phase, parents, family members, or other caregivers were noticing children displaying suspected ASD behaviors. Some behaviors seemed easily recognized yet others appeared to be less pronounced. Parents were watching and waiting to see whether their children's problematic behaviors would resolve or persist. Watchful waiting included two subphases: noticing suspected behaviors and searching for assessment and diagnosis.

Noticing suspected behaviors. In this first subphase, parents and other caregivers began noticing suspected ASD behaviors in children such as an inability to make eye contact, difficulties in social situations, delayed speech, problems with sleeping and eating, struggles with fine and gross motor activities, repetitive behaviors, and overreactions to environmental stimuli such as scents, noises, and crowded places. Some behaviors were noted in infancy. *"He didn't have good eye contact . . . I wasn't looking for it but noticed it."* Others noticed it during the toddler years:

> He was different probably just before he turned 3 years old like he'd get really latched on to things like really concentrate and just couldn't break that boredom cycle and had these really strange kind of hand gestures that he would be doing all the time and there were the sounds he'd make—odd noises at certain times and you know they might last for 30 minutes . . . he didn't interact socially.

When children became school age, others brought their attention to certain behaviors. *"His kindergarten teacher recognized it and she said that [child's name] is really withdrawn. He doesn't like me to touch him. He doesn't play with other kids."* A sudden regression in behaviors caused concern:

> I was thinking that he was deaf because he had been speaking and then all of a sudden he lost what speech he had and he wouldn't come when you sang out to him, he wouldn't pay attention to you anymore. He just totally ignored everything.

Parents spoke about experiencing a "gut feeling" as concerns became more evident:

> This gut feeling that was always there that we knew there was something not right . . . there was something wrong and you couldn't help it or put your finger on it . . . He just didn't like to be in public noisy places. He was a difficult sleeper . . . constant motion, movement was a big thing for him.

Parents were recognizing suspected signs and symptoms of ASD in their children leading them to search for assessment and diagnosis, subsequently confronting challenges within the publicly funded health care system.

Searching for assessment and diagnosis. A speech language pathologist was often one of the first health care workers to recognize signs of ASD. They would often recommend further assessment that prolonged the waiting:

> [We] waited eight months to get into speech . . . the speech language pathologist was the first one that even hinted that there could be something. She suggested that we go to get tested for autism . . . it was 19 months [on the wait list] from the time we started; [it] was 36 months when he got his diagnosis.

Parents spoke about how some health care providers had advised them to wait to see what happens in their children's developmental progress before accessing diagnostic services that resulted in delays. *"We saw our family physician and it was just kind of, 'no—wait and see, wait and see'."* The prolonged time it took for parents to get a diagnosis for their children was apparent:

> We noticed it when he was around 19 months . . . We got him referred when he was around 24 months . . . It took about 8 months to get in for testing. We went three times for testing . . . He was almost four years old when he got diagnosed.

Hoping to gain timely access to assessment and diagnostic services, some parents looked for service provision in other parts, or outside the province. "*I just used some of my health care connections and I saw a doctor in another part of the province who was quite comfortable making an autism diagnosis."* Often the waiting process was further complicated by inaccurate or missed diagnoses:

> He wasn't meeting his milestones as a baby . . . they always said, "He's just a very quiet baby and when he's two years old he'll be perfect just give him some time. He's a bit slower." So, I never thought anything of it . . . Then the pediatrician wanted to check for muscular dystrophy and cerebral palsy . . . Then we started all these very intrusive diagnostic tests . . . muscular dystrophy was ruled out, cerebral palsy was ruled out . . . saw the top pediatric neurologist in Canada and we did genetic counselling . . . global delay . . . Now he's diagnosed with autism.

Once an ASD diagnosis was received, parents began to understand what the diagnosis meant that led them into the second phase of the process.

Informed waiting

In "informed waiting," the concept of waiting can be described as "looking forward expectantly."[34] Parents were starting to become informed about ASD and what it meant with a desire to access timely and appropriate health services for their children. This second phase included 3 subphases: receiving the diagnosis, facing challenges in accessing services, and realizing the impact of an ASD diagnosis.

Receiving the diagnosis. Parents spoke about having varied reactions at the time their children received the diagnosis that included feelings of shock, disbelief, confusion, anger, sadness, worry, denial, and guilt. They also talked about how difficult it was to accept the diagnosis:

> At the beginning, I didn't believe it because my perception of autism was a little kid in the corner banging his head and that's not what [my son] was. [My son] was like really, really smart but he didn't socialize . . . [The pediatrician] said, "Have you seen the movie the Rain Man?" and I said, "Yeah." I said, "Are you telling me [my son] is autistic?" And he said, "Yeah." He said, "He's definitely on the spectrum . . ." I got three different

> opinions because I just didn't believe it. I knew he was different but didn't think it was something that would be labeled.

Other parents expressed how they had expected it and weren't really surprised their child had received a diagnosis of ASD:

> I wasn't surprised by the diagnosis. I've done a little bit of research while we were waiting for everything to happen and when it came back I was like that seems smack on to me . . . it explained the situation.

Still, others were shocked:

> You're so shocked when you hear it that you don't even know what to ask—like you don't know what to say other than, "Is this terminal? Is this something that's going to kill him? . . ." I kept thinking afterwards like this must be pretty severe if they've already got a society and it's right here pretty much attached to the [children' hospital] . . . like this must be really bad . . .

Feelings of disbelief, sadness, concern, and guilt were common reactions to receiving the diagnosis:

> Within like 30 minutes he [pediatrician] came out and he said, "You know, sorry your son has autism." After being given the diagnosis, I was like a mess for two days. I couldn't even talk. How did it happen? Why did it happen? Am I responsible for this?

Parents who had been expecting the diagnosis expressed relief because they believed support for their children would soon be provided. *"We knew he was autistic long before he had a diagnosis. We only got the diagnosis so he could get the services."* Others felt angry and bitter toward their health care providers indicating they had shown lack of empathy and indifference when the

diagnosis was provided. The economic and financial impacts of ASD were also becoming apparent. At the time, Applied Behavior Analysis [ABA] therapy was not publicly insured.

> Basically, you had to pay for your own therapist . . . $35,000 to $60,000 a year depending on the amount of hours . . . it blew us away! I just couldn't believe it. I was so angry with the doctors . . . I was very angry. At one point he had to tell me to calm down. It wasn't a nice conversation. My wife was crying obviously. It's very traumatic!

Once their children had been provided a confirmed diagnosis of ASD, parents were expecting timely access to therapies and supports for their children because they understood early intervention was important yet they were challenged once again by wait times.

Facing challenges in accessing treatment services. As parents attempted to gain access to treatment services and therapies for their children, wait times remained a concern:

> When you hear the word autism you're introduced to the fact there's a 12 to 18 month wait. So that's 12 to 18 months wasted. Then OT [occupational therapy] took us two years to get in, speech took us six months. It's unacceptable from my perspective. That's precious time wasted . . . ABA we were put on a wait list—it was a good six or seven months . . . The wait list was really, really long for speech [therapy] . . . We applied for [autism service dog] . . . it took three years to get him.

Parents were starting to weigh the pros and cons of deciding to wait for publicly funded services or facing the financial burdens associated with paying for private services on their own. *"The bad thing about [private service provider] is it's very expensive and it's not covered under* [public insurance]. *I'm paying $500 a term for him to go there whereas [public service] is free."* For those who had the financial means to pay for private services, they would reflect on the benefits of that:

> The thing with private services is that it was happening regularly and when we had private speech we knew who was coming through the door. There was a relationship . . . When you're paying for this out of pocket for the private system, there is a contract between you and them . . . you feel more as a consumer of a service when it's private.

Parents recognized the divide in service provision between health care and education:

> You've got two systems that are not working together . . . ABA therapists are not allowed in the school . . . You've got a healthcare system that doesn't communicate with the education system and you've got this disconnect.

Parents who had attempted to obtain financial supports from government agencies were being challenged by those bureaucracies:

> We applied for the special child welfare allowance. We filled it out twice and never heard about it. It's invasive and weird and difficult to fill out. They lost the first one. We never heard back from the second one.

Demands associated with numerous medical, school, and therapy appointments led many parents to the point of exhaustion. Parents reported using up sick leave and annual leave when they decided to leave work to meet those demands that led to additional stress.

Despite the challenges experienced with ASD therapies, some parents were relieved at the results. Many saw improvements in children's behaviors, speech, and social skills yet others thought their child had not improved as much as they would have liked and would have liked to see an individualized approach. Parents who had children in school were faced with additional challenges such as teachers demonstrating limited knowledge about ASD, a lack of student assistants, as well as inconsistencies that was viewed as detrimental for children with ASD. Some parents would need to relocate to larger centers as a means of accessing ASD services. The

impact that an ASD diagnosis was having on their families was apparent that placed greater burdens on families living in rural areas.

Realizing the impact of an ASD diagnosis. Parents were recognizing impacts on marital and family relationships, as well as finances. Parents spoke about how caring for their child with ASD was taking priority over their other children's needs that left them with feelings of guilt. Relationships with partners had either been strengthened or strained:

> We stayed married for financial reasons. So, it was either file for bankruptcy or live on the welfare system . . . So, he has a room in the house and my son and I have the rest of the house. We share a residence and he sees his son when he wants to. When he doesn't choose to, well we go on with our day unfortunately. It's not easy. We're trying our damnest to make it work . . . the divorce rate is high.

Parents expressed their thoughts about what was yet to come. "Contemplative waiting" describes the next phase wherein parents contemplate and anticipate their future with a child having ASD.

Contemplative waiting

In this final phase of the process, the concept of waiting can be described as, "remaining stationary in readiness or expectation."[34] In this phase, parents waited, planned, contemplated, pondered, and anticipated how their children's future and theirs might look. Parents also reflected on what was lacking at the time their child received their diagnosis and what might benefit other parents going through the same experience. This phase includes two subphases: pondering the future, and reflecting on the past and making recommendations.

Pondering the future. Parents were starting to question what a future might hold for them and their children affected by ASD:

> Is he going to have any friends? Is he going to be able to talk? Am I ever going to have any kind of parent-child communication in the regular sense with this kid? Will he grow up to be somebody who has a job and is able to support himself and have friends and a certain level of happiness . . . a happy, healthy life?

Some decided to focus on the present, apprehensive of what lay ahead. "Part of you doesn't really want to look for the future." Parents of children with more severe disability were especially concerned because of the high dependency needs of the child:

> He's an only child and when we're gone I don't know who's going to look after him . . . he may end up in a home or some facility being cared for or having workers full time caring for him . . . He's extremely low functioning probably going to require lifelong care and there's nobody else to care for him once I'm dead and gone—when he turns 21 then what would you like me to do with him? I'm trying to start thinking of his future.

Parents were wishing for a "normal" and fulfilling life for their children with an aim to integrate into society, get married, have children, and secure employment. Some had begun saving and planning for their child's future by contributing to registered disability savings plans. As they pondered the future, they also offered recommendations and suggestions for other families facing similar challenges.

Reflecting on the past, and making recommendations. Parents looked back on the services at the time their child was assessed and diagnosed providing recommendations to make the process better for others:

> In the beginning, I would have loved support . . . I just want to be able to phone the Autism Society and say, here's my problem and have somebody say, okay we know

> what's going on . . . a lot of time was spent trying to figure where things were and I just didn't have the energy for that.

They talked about how crucial it was for children to gain early and timely access to diagnostic and treatment services and learning to navigate the health care system was deemed important right from the beginning:

> The earlier the diagnosis the earlier you get started on this. I feel like when any parent gets a diagnosis there should be a list like this is what you do. You go here. These are the steps. It would be nice to give a card to a family that's going through it to say, you can call here and they will give you support—kind of like a helpline.

Parents also made suggestions about what they thought the government should provide such as investing in the employment training and support services for adolescents and young adults. They wanted their child to find suitable employment that would enable them to participate in their own futures rather than relying on government subsidies and the welfare system. "*He's going to have barriers to employment. If it's not addressed, then he's going to end up being dependent on government subsidies."*

Strategies in "Managing the Wait"

We conceptualize that the core concept governing parents' experiences of accessing services for their children with ASD is managing the waiting. We developed a 2 × 2 typology to describe how SES, parental self-advocacy, and severity of ASD symptoms impacted the overall process of managing the wait, with families having different capacities for managing or shortening the wait depending on these factors. Self-advocacy in health care has been described as "standing up for oneself"[35] and "a process of internalizing skills and resources to act in a way that supports [clients'] specific needs and goals."[36] In this instance, we describe parental self-advocacy as

being assertive, internalizing knowledge, skills, and resources as a means of making decisions on behalf of a child or adolescent diagnosed with ASD with the aim of accessing services.

In Figure 2, we show how high or low SES in combination with high or low parental self-advocacy provides different strategies parents used in "Managing the Wait." We used dotted lines in our typology to illustrate the dynamic aspect. Strategies vary over time as SES or parental self-advocacy change. If parents move to a higher level of SES or gain experience and knowledge around engaging with the health care system, that would correspond in a change of strategy. Severity of ASD disability was found to be a critical factor for all families trying to access services.

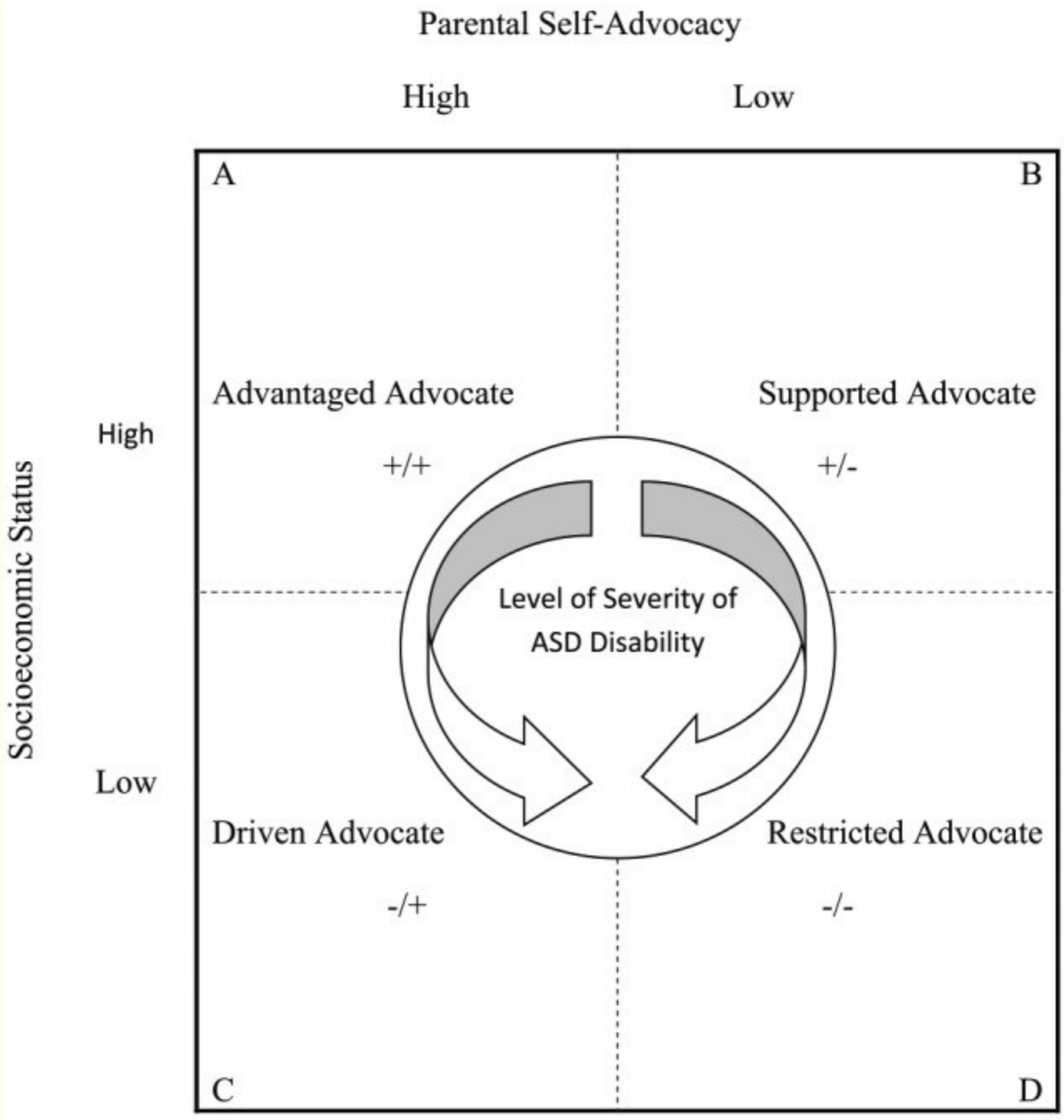

Figure 3.2. Parental strategies in the process of "Managing the Wait."

Parents having *high* self-advocacy skills in a *high* SES status can be described as "advantaged advocates." These parents are able to move forward and advance in acquiring services for their children because they have both the financial means and high self-advocacy skills:

> There was more flexibility . . . you feel more as a consumer of a service when it's [the service is] private . . . a lot of families obviously don't have that advantage, that personal social network that's connected indirectly with autism professionals, got his diagnosis faster . . . we would have been another year for sure getting a diagnosis had we not known people . . . [He] is lucky he's got parents that we're on this.

In contrast, parents who are "restricted advocates" are both financially limited in their ability to pay out-of-pocket expenses and have low self-advocacy skills that lessen their ability to act on behalf of their children. *"I don't know what the hell I'm doing half the time with autism . . . I'm scared half of the time . . . I'm a single parent . . . mental exhaustion, financial stress."*

Parents who are "supported advocates" may have the financial means to gain timely access to needed services, yet lack self-advocacy skills:

> I'm employed . . . we have insurance . . . basically her [child's] needs are taken care of . . . if we knew more, we probably would have done more . . . it's like we opened the door to this new world of autism and we didn't have a clue.

Parents who are "driven advocates" are strong advocates for their children yet financially disadvantaged. These parents find themselves remortgaging their houses, using credit cards, thus incurring substantial amounts of debt attempting to pay out-of-pocket expenses so their child can have access to services:

> You got a wait list and a child that has needs and at least you got a credit card that can fund it or that line of credit . . . we're $32,000 [in debt] still digging out . . . you do what you have to do . . . Pushing that little bit started at least to get me on to a waiting list for services . . . I had to push. I'm still pushing.

We found that level of severity of ASD disability was a central factor that impacted the process of "managing the wait." Parents of children with increased disability anticipated they would require additional services throughout the life course of their condition. In contrast, parents of children with less disability thought their children might have less need for services during the life course of their condition. The process of managing time was found to be a dynamic process. Therefore, as parents' SES and/or self-advocacy skills changed, so would their strategy.

Discussion

Findings from this study provide insight into how parents access diagnostic and treatment services for children diagnosed with ASD. "Managing the wait" was found to be the main concern for parents, which started from the time when they first began recognizing concerning behaviors and continued throughout the life course of their condition.

Parents were often the first to recognize and identify behavioral concerns. Ozonoff et al.[37] have also shown that parents often detect ASD concerns earlier than professionals. Parents who express early concerns about their child's nonverbal communication or unusual gestures can receive an earlier diagnosis and timelier access to services.[38] We found, however, that extensive delays in accessing diagnosis and supportive services for children with ASD were a more significant issue for families.[6,15,39,40] We also found that health care providers who either dismiss parents' concerns or reassure them that their child will "outgrow" concerning behaviors contribute to unnecessary delays.[41]

Many of the parents in our study expressed an overall dissatisfaction with both the health care and education systems. As a result, they become advocates for their children as well as all families affected by ASD. This has been reported by other researchers who describe how parents

of children with disabilities move from being an "advocate" for their own child to becoming an "activist" for all children.[42]

Parents reacted to an ASD diagnosis for their children with shock, confusion, anger, sadness, and worry. A recent metasynthesis showed parents have mostly negative emotional responses on receiving an ASD diagnosis for their children that included reactions of shock, despair, devastation, resentment, and anger.[18] Research has shown that when parents finally receive an ASD diagnosis, it provides a sense of relief. It legitimizes their concerns, providing evidence to obtain treatment and services for their children.[43] Parents in our study expressed a sense of relief about the ASD diagnosis because they finally had a label for what was going on with their child's development. They viewed this label as a means to obtain interventions and supports for their children in an attempt to reduce problematic behaviors related to ASD and increase communication skills. However, despite receiving a diagnosis, we found that parents still were required to "manage the wait" because they continued to face delays in acquiring ASD-related services for their children. Those types of delays have also been widely reported.[8,10,11,16]

In our study, parents were dissatisfied with the information provided to them at the time of the diagnosis. They believed they had not received enough information about support services, and talked about how certain professionals were not knowledgeable about how they could acquire support. Previous research findings suggest that the number of difference sources of information families receive at the time of ASD diagnosis significantly predict the informal and formal social supports parents receive, and families of low-income report significantly less support.[44]

Parents of children with ASD have additional expenses and added burdens to employment that can turn a middle-income family into a low-income family in a short period of

time. Indeed, many families of children with ASD earn 28% less than other families who do not have a child with ASD.[45] Health insurance plans do not often cover behavioral-related therapies and consider them educational rather than medical. As a result, parents can be left to pay these costs themselves.[45] Social and recreational activities specifically designed to benefit children affected by ASD can be expensive. Parents often spend hundreds or thousands of dollars a year sending their children to organized activities such as camps, and social and recreational activities to assist in their child's social and physical development.[45] In this study, parents described how they struggled to meet these types of financial challenges often paying out-of-pocket for these types of activities considered a benefit for their child.

The findings from this study demonstrate how parents' financial situations changed following their child's ASD diagnosis. Parents described financial hardship, increased levels of stress, hopelessness, and despair as they attempted to meet the financial challenges of parenting a child with ASD. In attempts to maintain full-time employment, parents struggled to balance the many scheduled appointments. This has also been previously reported that parents of children with ASD spend a significant amount of time finding, assessing, and retaining services, coordinating services, advocating for their children, and taking children to appointments.[46] In this study, we found parents quit full-time work or reduced their working hours to stay at home to care for their child affected by ASD often leaving one parent shouldering the financial burden for the family. That was also evident in other study findings.[46] Our study findings illustrate how parents end up spiraling into debt in attempts to pay for services and therapies for their children. Parents reported taking out multiple loans or would remortgage their homes in attempts to pay for out-of-pocket expenses deemed necessary in caring for a child with ASD. Similar financial concerns have been raised in other studies[17,18,27,47]

Health disparities include biological, behavioral, sociocultural, and environmental factors that can influence health-related outcomes.[48] SES, environment, and geography have reportedly led to disadvantages for parents of children with ASD.[49] In our study, families living in rural communities and single parent families faced geographical challenges needing to travel long distances to access ASD services only available in urban centers. Other researchers have reported similar findings.[50,51] Living in a rural area as well as low financial status is associated with receiving a later ASD diagnosis for children.[52,53]

Our study does have some limitations. We acknowledge that parents' report of their children's diagnostic and cognitive status may be a limitation of this study. Findings from this study may be not generalizable to the general population because of the nature of qualitative research design; however, similar study findings strengthen the likely validity of our results for other populations. The model of findings resulting from this study and the typology of strategies used by parents impacted by SES, parental self-advocacy, and level of disability is unique that adds to the current knowledge and that can be considered a strength of this study. We focused on the experience of parents accessing services for their children and adolescents. Challenges for families and individuals impacted by ASD continue beyond adolescence into adulthood. As a result, we need further research to explore the processes by which children with ASD transition into adolescence and adulthood to understand the impact on families throughout the entire life course of this condition.

Implications for Practice

It is evident from our study findings that parents are noticing early signs and symptoms of ASD in their children and identifying subtle clues such as limited eye contact, sleep problems, unusual diet, delayed speech, and other related symptoms. Health professionals need to recognize

parents' expertise in identifying early signs and involve them in the diagnostic process as early as possible.

Receiving the news that a child has ASD can have a profound effect on the family. Health professionals need to provide an adequate amount of time to deliver the diagnosis and provide support for parents at the time of diagnosis and afterward. Parents may be so overwhelmed at the time of diagnosis that they stop listening and miss important information that the health professional is communicating. The professional needs to present the information clearly in lay language so parents can better understand. Health professionals should schedule a follow-up meeting or phone call after the initial time of diagnosis to provide an opportunity for parents to ask questions, talk about any concerns, and, or ask for resources and supports. Health professionals must also consider parents' financial resources when providing information about treatment and intervention services. They should provide information to parents about any financial resources that may be available for those who need them.

Diagnosis should not be a means to an end but part of an ongoing life-stage process. Professionals must impart a sense of optimism to families about their child's future. Health professionals should recognize children with ASD and their families require lifelong provision, management, and service coordination.

Conclusions

With increasing ASD prevalence rates, not only in Canada but also around the world, it is important for parents to obtain timely access to diagnostic and treatment services for affected children. The health care system needs sufficient resources to be able to provide timely access to diagnostic and intervention services that can benefit individuals with ASD over the life course of their condition. It is also important to address the social justice issues faced by these families. In

a country where publicly funded health care is readily available, children and youth with neurodevelopment and mental health conditions deserve to be cared for at the time they need it so they can reach their full potential and become contributing members of society. Our results offer a unique perspective on families grappling with ASD as illustrated in the dynamic interplay of SES, parents' ability to advocate for a child with ASD, and level of severity of ASD symptoms. Our findings illustrate that strategies used by parents to "manage the wait" to access services for children and adolescence with ASD during the life course of their condition are not static, but ever changing and dynamic.

Acknowledgments

We wish to thank the parents for taking the time to share their experiences with us for this research study, and Patrick Murphy and Shauna Wells who conducted the interviews. We would also like to thank the Autism Society of Newfoundland and Labrador for their assistance.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was financially supported by the MITACS Canada and the Canadian Institute for Health Research (CIHR).

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Author Contributions

All authors designed the study. RA coordinated data collection. All authors were involved in data analysis, writing, and reviewing the final manuscript.

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Chapter 4: Manuscript 2

Introduction and Overview

The research from Chapter 3 identified parental advocacy as a key feature in how parents 'manage the wait' in accessing ASD diagnostic services for their children. As such, we used a qualitative descriptive exploratory methodology to further explore the concept of advocacy in parents and caregivers of children and youth diagnosed with ASD in four provinces in Atlantic Canada. In this study, we describe parental advocacy efforts in the journey of parenting a child with ASD. This chapter highlights when, how, and why parents advocate on behalf of their children as they navigate barriers and supports in medical, educational, and social contexts of their child's environment.

Co-authorship Statements

- Joanne Smith-Young developed the research design, supervised by Dr. Roger Chafe and Dr. Rick Audas.
- Joanne Smith-Young drafted the manuscript.
- Joanne Smith-Young, Dr. Roger Chafe, Dr. Rick Audas and Dr. Diana Gustafson edited and critically appraised the manuscript.
- Joanne Smith-Young, Dr. Roger Chafe, Dr. Rick Audas and Dr. Diana Gustafson read and approved the final manuscript.

This research draws on a data set that was part of the Atlantic Canada Children's Effective Service Strategies in Mental Health (ACCESS-MH) project conducted in Newfoundland and Labrador, Prince Edward Island, New Brunswick, and Nova Scotia.

"I know how to advocate": Parents' experiences in advocating for children and youth diagnosed with autism spectrum disorder

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A version of this article appears in Health Services Insights Open, 2022,

https://doi.org/10.1177/11786329221078803

Abstract

Background: Parental advocacy is a dynamic process that changes depending on the circumstances and needs of the child and parent. Communication deficits related to an Autism Spectrum Disorder (ASD) diagnosis often necessitate parental advocacy. This study describes how parents and caregivers of children and youth diagnosed with ASD engage in parental advocacy, the challenges they encounter and the advocacy skills they develop.

Method: We used descriptive exploratory methodology informed by reflexive thematic analysis. The aim of the study was to explore advocacy in parents and caregivers of children and youth diagnosed with ASD.

Results: We conducted in-depth, semi-structured interviews with 15 parents of children and youth with an ASD diagnosis living in four provinces of Atlantic Canada. The pathway in parents'

advocacy journey included: (1) Expressing concerns; (2) Seeking help, assessment, and diagnosis; (3) Acquiring services; (4) Removing barriers; and (5) Developing advocacy skills.

Conclusions: Our findings illustrate the process of parental advocacy, skill development, and the barriers parents encounter in advocating for their children with ASD. Future research might explore how health professionals can support parents' advocacy efforts.

Keywords:

Child advocacy, autism spectrum disorder, parents, qualitative research

Received: July 30, 2021. **Accepted:** January 18, 2022.

Type: Original Research

Funding: The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was financially supported by the Canadian Institute for Health Research (CIHR).

Declaration of Conflicting Interests: The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Background

Autism Spectrum Disorder (ASD) is a chronic neurodevelopmental disorder, with patients often showing symptoms before the age of 4.[1] There is no blood or genetic test to diagnose the disorder. Clinicians usually rely on observations, medical histories, and a variety of diagnostic and assessment tools to determine whether an individual has ASD.[2] Common features of ASD include atypical eye contact, hyperactivity, and repetitive body movements such as rocking or hand-flapping, with patients having a wide range in the severity of their symptoms.[2] Individuals with ASD may also have mild to moderate intellectual disabilities, but again the severity of impairment varies widely from patient to patient.[3] One of the defining features of ASD is a significant deficit in social, communication, and interaction skills.[1] For example, children with ASD display lack of normal back-and-forth conversations, failure to initiate or respond to social interactions, and difficulties maintaining and understanding relationships.[1] These social deficits can increase the demands on parents to advocate directly on behalf of their children.

Children with ASD require access to a range of health and educational services and supports. Parents are often the main advocates for their children across these various programs.[4] Parents need to report their perceptions of their children's health conditions to medical and other professionals to receive a diagnosis and access appropriate services. Children with ASD often have additional co-morbidities, such as Attention Deficit Hyperactivity Disorder, seizure disorders, anxiety, and gastro-intestinal disorders. Co-morbidities can make accessing diagnostic and treatment services more difficult.[1]

Parents of children with ASD are faced with many challenges. A Canadian study showed that having a child with ASD resulted in parents experiencing a sense of isolation because of a perceived lack of understanding from society and unsupportive system.[5] Results showed experts

and professionals lacked the necessary knowledge and expertise in dealing with the needs of families.[5] Parents experience a sense of loss both for themselves and other family members.[5] Having a child diagnosed with ASD has direct and persistent impacts on the family, including financial, social, and marital and sibling relationships.[2] Marital difficulties can lead to family breakdown and divorce.[6] Challenges in caring for a child with ASD can result in higher levels of stress that can affect parents' mental health and well-being.[6]

Parents are sometimes reluctant to advocate in the school system for their child with ASD because they lack essential knowledge of the education process; thus, they often request support from a special education advocate when it is available to them.[7] When disagreements or disputes occur between the parents and the school administrators about a student, mediation is an option. Mediation is a voluntary process aimed at establishing agreement between parents and administrators.[8] If mediation is unsuccessful, then a due process hearing is a legal proceeding that attempts to resolve the dispute.[8] In the US, parents of children with ASD are more ten times more likely to pursue legal advocacy when compared to comparator groups in other disabilities categories. Some scholars argue that this is "likely due in part to the school systems' limited success in effectively addressing this complex disability (p. 98)."[9]

Advocacy is a dynamic process that changes depending on the circumstances and needs of the child and parent. Parents are considered natural advocates because of their assumed commitment to the well-being of their child.[4] Many parents view advocacy as a moral obligation or expectation.[10] Advocacy can be an active coping strategy for parents of children with disabilities.[11] However, not all parents and guardians are in a position to effectively advocate for a child with ASD. There is debate about whether parents sometimes intervene too much on their children's behalf.[12]

Researchers describe advocacy in the ASD literature as "any action taken by a parent on behalf of their child or other children with ASD to ensure adequate support, proper level of care, and basic human rights (p. 74)."[11] Advocacy skills for parents of children with ASD may include understanding ASD, using clear and effective communication, being organized, and managing difficult situations when they arise.[13] Several contextual factors may increase or decrease parental advocacy over time. Some of these factors include financial status, education and skills, time commitment, severity of the child's condition and age of diagnosis.[14]

Financial status

Economic status and family income can affect parents' level of empowerment and their ability to advocate for their children with ASD.[14,15] High-income parents are better able to meet their child's needs for services and support by paying out-of-pocket.[11] Parents are often willing to pay significant sums of money to help their children often causing financial hardship.[16] Parents report feeling "blessed" when they have both the financial status, education, and skills to "fight" for their children diagnosed with ASD.[17]

Education and skills

Parental advocacy is an ongoing and multifaceted communicative process that includes staying informed and educated.[18] To advocate effectively, parents need to educate themselves to gain an understanding of the relevant social, economic, and political environments and become familiar with service delivery, legislation, and budgetary issues.[11] Parents are often challenged in their advocacy efforts because they have difficulties in navigating the system.[19] It seems parents become more comfortable advocating for their child as they become more educated and skilled with their child's diagnosis.[20] Parents are more likely to engage in advocacy efforts when they

develop effective self-efficacy skills.[10] In fact, parents who achieve a mastery of skills in their ability to advocate feel empowered to act on their child's behalf.[14]

Time commitment

Advocacy and caregiving can be a full-time activity for parents with one parent often having to give up work to advocate.[16] Meetings scheduled at short notice make it difficult for working parents or parents involved in childcare and other responsibilities to attend. The time parents spend traveling from rural to urban centers to acquire ASD services is another challenge to parental advocacy efforts.[15] Time and resources impact parents' ability to engage in advocacy.[19] Parents tend to become more involved in broader systemic advocacy after their children are older or their conditions improve when they have more time to do so.[17]

Severity of condition and age of diagnosis

The severity of the child's ASD diagnosis affects parents' conceptualization of autism in ways that influence their ability to advocate.[15,17,21] Parental advocacy also depends on the age of the child with ASD.[17]

This paper addresses a gap in the existing literature about the circumstances surrounding parental advocacy for children and youth with ASD. This descriptive exploratory study examines the question: "When, how, and why do parents of children and youth with ASD engage in parental advocacy and what barriers, if any, do they encounter?" Improving our understanding of parents' experiences of advocacy may help other parents of children and youth with ASD be effective advocates. Results from this study will also point to ways that service providers can promote parental advocacy by developing collaborative and constructive partnerships with parents and providing timely and appropriate services over the life course of the condition.

Method

Design and data collection

This paper draws on a data set that was part of the Atlantic Canada Children's Effective Service Strategies in Mental Health (ACCESS-MH) project conducted in Newfoundland and Labrador, Prince Edward Island, New Brunswick and Nova Scotia. One of the goals of the ACCESS-MH project was to explore the journeys of parents with a child or youth diagnosed with a developmental disorder, including ASD.

We used qualitative descriptive exploratory methodology[22-25] to explore and describe parents' experiences in raising a child diagnosed with ASD in relation to advocacy. Purposeful sampling was used to recruit participants for the study. We developed a poster to recruit participants through various ASD advocacy groups within the four Atlantic provinces who distributed the poster for us and endorsed our research. Interview data were collected from parents who identified as having a child or youth diagnosed with ASD. Data were subject to reflexive thematic analysis.[26] Two research assistants under the supervision of the senior researchers from the project team conducted face-to-face interviews with parents in a private office setting. The interviewers were male and female university students. None had a child with ASD. Field notes were taken during each interview. Memorial University's Human Investigation Committee provided ethics approval for this study. Each consenting participant provided written informed consent prior to being interviewed and audio-recorded.

During hour-long in-depth, semi-structured interviews, parents were asked to describe their journey of parenting a child with ASD. They discussed their child's concerning behaviors prior to receiving a diagnosis, how they obtained services and supports for their children, and

any barriers faced in their advocacy efforts. Parents also offered recommendations for helping other parents who may be going through the same type of journey.

Interviews were transcribed verbatim. All identifiers were removed and numeric codes were used (e.g., P-1, P-2, etc.) to identify participants to assure patient confidentiality.

Data management and analysis

The data analysis process was informed by Braun and Clarke's 6-phase process for conducting a thematic analysis, which includes 6 steps: familiarizing yourself with the data, generating initial codes, searching for themes, reviewing themes, and defining and naming themes.[26] In order to achieve data familiarity, the first author (JSY) engaged in repeated reading of the transcripts helping to move the analysis beyond a focus on the most obvious meanings. During initial readings of the transcripts, parental advocacy inductively emerged as a prominent aspect of support seeking journeys, even though the original interview protocol did not initially focus on this topic. Once parental advocacy was defined as a relevant concept, it was used as a sensitizing concept in data analysis.[27,28] Data collection ceased at the point where there was enough data to "build a comprehensive and convincing theory (p. 148)"[29] in the sense of theorizing based on data collection.

Three authors (JSY, RC, and RA) corresponded several times throughout the data analysis process to identify preliminary codes and themes, and discuss patterns of behaviors. All data relevant to the research question were coded. This process identified the first patterns in the data by grouping similar data segments. Similar codes were then clustered together to create a visual map of key patterns in the data that contained overarching themes. The first author (JSY) kept a log of thoughts and reflections on preliminary and developing codes during the thematic analysis process, as recommended by Braun and Clarke.[26] All authors (JSY, RC, RA, and DG)

reviewed the themes to ensure they fit with the coded data and the overall data set. Discrepancies in coding were discussed until consensus was achieved. We then selected quotations deemed particularly representative of the themes agreed upon by all authors (JSY, RC, RA, and DG).

To ensure a rigorous study design, we used the verification strategies outlined by Morse[30]: methodological coherence, appropriateness of sample, concurrent data collection and analysis, and theoretical thinking and theory development. Methodological coherence includes attention to congruence between the research question and the methodological components.[30] The topic under study is well suited to qualitative descriptive exploratory methodology because our goal was to understand parents' experiences of advocacy as described in parents' own words. Our data were collected from parents of children with ASD who had engaged in advocacy and were knowledgeable about the phenomenon under study making them an appropriate sample.[30] We engaged in concurrent data collection and analysis. This iterative process required that we moved back and forth between what was known and what further knowledge was needed.[30] We were open and flexible to ideas and consulted with each other as the process unfolded. This fulfilled the final strategy of in an emergent process of theoretical thinking and theory development.

Results

Interview data were collected from 15 parents of children and youth diagnosed with ASD living in Atlantic Canada. Table 1 shows the participant demographics.

Table 4.1. Participant demographics.

Participant demographics		Number of participants
Province	Prince Edward Island	5
	New Brunswick	1
	Nova Scotia	3
	Newfoundland and Labrador	5
	Did not respond	1
Community	Urban	7
	Remote	6
	Did not respond	2
Gender of parents	Male	1
	Female	14
Age categories	31-40	3
	41-50	8
	51-60	4
Marital status	Married/Common law	11
	Divorced/Separated/Widowed	4
Education level	High school	3
	College diploma/some university	1
	Undergraduate degree	4
	Graduate degree	7
Employment status	Employed full time	13
	Unemployed	2
Gender of child	Male	12
	Female	3
Age of diagnosis of ASD	2-5 y	8
	6-9 y	4
	10-14 y	3
Child's diagnosis	ASD	8
	ASD and other disorders including anxiety, depression, eating disorder, sensory integration disorder, obsessive compulsive disorder, oppositional defiant disorder, attention deficit hyperactivity disorder, conduct disorder)	7
Total yearly household income	$20 000 to less than $30 000	2
	$60 000 to less than $70 000	1
	$70 000 to less than $80 000	2
	$80 000 to less than $90 000	1
	Over $90 000	6
	Did not respond	3

One parent [P-14] did not wish to be quoted directly. We did not include any direct quotes from this participant, but their data were included in our analysis.

Advocacy was a key feature in parents' descriptions of their journey with a child diagnosed with ASD. Parents regarded advocacy as a dynamic activity that changed depending on the circumstances and their needs or that of their children. Advocacy efforts required skill development and confronting barriers to advocacy that was central to their advocacy work. Thematic analysis revealed that the pathway in parents' advocacy journey included 3 main themes and various sub-themes, as reflected in Table 2: (1) Engagement in Parental Advocacy (expressing concerns, seeking help, assessment, and diagnosis, acquiring services, and raising awareness); (2) Challenges or Barriers (time commitments, financial challenges, lack of knowledge and support, lack of service availability, system bureaucracies, and perceived stigma); and (3) Development of Advocacy Skills (active involvement/engagement and self-learning strategies).

Table 4.2. Primary and secondary themes in parents' advocacy journey.

Engagement in parental advocacy	Challenges or barriers	Development of advocacy skills
• Expressing concerns • Seeking help, assessment, and diagnosis • Acquiring services • Raising awareness	• Time commitments • Financial challenges • Lack of knowledge and support • Lack of service availability • System bureaucracies • Perceived stigma	• Active involvement/engagement • Self-learning strategies

Theme 1: Engagement in parental advocacy

Expressing concerns. Advocacy efforts began when parents first identified concerns about their child and started to connect those concerns with suspected ASD behaviors. Some parents recalled noticing signs during infancy. "*I noticed probably within the first three months*

that my child really didn't really love to be snuggled" (P-4). They identified difficulties with language skills, demonstrating ritualistic, repetitive and restricted behaviors, reacting to sounds and lights, having tantrums, or becoming overly upset when routines were changed. "*He really obsessed over those routines. If we didn't do them that way, he would be very upset, and he wouldn't settle down*" (P-7). Parents described feelings of uncertainty, fear, and guilt during this time. Some parents expressed disbelief when others expressed concerns about their child's behaviors that they hadn't noticed themselves.

> I never saw it myself…I just assumed every 3-year-old knows what a Pachycephalosaurus [type of dinosaur] is and it was okay he was reading novels in kindergarten…he was just being a little inappropriate and struggling to make friends. (P-1)

Demonstrated behaviors such as separation anxiety and other forms of anxiety would trigger some parents' concerns. Feelings of uncertainty and concern for their child's condition motivated parents to take action in seeking help, assessment, and diagnosis for their child.

Seeking help, assessment, and diagnosis. Parents first started seeking help within the healthcare system. They wanted to find out what was the reason for their child's symptoms and challenging behaviors. Parents reported on their encounters with health care providers in seeking help. Parents demonstrated strong emotive reactions during this time. At times parents' advocacy efforts were described as combative with health professionals who took a "wait and see" approach that led them to look elsewhere for answers.

> He [pediatrician] was like, well, wait and see over the next – because he was so young – over the next 3 to 6 months and I was like, 'Are you…kidding me? You just told me you think my kid might have autism, I'm not doing the wait and see approach'…I went home

> and called [another pediatrician] and she booked us in like two weeks later - so we saw her within 2 weeks and she did the Autism Diagnostic Observation Schedule [ADOS] on the spot…she did the full testing at the initial visit and gave us the diagnosis…for sure we hopped the queue because until you get a diagnosis you don't have access to autism intervention… if I wasn't aggressive, if I hadn't called them, it would probably have taken another 6 to 12 months I would say. (P-10)

This "wait and see" approach that health providers used resulted in some parents having to go to extremes to demonstrate their concerns. The parent of a three-year-old believed her concerns were being ignored and reacted this way.

> I knew a lot of his anxiety triggers so I kind of provoked him. He had a complete meltdown at the developmental pediatrician's office. She felt at that time it was a good time to have him assessed. So, he was assessed at 3 years, 3 months and found to be on the spectrum…you're relieved but you're angry that it took that long. (P-12)

Parents advocated for their children by searching for a "good fit" between the health care providers and their child that often resulted in paying privately for what they considered better care services.

Parents articulated a genuine appreciation for those who provide supports. "*Some of my support is my pastor at [church]*" (P-5). Parents appreciated school administrators who were accessible, supportive, and addressed their concerns. "*The amount of support that I've had from the School Board here is unbelievable.*" (P-9)

> He's had a wonderful school to be able to adjust to his needs – have regular meetings at the beginning of the year…we meet partway through the year to talk about how things are going. These meetings have like six to eight people in them – his teacher's there, the

> resource teacher's there, the vice principal's there, the autism consultant's there, the guidance counsellor's there, [husband] and I are there. So, we're communicating all the time with each other…you develop a real rapport with them and a trust relationship with them and that's important. (P-3)

Parents expressed appreciation about flexibility in the workplace that enhanced their ability to advocate.

> I'm so lucky I work here. My manager is so sympathetic and allows me to have the flexibility that I need to ensure that I can do what I need to do with him. So, if I need to come in late then I just work an extra 15 minutes. If I need to take a day off and I don't have any time left, I'll just work it on the weekend. My schedule has been pretty flexible. (P-13)

Once parents received a formal diagnosis of ASD for their child, the next step was to acquire the necessary services that led them to the next phase of advocacy in acquiring ASD-related services and supports for their child.

Acquiring services. Attempts at acquiring services for their child was especially challenging for parents. Parents described a sense of urgency and time pressure because they had learned early on that intervention was important for a child diagnosed with ASD to have the best outcome possible.

> You feel like you're in a race. At the time he was 3 years, 3 months and services would end at 6 [years of age] so we were like we've lost – we had suspicions since he's 18 months, we've lost over a year and a half. We've only got a year and a half left – like you feel like you're constantly having to run…you're trying to get your ducks in a row like, okay, I'm going to put an ad out [for a behavioral support worker]. (P-12)

Some health professionals offered services and supports for parents as they waited for an official diagnosis. "*She [child psychiatrist] said, 'I'd like to provisionally diagnose him with ASD.' They started dipping into different things they could help us with even though he hadn't been formally diagnosed…there was a wait time for diagnosis*" (P-8).

Parents who had the financial means to acquire ASD services for their children reported feeling "lucky" (P-10). Parents who could afford it provided art, music, aquatic, and equestrian therapies in addition to Applied Behavioral Analysis (ABA) therapy. ABA therapy is the practice of applying the psychological principles of learning theory in a systematic way to modify behavior. The practice is used most extensively in special education and the treatment of ASD.[31]

> He's been super lucky…40 hours of therapy…we've hired privately…a speech pathologist that we hired privately and he gets private lessons for kids on the spectrum for swimming and he's in a therapeutic riding program…we have basically unlimited educational and financial resources between us so we've been able to do all the things he needs and we've been able to buy all the supplies that the therapists need…we've been very lucky, for sure. (P-10)

Gaining knowledge about ASD increased parents' confidence in their ability to advocate for services.

> He [psychologist] makes an incredible report for the parents…it's books you can read, organizations you can contact, government programs that might be able to help, suggestions of social skills development…so that became our map because we didn't have anything else to go by…one of the things that was suggested was getting in contact with the Autism Society and so we did that and that was another great resource. (P-3)

For parents of school-age children and youth, securing an official ASD diagnosis for their child meant they were able to acquire additional educational supports.

> We got an increase of services actually in the school because now he had an actual diagnosis – it wasn't just a learning disability. So because of that like the doors opened. Like we managed to get the autism support specialist and the consultant that works in the schools to work with [child] or observe him and things like that and the team meetings got bigger in terms of people around the table, and they got more frequent. (P-2)

Parents described their advocacy efforts as being watchful and diligent to ensure the system met their child's needs. Once again, parents displayed strong emotions attempting to ensure supports and services for their children. Parents described how they planned aggressive tactics at times to ensure their child's needs and rights to services were met.

> When he was in school, I had to fight to get some funding from the Autism Support Program with the Department of Education and I really had to demolish doors…their guidelines were very, very fuzzy and the policies were like non-extent…it was terrible and so I had to fight, and I had to pick up the phone and go straight to the director of the program. (P-2)

Raising awareness. Parents wanted to raise awareness that it can be difficult to recognize signs of ASD because it did not always present itself in a typical manner. They talked about ASD being an "*invisible*" (P-1) condition that made it even more challenging to recognize. Parents also wanted to dispel myths about ASD and once again described strong emotional reactions during this time.

> Not all autism presents itself in the typical way. Neither one of my kids flapped their hands or did any of the typical autistic stuff. It was all throwing food, blinking their eyes,

> fluttering and stuff like that. They need more awareness or at least don't be dismissive…it needs to be done earlier because I think of the months, the years that were wasted…I'm on the top of a mountain screaming my guts out and no one's listening…no one can hear me, and someone needs to help this child. (P-11)

Parents talked about the emotional aspect of raising a child with ASD and changing public perceptions about the condition.

> You do go through a depression, and you mourn not only their lives but your own. You're not going to have grandchildren. You're not going to have this…It's something to overcome at times but for the most part it's been pretty beneficial. His memory is amazing. His abilities are incredible. (P-1)

Parents were seeing possibilities for their children if supportive services were made available to them.

> He's a technology wizard. He can take apart and put together a computer. He reinstalled the operating system on my home computer without my knowledge when he was eight or nine…He said, "I'm a great fixer mom, I'm going to be an IT guy"…I don't know if he'll ever be independent. The possibility is there if he can have the services to support him. (P-13)

Central to parental advocacy work was removing barriers to challenges faced in their advocacy efforts and developing advocacy skills.

Theme 2: Removing challenges or barriers

Parents described five challenges or barriers in their advocacy efforts and offered some solutions to the challenges faced. Barriers included: (1) time commitments required related to parenting a child with ASD; (2) financial challenges; (3) lack of knowledge and support from health care

providers, other professionals, and family members; (4) lack of service availability and system bureaucracies; and (5) perceived stigma regarding an ASD diagnosis.

Time commitments. Parents described the time commitments involved in parenting a child with ASD. Time spent traveling and coordinating appointments in the health care system and education system was often challenging and time-consuming. Parents were required to balance work and other family members' needs. Some parents reported they had quit work in order to have more time to advocate and care for their child with ASD.

Time spent coordinating services and supports for their child with ASD and seeking out opportunities that could aide in their child's development such as, meeting with teachers and school administrators, as well as arranging recreational activities that would benefit their children. They mentioned the time commitment involved in advocacy work.

> Advocacy things are often run by parents and parents with a child with special needs don't have a lot of time to publicize and do the kinds of things like that – you don't have time to go to the annual general meeting when there's no babysitting and you can't hand your kid off to anybody. (P-10)

Financial challenges. Parents confronted financial barriers in their advocacy efforts and attempts at acquiring services for their child. "*It's about $1,200 to pay for the assessment to get it quicker…we couldn't really afford it*" (P-8). Those who could afford to pay for services felt lucky but other parents talked about feeling "emotionally and physically-drained" in their financial struggles to pay for services.

> We're going into debt…My father had offered his house for sale to fund the visit [to specialists in another country] and any treatment that we needed…Once a semester I have to dish out $75 for social thinking. Once a year I dish out $400 for horse camp. Art

> therapy is $20 a pop…Parents are physically, mentally and financially drained…everybody is in debt … the average family is 25 to 100 K in debt because of autism…we've refinanced our house twice because of autism. I'm not ashamed to say that…it's the middle-class people who are struggling financially…they don't care if I'm paying off student loans. They don't care if we're putting food in my mother-in-law's fridge. (P-11)

Parents made a decision to wait for public healthcare services or seek out private healthcare services to get their child assessed more quickly. For instance, participants who could afford it reported paying privately for psychoeducational assessments as means of achieving a formal diagnosis to achieve needed services for their children.

> Nothing's official until the doctor puts the approval…once we know what's happening and where we're at with it and the doctor starts helping us – we can make use of the programs with the government – disability tax credit for the kids so that it's a little easier to help with his upbringing, do different things and working with different tools and different programs. (P-5)

Lack of knowledge and support. Parents spoke about the lack of information about services and supports available to them for their children, "*The information is not there…there are little potholes of help but there's nobody there who's really put all this together*" (P-4). Parents described interactions with service providers as either positive or negative.

Negative interactions created a sense of distrust that demonstrated some negative emotional responses in their advocacy efforts.

> The first psychiatrist we went to see ended up being an absolute disaster…I thought my husband was actually going to hit him. He was getting so mad he was just shaking

> because he was becoming verbally abusive to me…And he started just putting his finger in my face like this and shouting at me and our child is sitting there witnessing this. And so, we left and we walked out the door and we kind of stopped and we said, "Okay, so how do we get another psychiatrist because we're never walking in there again." (P-3)

Parents felt unsupported when they shared with family and friends their concerns about their child. Other parents talked about not knowing where to turn to look for support. "*I'm not a doctor! I don't know what to do! - I'm just a parent who's trying to get help for their daughter*" (P-4).

Parents were gaining knowledge about why it was important to receive a formal diagnosis in order for them to obtain necessary ASD early intervention programs for their children. However, they confronted barriers that included wait times and dismissive health care workers that were taking a "watch and wait" approach. Parents with knowledge of child development had some insight into ASD symptoms, yet some parents felt health care providers were dismissing their concerns.

> I have a minor in psychology, so I was familiar with child development, and I just noticed he wasn't hitting his milestones and seeing our General Practitioner you know, it's the typical story – boys don't develop as quickly as girls…a wait and see basis. (P-12)

Parents perceived challenges related to hierarchical struggles in their encounters with health professionals.

> He was the type of doctor who was patronizing you like he thought that everybody was like at this intellectual level and then he was here–it was terrible and he would not be open-minded and he was just stuck in his run and there was no way to discuss it in a very free way. (P-2)

Parents were learning about ABA services that were available for children with ASD, which can support developing relevant skills and behaviors. Parents were aware of the importance of early intervention and sought out ABA services that were available to them. However, parents felt unsupported and challenged in their efforts to find suitable service providers that were considered compatible with their child's individual personality. One participant decided to "double the salary and pay out of pocket" for a home therapist who they considered had a good rapport with their child.

> The parents are left to advertise, to find, to interview, to know what to look for, how to pay them…we went 7 months without an ABA therapist because not only could we not find people to apply, let alone hire someone. (P-11)

Lack of service availability and system bureaucracies. Parents living in rural or remote areas of the province faced challenges of limited access to services that were only available in urban centers requiring them to travel long distances to seek help for their child

> The local hospital had very limited resources where we live. We live in a small town of 500 and [location of county] itself isn't that big…we had to just kind of wait until we could see somebody and help us, like two and a half hours away. (P-7)

Parents wanted to educate others and learn from their experiences in confronting barriers in navigating the system searching for ASD diagnostic services and supports.

> If you don't feel something's right and you're getting ready to get pushed out the door, if you need to be a little bit strong in your advocacy, be stronger…I'm my child's expert…I'm the one that's with him every day 24/7. I'll take their advice if I think it's what's best and it fits for him. (P-12)

Perceived stigma. Parents talked about instances when they felt blamed for their child's inappropriate behaviors displayed in public and described they were "*made to feel like it was our fault somehow*." (P-3) Parents expressed opinions about disclosing their child's ASD diagnosis. Some thought it best to be open about it yet others felt it best to keep it to themselves because they feared stigmatization.

> People look at the disability before they look at the person…I never ever wanted his diagnosis to be a crutch. I always wanted to see the potential…we kept it a secret because we wanted people to treat him typically (P-12).

Parents talked about the myths surrounding ASD as being a barrier.

> I didn't think my child could be like sweet and friendly and have autism - the myths are certainly alive and well and the thing about no empathy and stuff like that – you know people [with ASD] can talk…the second barrier would be the myths about autism (P-10).

As parents faced various challenges in the process of advocacy, they were also learning to develop advocacy skills that would help them overcome some of the confronted barriers.

Theme 3: Development of advocacy skills

Parents identified several skills in advocating for their child that included being actively involved and engaging with health care providers and other professionals as well as self-learning strategies.

Active involvement. Parents became actively involved with care providers as they gained knowledge and began to identify signs of ASD in their children.

> He was five [years old]…he saw a pediatrician and immediately after a 20-minute interview, "He's got ADHD." I went home and I kind of researched and I said, "No, this is not my kid. This is not right." I can see the parallels and I can understand but it felt

> wrong…[later the child was diagnosed with ASD after the [general practitioner] GP put them in touch with a psychologist]…she said it really is Asperger's and I was like the first paragraph of the book that I picked, and I was like there's my kid (P-1).

Parents described a wide range of behaviors including some negative emotional reactions in their advocacy efforts to obtain supports and services for their children. "*I'm very proactive in seeking help [for my child]…where there's a will, there's always a way*" (P-6).

> I'm a very strong advocate and I've kicked doors, but I had to work really hard…I've been yelling and screaming on the top of my lungs sometimes to get him to where he is…that's basically how we've navigated through the system…My husband and I also did a presentation…talked about our experience and how he [son] fell through the cracks many, many, many – too many times (P-2).

Parents spoke about educating teachers and students in their child's school about ASD in an effort to gain understanding and support. "*I was actively involved with the principal. I was involved with the teachers. I was in the classroom*" (P-6).

Self-learning strategies. Parents were learning what skills were important in being an effective advocate. They talked about the importance of being realistic and self-aware in their advocacy efforts.

> I can be an advocate but I'm not somebody who's going to the media and complaining and bitching. I'm just not doing it. Advocate for your child when you need to advocate for your child but be realistic (P-13).

Parents reflected on ASD journey and the need for support for families. "*I think there needs to be more support for the parents…there needs to be more family support*" (P-15). Parents self-

reflected on their own experiences with advocacy and talked about what other parents needed to support them in their journey of advocating for a child with ASD.

> I am an advocate now working with people who don't have the voice, don't know how to use it or can't figure out what to do or just accept what's happening…we have a group on Facebook…It's made me probably stronger than I've ever been before…I had no choice. I never want anybody to have to go through what we did. I feel in each community there should be a resource centre for families…better supports (P-7).

A parent described how their advocacy experiences had helped them to notice signs and symptoms in a younger sibling and how they felt better prepared to obtain supports and services for their second child.

> This youngster [a younger sibling] came out into the living room one day, looked up out of the corner of his eye and started fluttering his eyelids. Me and [husband] looked at each other and said he has it too…Eighteen months just like that he fluttered his eye lids…we phoned Dr. [name]. Get the speech on the wait list, get the OT on the waitlist. Put him on the wait list. We were just from day one - we know the routine now so here give me that form, give me that form - I have to fill it out and get him on the waitlist (P-11).

Once parents gained the knowledge and skills to advocate effectively, they felt more confident in their ability to further their advocacy efforts. Parents described how it was important to raise awareness about ASD and educate others so they could benefit from their lived experiences.

> I have enough education and drive and knowledge to have continued to push for my son…every bit of support that we got I had to fight for, pretty much tooth and nail fight

for and lot of other parents don't have the education or the energy to do that…people shouldn't have to fight so hard (P-9).

Figure 1 is a thematic representation of the pathway in parents' advocacy journey with children and youth diagnosed with ASD. Each of the large circles represent the pathway to engaging in parental advocacy and inform the removal of barriers and challenges to advocacy. Developing advocacy skills is central to this process.

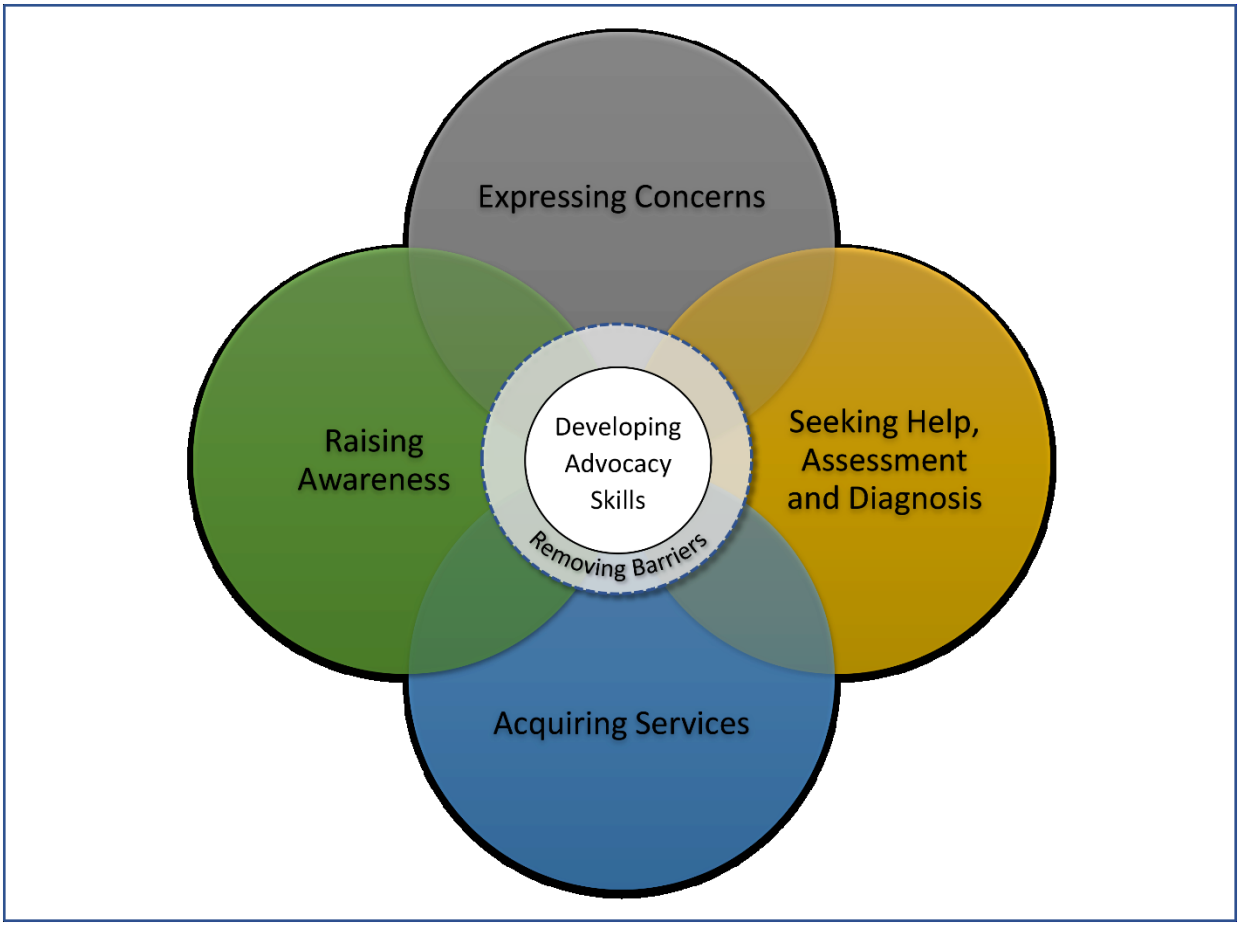

Figure 4.1. Pathway in parents' advocacy journey with children and youth diagnosed with ASD.

Discussion

The purpose of this study was to explore parental advocacy efforts in the journey of parenting a child with ASD. We offer a unique perspective by offering a thematic representation of the

pathway in parents' advocacy journey with children and youth diagnosed with ASD. This illustrates when, how, and why parents advocate on behalf of their children as they navigate barriers and supports in medical, educational, and social contexts of their child's environment. The study findings reveal the barriers faced and the strategies used to overcome some of these challenges in the process of advocating for their children with ASD. We also describe the advocacy skills parents develop to support them as they continue their journey of advocacy throughout the life course of their child's condition.

We found parental advocacy work to be dynamic as parents face uncertainty, seek help, acquire services, and promote awareness. Through various challenges and uncertainties faced, they continued their advocacy efforts to acquire services and supports for their children. Parents used their roles as parent advocates as a means to gain access to services in the health care and education system as well as in the community. In raising awareness, parents wanted to share their experiences and educate others as a means of promoting advocacy for parents of children and youth diagnosed with ASD to provide better outcomes for children in their life-long journey with ASD.

Our findings lend support to the work done by others. It is well recognized that parents of children with ASD and other chronic conditions or disabilities employ advocacy as a management or coping strategy that provides them with a sense of control over the various uncertainties faced.[32 -34] Parents identify barriers faced in their advocacy work including time commitments involved in parenting a child with ASD, financial challenges, lack of knowledge and support from service providers and others, lack of service availability and system bureaucracies, and perceived stigma related to their child's ASD diagnosis that is consistent with previous findings.[32,33,35,36] An online advocacy tool[37] is available for parents of children with

ASD, which includes information about the importance of teaching self-advocacy skills to parents and children with autism throughout the life course of the condition.[37] The model of findings developed from this study provides an illustration to where these learned advocacy skills can be best used to achieve the desired best outcome for children with ASD. Understanding the advocacy process and steps to follow will help parents prepare and further develop their advocacy skills. Raising awareness about ASD, educating others, and supporting other parents in their journeys is important for parents that is echoed by others.[38]

Social psychology theories offer frameworks to inform advocacy and policy change efforts.[39,40] For example, the "Grassroots" Theory of Change Model proposes that individuals affected by a problem act jointly to achieve social change using strategies such as mobilizing, training, developing awareness, and capacity-building.[40] Results from this study demonstrate how parents can be actively involved and engaged in their advocacy efforts to raise public awareness of ASD. Service providers need to encourage parents to participate in advocacy training programs that are available as a means to achieve needed policy changes in the education and health systems.

Results from this study bring attention to the barriers parents face in their advocacy efforts and highlight the importance of reducing these challenges. Research in the U.S. studying advocacy training programs for parents of children with disabilities, including ASD, show significant gains in motivation, empowerment, and knowledge of special education[41,42] and legislative rights.[42] Another recent study aimed at understanding the impact of a volunteer advocacy project (VAP) on topics related to special education law and advocacy skills shows that families more likely to request an advocate if they live in an urban setting and have a child with ASD who attends elementary school.[7] A recent pilot study of a special education advocacy

program for Latinx-minority parents of children with ASD indicates that the program increased parental knowledge, but did not increase parents' self-perceptions of empower and advocacy.[43] This suggests that parents may need more support.[43]

We recognize the strengths and limitations to this study. This study reveals a thematic representation of parents' advocacy journey. This new knowledge adds to our understanding of the advocacy skills parents must acquire when facing barriers to diagnosis and treatment for their children with ASD. Our sample for this qualitative study was restricted to parents living in Atlantic Canada and overrepresented highly educated, high-income mothers. These unique factors may limit the transferable of our populations.

To provide a 360° perspective on this issue, future research might explore the experiences of providers, policy makers, and adults with ASD to understand their perspectives on the strengths and limitations of the ASD service delivery system and explore strategies to promote parental advocacy. Future work may include conducting an intervention study focused on increasing parental advocacy to increase parents' confidence in their ability to advocate on behalf of their children and to foster self-advocacy in adults through the life course of their condition.

Implications for Practice

Results from this study raise several implications for practice. Although patient- and client-centered care is well recognized and widely accepted in health care settings, it is apparent from our findings that many parents of children with ASD do not experience this commitment to partnership. Parents contribute valuable information drawing on their understanding of their child and their observations of their child in their natural daily environment. This study highlights the importance of health care providers recognizing parents' input and encouraging

their advocacy efforts by including them in the decision-making process. A tailored approach for parents living in rural areas may address the additional geographical challenges related to accessing ASD services. Service providers are encouraged to link parents to appropriate ASD services early in the diagnosis process. Family physicians can refer parents to their local or provincial ASD advocacy group (e.g., Autism Society of Newfoundland and Labrador) to provide information about ASD and assist parents to navigate the ASD delivery system (e.g., information about provincial or local government programs and services that are available for families). There is a need for free community-based programs and services for parents, including respite care, self-care services, and parent counseling.

Conclusions

The aim of this study was to gain a better understanding of the experience of advocacy in parents of children with ASD. Parental advocacy is a life-long process for parents of children with ASD. Advocacy is an ongoing effort where parents must continually anticipate their next course of action to acquire necessary supports for their children throughout the life course of their condition. Advocacy work includes providing a future to make things better for their child as they progress in their ASD journey. Parents are motivated through their advocacy efforts to support other parents navigating the process to avoid some barriers and have a more positive experience for them and their child.

Acknowledgements

We would like to thank the parents for taking the time to share their experiences with us for this research study. We would like to thank the research assistants who conducted the interviews. We would also like to acknowledge the ACCESS-ML team project members for sharing their data

for this study. We are grateful to the anonymous reviewers whose comments improved the clarity of our argument.

Author Contributions

The first three authors (JSY, RC, and RA) designed the study. RA coordinated data collection. All authors (JSY, RC, RA, and DG) were involved in data analysis, writing, and reviewing the final manuscript.

Ethical Approval/Patient Consent

Ethics approval was granted by the Memorial University's Human Investigation Committee. Each consenting participant provided written informed consent prior to being interviewed and audio-recorded.

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Chapter 5 (Manuscript 3)

Introduction and Overview

The research from Chapters 3 and 4 identified barriers and facilitators that parents encountered locally in NL and four Atlantic provinces in Canada in accessing ASD assessment and diagnostic services for their children. Those results directed me to conduct a systematic review so I could better understand the barriers and facilitators that parents encountered in Canada as well as other parts of the world as a means of offering recommendations for policy, practice and research to address the barriers parents and guardians face in accessing ASD diagnostic services for their children. This chapter highlights the review findings from this systematic review that was conducted using JBI methodology for systematic reviews of qualitative evidence.

Co-authorship Statements

- Joanne Smith-Young developed the study.
- Michelle Swab conducted the literature search. Following identification of citations Michelle Swab prepared the citations for screening of titles and abstracts.
- Joanne Smith-Young and Dr. April Pike or Dr. Roger Chafe screened the titles and abstracts.
- Full texts of selected studies were retrieved and assessed against the inclusion criteria by Joanne Smith-Young and Dr. April Pike or Dr. Roger Chafe.
- Studies that met the inclusion criteria were critically appraised by Joanne Smith-Young and Dr. April Pike or Michelle Swab.
- Research findings were extracted by Joanne Smith-Young and Dr. April Pike independently.

- Joanne Smith-Young and Dr. April Pike studied the extracted findings and grouped them into categories.
- The synthesized findings were drafted by Joanne Smith-Young and discussed with Dr. April Pike. Feedback was provided by Dr. Roger Chafe.
- Joanne Smith-Young drafted the manuscript.
- Joanne Smith-Young, Dr. April Pike, Dr. Roger Chafe, and Michelle Swab edited and critically appraised the manuscript.
- Joanne Smith-Young, Dr. April Pike, Dr. Roger Chafe, and Michelle Swab read and approved the final manuscript.

Parents' and guardians' experiences of barriers and facilitators in accessing autism spectrum disorder diagnostic services for their children: a qualitative systematic review

Systematic review registration number: PROSPERO CRD42018100127

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Manuscript published online October 31, 2024 in *JBI Evid Synth* 2024;22(00):1-63.

Abstract

Objective: The objectives of this review were to comprehensively identify the best available qualitative evidence about parents' and guardians' experiences of barriers and facilitators in accessing autism spectrum disorder (ASD) diagnostic services for their children; and to develop recommendations based on the review for addressing barriers to timely diagnosis and early intervention.

Introduction: Early identification of ASD is a priority because the best chance for improving symptoms occurs through early and intensive intervention. A definitive ASD diagnosis is often a prerequisite for children to access publicly funded services, yet obtaining a diagnosis in itself can be stressful, frustrating, and time-consuming for many families. It is essential to understand the barriers and facilitators parents and guardians face in accessing ASD diagnostic services for their children.

Inclusion criteria: This qualitative systematic review considered studies conducted worldwide that included parents and guardians of children up to 18 years of age and who had accessed or who were attempting to access ASD diagnostic services for their children.

Methods: This review was conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence. A literature search included CINAHL (EBSCOhost), CINAHL Plus (EBSCOhost), MEDLINE (EBSCOhost), APA PsycInfo (EBSCOhost), Social Services Abstracts (ProQuest), and ERIC (EBSCOhost), and EMBASE. Gray literature sources included ProQuest Dissertations and Theses, Google Scholar, Google, OpenGrey, other online resources (government and organizational websites), and reference lists of retrieved records. No language, date, or country limits were applied to the searches. Retrieved records from the academic databases, gray literature, and reference lists of retrieved records were screened, with potentially relevant records examined in full against the inclusion criteria. Eligible studies were critically appraised for methodological quality and those included in this review were subjected to data extraction of descriptive details and the study findings relevant to the review question. Study findings were synthesized and assigned confidence scores. All reviewers agreed upon the categories and finalized synthesized findings.

Results: The 36 included studies varied in qualitative research designs with high methodological quality. There were approximately 661 eligible participants, and 55 credible and unequivocal research findings. The research findings yielded 6 categories and 3 synthesized findings with moderate confidence scores. Parents' and guardians' ability to access ASD diagnostic services for their children is affected by i) encountering health care providers who actively listened to and addressed parents' and guardians' concerns, instead of dismissing them, providing a sense of support and validation; ii) facing extended waiting times and associated financial burdens

resulting in frustration and associated financial impact when delays occurred; and iii) encountering health care providers lacking specialized knowledge about ASD contributing to parents' and guardians' confusion due to inaccurate or conflicting diagnoses related to ASD co-morbidities.

Conclusion: Many parents described their journey in accessing ASD assessment and diagnostic services for their children as cumbersome. Parents' and guardians' experiences were affected by level of perceived support by and knowledge of health care providers; confusion surrounding inaccurate/mixed diagnoses related to ASD; lengthy delays; and systemic and contextual barriers in navigating the pathway to ASD assessment and diagnosis that included socioeconomic and cultural disparities.

Review registration number: PROSPERO CRD42018100127

Keywords: autism spectrum disorder; barriers and facilitators; children; diagnostic services; parents

JBI Evid Synth 2024; 22(00):1-63.

Summary of findings

Parents' and guardians' experiences of barriers and facilitators in accessing autism spectrum disorder diagnostic services for their children					
Bibliography: Smith-Young J, Pike A, Chafe R, Swab M. Parents' and guardians' experiences of barriers and facilitators in accessing autism spectrum disorder diagnostic services for their children: a qualitative systematic review. JBI Evid Synth. 2024;22(00):1-63					
Synthesized finding	Type of research	Dependability	Credibility	ConQual score	Comments
Parents' and guardians' ability to access ASD diagnostic services for their children is affected by encountering HCPs, who	Qualitative	High	Moderate – downgraded 1 level	Moderate downgraded 1 level due to moderate credibility	18 findings from 14 studies of high dependability. Credibility is downgraded 1 level due to a mixture of unequivocal

actively listened to and addressed parents' and guardians' concerns instead of dismissing them, providing a sense of support and validation.					(n=13) and credible (n=5) study findings; majority unequivocal 72%.
Parents' and guardians' ability to access ASD diagnostic services for their children is affected by facing extended waiting times and associated financial burdens and resulted in frustration and associated financial impact when delays occurred.	Qualitative	High	Moderate – downgraded 1 level	Moderate downgraded 1 level due to moderate credibility	18 findings from 15 studies of high dependability. Credibility is downgraded 1 level due to a mixture of unequivocal (n=13) and credible (n=5) study findings; majority unequivocal 72%.
Parents' and guardians' ability to access ASD diagnostic services for their children is affected by HCPs lacking	Qualitative	High	Moderate – downgraded 1 level	Moderate downgraded 1 level due to moderate credibility	19 study findings from 17 studies of high dependability. Credibility is downgraded 1 level due to a mixture of

specialized knowledge about ASD, contributing to parents' and guardians' confusion surrounding inaccurate or conflicting diagnoses related to ASD co-morbidities.					unequivocal (n=9) and credible (n=10) study findings; majority credible 53%.

ASD, autism spectrum disorder; HCP, health care provider
Derivation of ConQual scores is based on the JBI method.[1]

Introduction

Autism Spectrum Disorder (ASD) is a range of neurodevelopmental disorders identified by the presence of persistent deficits in social interactions and communication, as well as restricted repetitive patterns of behaviors.[2] ASD is an umbrella term that covers conditions such as childhood autism or atypical autism.[2] Its etiology is multifactorial.[3] There is a genetic basis for ASD and it is associated with immune dysregulation and inflammation, oxidative stress, environmental toxicant exposures, and mitochondrial dysfunction.[4] Older paternal age, complications during pregnancy, premature birth, low birth weight, and jaundice in neonates are associated with ASD.[3] Individuals with ASD are at higher risk for other disorders, including fragile X syndrome, allergies, asthma, epilepsy, gastrointestinal disorders, persistent viral infections, feeding disorders, anxiety disorder, bipolar disorder, attention deficit hyperactivity disorder (ADHD), Tourette syndrome, obsessive-compulsive disorder (OCD), sensory integration dysfunction, sleeping disorders, immune disorders, autoimmune disorders, neuro-

inflammation, and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infection.[5]

ASD is an increasingly prevalent condition. The most recent published data from the United States indicate that ASD affects one in 44 children in that country.[6] Other developed countries have reported a rising prevalence in autism cases: 86 cases per 10,000 children in Canada, 91 cases per 10,000 children in Sweden, 88 cases per 10,000 children in Australia, and an alarming 151 cases per 10,000 children in Qatar.[7] Globally, it was reported that around 1 in 100 children has autism.[8] Canadian data indicated that children and youth with ASD were diagnosed at a median age of 4.7 years.[9] The global mean age at diagnosis of ASD was reportedly 60 months.[10] The economic and social burden of ASD is also high. In the United States (US), the lifetime societal cost of autism cases identified in the 30 years between 1990 and 2019 was estimated to be US$7 trillion[11] If costs for the next decade (2020-2029) are included, the lifetime cost will reach up to US$15 trillion.[11] The average lifetime cost of autism per person was calculated to be US$3.6 million.[11] If prevalence continues to rise at the same rate as the past 30 years (1990-2019), over 2 million new cases will be identified and the cost will be another US$7.5 trillion, for a total of almost $US15 trillion.[11]

There is no specific biological or genetic test to diagnose ASD. Diagnosis is made by specially trained physicians and psychologists who administer ASD-specific behavioral evaluations. These evaluations may also involve a pediatrician, speech and language pathologist, occupational therapist, and geneticist.[12] ASD is usually detected in early childhood and it can be reliably diagnosed by age 18 months.[13] However, Fountain and associates (2011) found that that later diagnosis often occurs in children and adolescents who are from low socioeconomic backgrounds, non-White (identified as Black, Hispanic and Asian/Pacific ethnicities), and who

exhibit less severe symptoms.[13] Four to 5 times as many boys are diagnosed with ASD as compared to girls.[5] This disorder is a lifelong developmental disability that can negatively influence a person's educational and social attainments, as well as employment opportunities. While some people with ASD can live independent and productive lives, others have severe dysfunctions and require lifelong care and supportive services. The level of intellectual functioning is extremely variable, extending from profound impairment to superior cognitive skills. Experts agree that early intensive behavioral interventions can positively affect overall health outcomes, [14,15] hence early diagnosis means more intensive therapy can begin sooner, resulting in improvements in cognitive, language, and adaptive skills.[16,17] Despite the benefits of early diagnosis, most countries report the median age of ASD diagnosis to be more than 24 months. Canadian data indicate a median age in ASD diagnosis between 39 and 55 months.[18] A study in the United Kingdom reported a median age of diagnosis of 55 months.[19]

A number of barriers in accessing ASD diagnosis have been identified in several primary studies, including stigma[20,21]; living in a rural community[20,22]; transportation issues[23,24]; ineffective screening tools[21]; dismissive, hesitant, or unskilled health professionals[20,25]; inadequate insurance coverage[20,21]; cultural/immigrant status[13,22,26];. and difficulty navigating the system[23,24] Some of the facilitators in accessing ASD diagnostic services that were identified in primary studies include higher levels of parental education[13, 27] and higher socioeconomic status.[13,21,24,27]

A good understanding of the barriers and facilitators in accessing ASD diagnostic services gained from a systematic review of the literature could assist health care professionals and policy makers in breaking down barriers to timely diagnosis and early intervention. Some researchers have completed qualitative syntheses of literature related to investigating the barriers

and facilitators of parenting programs for children with behavioral issues.[28] Other researchers have conducted meta-syntheses about parents' and guardians' experiences of advocating for a child diagnosed with ASD,[29] lived experience of parents of children with ASD,[30] and parenting or caring for a child diagnosed with ASD.[31-33] There are also meta-syntheses conducted about parenting stress in families of children with mental health disorders, such as ADHD and ASD,[34] and exploring early interventions for children with ASD.[35] However, to our knowledge, no qualitative syntheses have been conducted on parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children. The authors completed a preliminary search of databases (PubMed, CINAHL, JBI EBP Database, the Cochrane Library, the Campbell Library, and PROSPERO). No current or in-progress systematic reviews were identified on this topic. This systematic review will fill that gap in the literature.

Review question

What are parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children?

Inclusion criteria

Participants

We considered studies conducted worldwide that included parents and guardians (ie, persons legally responsible for the child's care and upbringing), who have accessed or who are attempting to access pediatric ASD diagnostic services (ie, organized procedures, tests or methods for the purpose of providing an ASD diagnosis) for their children and adolescents (up to the age of 18 years of age) on an inpatient or outpatient basis. The diagnosis of ASD is considered to be a significant life event for families[36]; therefore, we anticipated that their

experiences could be recalled. Studies involving other participants were included if the data from the parents or guardians could be separated from the larger sample.

Phenomena of interest

The phenomenon of interest was parents' and guardians' experiences of barriers and facilitators accessing ASD diagnostic services for their children.

Context

The context for this systematic review was inpatient and outpatient settings in any country worldwide. Regions/countries may have different health system contexts; however, the barriers and facilitators in accessing ASD diagnostic services for parents and guardians of children with ASD could be similar. Contextual factors include cultural and socioeconomic disparities that were identified in the characteristics of the included studies.

Types of studies

This review considered studies that focused on qualitative data about the experiences of barriers and facilitators for parents and guardians in accessing ASD diagnostic services for their children. These studies included, but were not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Mixed method studies with qualitative results related to the topic were also included so that no relevant study findings were missed, and this is a slight deviation from a priori protocol.[37]

Methods

This systematic review was conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence.[38] The review was guided by a priori protocol[37] and has been registered in PROSPERO (CRD42018100127).

Search strategy

The aim of the search strategy was to locate studies relevant to the phenomenon of interest by searching for published studies through academic databases and unpublished studies through gray literature sources. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the titles and abstracts, and of the index terms used to describe the articles. This informed the development of a search strategy (Appendix 5.I) that was tailored for each information source. Databases searched included CINAHL (EBSCOhost), CINAHL Plus (EBSCOhost), MEDLINE (EBSCOhost), APA PsycINFO (EBSCOhost), Social Services Abstracts (ProQuest), ERIC (EBSCOhost), and EMBASE. Gray literature sources included ProQuest Dissertations and Theses (ProQuest), Google Scholar, Google, OpenGrey, and other online resources (government and organizational websites). All Google Scholar and Google results retrieved by the searches documented in Appendix 5.I were reviewed for relevant studies. The database search was conducted May 18, 2022, and an updated search was conducted June 7, 2023. The reference lists of all studies selected for critical appraisal were screened to identify other potentially relevant studies. No date or language limits were applied to the search. Only studies published in English or that had available English translations were included. Those published in other languages were not included as we did not have any resources for translation.

Study selection

Following identification of citations from the academic database and gray literature sources, the citations were prepared by MS for screening of titles and abstracts. The academic database findings were collated and imported into EndNote v.X8 (Clarivate Analytics, PA, USA) and duplicates removed. The citation set was then uploaded into Covidence (Veritas Health

Innovation, Melbourne, Australia) for screening. Following a pilot test, titles and abstracts were screened by 2 independent reviewers (JSY and AP or RC) for assessment against the inclusion criteria for the review. Differences between reviewers' screening assessments were discussed and resolved through consensus. Studies that met or potentially met the inclusion criteria were retrieved in full and their details imported into JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia). The full text of selected studies were retrieved and assessed in detail against the inclusion criteria by 2 reviewers (JSY and AP or RC). Full-text studies that did not meet the inclusion criteria were excluded from further review. Reasons for exclusion are provided in Appendix 5.II. Studies that met the inclusion criteria underwent a process of critical appraisal. The results of the search are reported in a Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram[39] (Figure 5.1)

Assessment of methodological quality

Studies that met the inclusion criteria were critically appraised by 2 independent reviewers (JSY and AP or MS), with appraisals compared and differences resolved through discussion and consensus. The appraisal was conducted using the JBI critical appraisal checklist for qualitative research.[38] The checklist is composed of 10 questions that are applied to each study and represent criteria concerning study methodology, methods, and findings; research ethics; and researcher influence on the research (see Table 5.1).

Table 5.1: Critical appraisal of included (n=36) and excluded (n=46) qualitative studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total % Yes scores
Included (n=36)											
1.Alsayyari, 2017[40]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
2.An et al., 2020[41]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
3.Anderson et al., 2020[42]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
4.Bell, 2010[43]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
5.Dababnah and Bulson, 2015[44]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%

6.deVerdier et al., 2019[45]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
7.Ducey, 2009[46]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
8.Finnegan et al, 2014[47]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
9.Fowler and O'Connor, 2021[48]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90%
10.Freeman and Paradis, 2023[49]	U	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
11.Gonzalez, 2020[50]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
12.Hannon and Hannon, 2017[51]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
13.Heslip, 2009[52]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90%
14.Ho et al., 2014[53]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
15.Hosseinpour et al., 2022[54]	U	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
16.Jackson et al., 2019[55]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
17.Kalash, 2009[56]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
18.Kelly, 2017[57]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
19.Lappé et al., 2018[58]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
20.Lindly et al., 2023[59]	U	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
21.Locke et al., 2020[60]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
22.Lutz, 2008[61]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
23.Mann, 2013[62]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
24.Mulligan et al., 2012[63]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90%
25.Newman, 2008[64]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
26.Perlman and Howe, 2022[65]	U	Y	Y	Y	Y	U	Y	Y	Y	Y	80%
27.Piepenbring, 2017[66]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90%
28.Preece and Lessner Lištiaková, 2021[67]	N	Y	Y	Y	Y	N	Y	Y	Y	Y	80%
29.Shattnawi et al., 2021[68]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90%
30.Smith-Young et al., 2020[69]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
31.Smith-Young et al., 2022[70]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90%
32.Sulaimani, 2018[71]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
33.Templeman, 2019[72]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
34.Truett, 2012[73]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
35.Ulfoshio, 2017[74]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
36.Vanegas et al., 2023[75]	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	90%
Excluded (n=46)											
37. Avdi et al., 2000 (Appendix IV)	Y	Y	Y	Y	Y	U	N	N	N	U	50%
38. Bloch and Gardner, 2007[76]	U	Y	Y	Y	Y	N	N	Y	Y	Y	70%
39. Braiden et al., 2010 (Appendix IV)	U	Y	Y	U	U	N	Y	N	N	N	30%
40. Carinci, 2007 (Appendix IV)	N	Y	Y	U	U	N	N	N	Y	Y	40%
41. Chamak and Bonniau, 2013[77]	N	U	U	U	U	N	N	N	N	U	0%
42. Chao et al., 2018[78]	U	Y	Y	Y	Y	U	N	U	Y	Y	60%
43. Chavez et al., 2022(Appendix IV)	U	Y	Y	U	Y	N	U	Y	Y	U	50%
44. Coffield et al., 2021[79]	N	U	Y	U	U	N	Y	Y	Y	Y	50%
45. Connolly and Gersch, 2013[80]	Y	Y	U	U	U	Y	N	N	Y	U	40%
46. Crais et al., 2020[81]	U	U	Y	N	N	N	Y	Y	Y	Y	50%
47. Cramm et al., 2019 (Appendix IV)	Y	Y	Y	U	Y	N	N	Y	Y	Y	70%
48. De Aguiar and Pondé, 2020 (Appendix IV)	Y	Y	Y	Y	Y	U	N	Y	Y	Y	80%
49. Drummer Taylor, 2006 (Appendix IV)	U	N	Y	Y	Y	N	Y	Y	Y	Y	70%
50. Ebert and da Silva, 2015 (Appendix IV)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	90%
51. Etchison, 2022 (Appendix IV)	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	90%
52. Ewart, 2003 (Appendix IV)	Y	Y	Y	Y	Y	Y	N	Y	N	Y	80%
53. Gane, 2008 (Appendix IV)	U	Y	Y	Y	Y	N	N	Y	Y	Y	70%
54. Hailu, 2020 (Appendix IV)	Y	Y	N	N	U	Y	Y	Y	Y	Y	70%
55. Hutton and Caron, 2005[82]	N	N	N	U	U	N	N	Y	Y	Y	30%
56. Jagatheesan et al., 2010 (Appendix IV)	U	Y	Y	Y	Y	Y	Y	N	N	N	60%
57. Knussen and Brogan, 2002 (Appendix IV)	N	U	U	U	U	N	N	N	Y	N	10%

58. Laird, 2012 (Appendix IV)	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	90%
59. Lamba et al., 2022 (Appendix IV)	N	U	U	U	U	N	Y	Y	N	Y	30%
60. Link, 2007 (Appendix IV)	Y	Y	Y	Y	Y	Y	Y	N	N	Y	80%
61. Manano and Clasquin-Johnson, 2023 (Appendix IV)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	90%
62. Midence and O'Neill, 1999[83]	Y	Y	N	N	Y	N	Y	Y	N	Y	60%
63. Mitchell and Holdt, 2014[84]	U	Y	Y	Y	Y	N	N	Y	N	Y	60%
64. Moodie-Dyer et al., 2014[85]	N	Y	Y	Y	Y	N	Y	Y	N	Y	70%
65. .Novoa, 2015 (Appendix IV)	Y	Y	Y	Y	Y	U	N	Y	Y	Y	80%
66. Osborne and Reed, 2008 (Appendix IV)	N	N	N	N	N	N	Y	Y	N	Y	30%
67. Pearson et al., 2019 (Appendix IV)	N	U	U	N	U	N	Y	N	Y	U	20%
68. Pearson and Meadan, 2018[86]	N	N	Y	Y	Y	N	Y	Y	Y	Y	70%
69. Potter, 2017 (Appendix IV)	N	U	U	U	U	N	N	Y	Y	U	20%
70. Rabbitte et al., 2017 (Appendix IV)	Y	Y	Y	Y	Y	N	Y	N	Y	Y	80%
71.Ryan and Salisbury, 2012[87]	N	N	Y	Y	Y	N	U	Y	Y	U	50%
72. Sakai et al., 2019 (Appendix IV)	N	N	Y	U	N	N	U	Y	Y	U	30%
73. Schelly et al., 2019 (Appendix IV)	N	N	N	N	N	N	U	N	Y	U	10%
74. Schwartz, 2001 (Appendix IV)	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	90%
75. Stahmer et al., 2019 (Appendix IV)	N	Y	Y	Y	Y	N	Y	Y	N	Y	70%
76. Tait et al., 2016[88]	N	N	Y	N	N	N	N	Y	Y	Y	40%
77. Tarian, 2015(Appendix IV)	N	U	Y	Y	Y	Y	Y	Y	N	Y	70%
78. Tekinarsian, 2018[89]	Y	Y	Y	N	Y	N	Y	Y	N	Y	70%
79. Twomey and Shevlin, 2017(Appendix IV)	N	Y	Y	Y	Y	N	N	Y	N	Y	40%
80. Yi et al., 2020[90]	Y	Y	Y	Y	Y	N	Y	Y	N	Y	80%
81. Zarafshan et al., 2019[91]	N	U	Y	N	N	N	N	Y	Y	U	30%
82. Zuckerman et al., 2014[25]	N	Y	Y	Y	Y	N	Y	N	Y	Y	70%
Total % Yes scores	50%	79%	87%	74%	79%	34%	71%	84%	77%	84%	

N, no; U, unclear; Y, yes.

JBI Critical Appraisal Checklist for Qualitative Research:

Q1 = Is there congruity between the stated philosophical perspective and the research methodology?
Q2 = Is there congruity between the research methodology and the research question or objective?
Q3 = Is there congruity between the research methodology and the methods used to collect data?
Q4 = Is there congruity between the research methodology and the representation and analysis of data?
Q5 = Is there congruity between the research methodology and the interpretation of results?
Q6 = Is there a statement locating the researcher culturally or theoretically?
Q7 = Is the influence of the researcher on the research, and vice-versa, addressed?
Q8 =Are participants and their voices, adequately represented?
Q9 = Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?
Q10 =Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data

Possible responses to the questions are “yes,” “no,” or “unclear.” The decisions regarding the approach to critical appraisal were made on the basis of 2 considerations: i) the need to retain a sufficient number of studies that might otherwise have relevant findings of suitable quality (ie, findings with supporting participant voices that lend them credibility) to address the question for this review and enable a comprehensive meta-synthesis, and ii) the assessment of confidence in the synthesized findings (i.e., ConQual scores[1] would inform readers of the level of confidence they can place in the value and usability of the synthesized findings).

There are no guidelines regarding which specific criteria and the number of criteria that should receive “yes” responses to constitute acceptable methodological quality in any particular review, hence, decisions about the appraisal approach are determined by the reviewers. The protocol for this review[37] does not provide a predetermined approach; however, before commencing critical appraisal, JSY and AP decided that studies would be included or excluded in the review on the basis of the results for 8 criteria (#2, 3, 4, 5 and 7, 8, 9, 10), which were considered to reflect the quality of research decisions, methods, findings, and interpretation of findings. A “no” response for any of the 8 criteria would constitute exclusion of the study. Of criteria #6 and #7, which reflect researcher perspective, acknowledging criteria #7 as essential is consistent with accepted standards for reporting qualitative research in which there is a requirement that authors address researcher reflexivity.[92,93] Criteria #1 and #6 were deemed not to be essential to methodological quality. We recognized that those criteria are often not reported in research studies, especially qualitative descriptive study designs, and, notably, would not have any meaningful effect on the results of the review.[94] The critical appraisal assessments were conducted by two reviewers (JSY and AP or MS) independently. Any disagreements that arose

between the reviewers were resolved through discussion. The results of critical appraisal of eligible studies are reported in narrative form and in Table 5.1.

Data extraction

Qualitative data was extracted from studies included in this review by 2 independent reviewers (JSY and AP) using the standardized data extraction tool[38] from JBI SUMARI.[95] The data extracted included specific details about the populations, context, culture, geographical location, study methods, and the phenomena of interest relevant to the review question and specific objectives. Findings and their illustrations were extracted and assigned a level of credibility [see Appendix 5.III]. Any disagreements that arose between the reviewers were resolved through discussion. The specific research findings were extracted by JSY and AP independently. The findings were identified through repeated reading of the results sections of the studies. Text was accepted as a finding if it was a verbatim statement or phrase indicating the study author's description or interpretation of narrative data, and if it was accompanied by direct participant voice (ie, quotation).

Only findings that were clearly recognizable as based on the experiences of parents and guardians in accessing ASD diagnostic services for their children were extracted. Each extraction was assigned 1 of 3 levels of credibility by SS and JSY independently: unequivocal (author's description or interpretation unquestionably supported by participant voice and not open to challenge); credible (association between author's words and participant voice not fully apparent, plausible but could be challenged), or unsupported (author's words and participant voice not connected, undeniable lack of fit and, or participant voice not providing clarity for author's description interpretation). Differences between the reviewers on whether extracted data

represented a relevant finding and on the level of credibility were discussed and consensus was reached. Only unequivocal and credible findings were used for data synthesis.

Data synthesis

The qualitative research findings were pooled using JBI SUMARI with the meta-aggregation approach.[38] This involved the aggregation or synthesis of findings that generated a set of statements that represented that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.

Two members of the review team (JSY and AP) collaboratively studied the extracted findings and grouped them into draft categories based on similarity in meaning. They then individually reexamined the draft categories and their associated findings, then discussed and refined them over a period of 3 weeks. The synthesized findings were drafted by JSY and discussed with AP to confirm and further revise as needed. Feedback was provided by RC who is a professional with expertise in pediatric research.

Assessing confidence in the findings

The final synthesized findings were graded according to the ConQual approach[1,38] to establish the level of confidence that knowledge users may have in the synthesized findings for informing practice, policy, and research. With this approach, a confidence level (ConQual score) of high, moderate, low, or very low is determined for each synthesized finding according to the dependability and credibility of the research findings underlying the synthesized finding. First, dependability is determined for the individual studies comprising the synthesized finding according to the responses to 5 criteria on the JBI critical appraisal checklist for qualitative

research.[38] The dependability for each study, which may be high, moderate, or low, is then transferred to each research finding from the study. The aggregated level of dependability from across the research findings, which takes into account the relative number of low, moderate, and high dependability findings, is the dependability score for that synthesized finding. The credibility score for each synthesized finding is based on the proportion of unequivocal and credible findings represented in the synthesized finding. See the Summary of Findings for explicit details on ConQual scores = for this review.

Results

Study inclusion

The search strategy produced 5964 records from the academic database searches. After removal of duplicates, 5828 records were retained for title and abstract screening. Through screening, 5695 records were designated as not meeting inclusion criteria and 133 reports were assessed for eligibility. Of these, 58 were excluded from the review. As a result, 75 studies were assessed for methodological quality. Of these, 41 were excluded on critical appraisal and a total of 34 studies included in the systematic review. In addition, 43 records were retrieved through other sources. After removal of duplicates, 28 records were retained for title and abstract screening. Of these 28 reports were assessed for eligibility, 21 were excluded from the review with reasons and 7 studies were assessed for methodological quality. Of these, 5 were excluded on critical appraisal and 2 studies included in the systematic review. Hence, taken together, there were 79 studies assessed as ineligible (see Appendix 5.II for a list with assigned reasons) and 36 studies[40-75] assessed as eligible and included in the review. The reasons for exclusion of the 79 studies, from most to least common, were as follows: the studies were not about the phenomenon of interest (n=29); the age range of the children with ASD were not specified (n=21) or did not meet age of

inclusion (n=12); the studies were quantitative (n=5), or no relevant findings were discernible for participants of interest (n=8); article not available (effort to contact author unsuccessful) (n=2); mixed sample – findings related to ASD not discernible (n=1); and findings were same as dissertation already included in the review (n=1). The 36 included records consisted of 21 journal articles and 15 doctoral theses or dissertations. See Figure 5.1 for an overview of the search and study section and inclusion process, which follows the PRISMA guidelines.[96]

Methodological quality

Based on the 8 critical appraisal criteria that were used to determine methodological quality, all 36 studies were considered to have high methodological quality, achieving "yes" scores on all 8 criteria. See Table 5.1 for critical appraisal results for the included studies (n=36) and excluded studies (n=46).

A reference list of the studies excluded due to methodological quality and the reason for each exclusion is provide in Appendix 5.IV. For over half of the studies (n = 24), the main reasons for exclusion were because of the influence of the researcher on the research and vice-versa (criterion #7) was not addressed. In addition, evidence of ethical approval (criteria #9) for 19 of the excluded studies was not met. Fifteen (33%) of the excluded studies were considered low methodological quality based on having achieved "yes" scores on only 1 to 4 criteria (≤ 50% of criteria) of the 8 requisite critical appraisal criteria. Of note, for the 2 criteria that were not taken into account in the critical appraisals (#1: Is there congruity between the stated philosophical perspective and the research methodology? #6: Is there a statement locating the researcher culturally or theoretically?), only 50% of both included and excluded studies received a "yes" for criteria #1 and only 34% received a "yes" for criteria #6.

Characteristics of included studies

An overview of the characteristics of the included studies is provided in Appendix 5.V. The 36 included studies took place in 12 different countries: US (n=17), United Kingdom (n=5), Canada (n=5), Australia (n=1), Nigeria (n=1), Saudi Arabia (n=1), China (n=1), Sweden (n=1), Jordan (n=1), Palestine (n=1), Iran (n=1), and Kazakhstan (n=1). Seven of those countries were classified as high-income countries; 3 countries were classified as upper-middle-income countries; and 2 countries were classified as lower-middle-income countries by the World Bank in 2021.[97]

Study methodologies were varied. The methodologies were described as phenomenology (n=15), grounded theory (n=4), or ethnography (n=1). Some studies methodologies were described with generic terminology, such as qualitative methodologies (n=10) or descriptive narrative (n=3). Two studies were described as case studies and 1 as mixed methods. Over half of the included studies were informed or guided by particular theories, models, or philosophical perspectives.

The studies were published from 2008 to 2023, with the majority (n=24; 67%) published between 2017 and 2023. Lack of data for earlier studies may be due to the rising rate of ASD in recent years.[98] Dates of data collection, which were determinable for only 6 of the studies, ranged 2010 to 2022.

The most common methods of qualitative data collection were through interview, including in-person, face-to-face (n=18), a combination of virtual and face-to-face (n=6). In addition, focus group (n=2) and researcher-administered questionnaires (n=1) and other interview methods not described (n=9) were used. Predominately, data elicitation was described

as semi-structured or open-ended (n=31). The data were descriptively or inductively analyzed with the products being phases, themes, and sub-themes or categories.

The proposed phenomena of interest varied across included studies. About 40% of studies had parents' and guardians' experiences of accessing ASD diagnostic services for their children as the primary focus. The primary phenomena of interest for the majority of studies focused on the lived experiences of parents and guardians of children with ASD diagnosis, parents' and guardians' coping and adjustment to an ASD diagnosis, and availability and access to ASD services during and after diagnosis. The study samples consisted of between 4 and 171 participants. Across the studies, there were approximately 661 eligible participants for this review who were parents and guardians of children with ASD. Based on available information, several observations were made. Participants were predominantly parents and guardians of children with ASD between the ages of 1.5 and 18 years. Where parent gender was identified (n=414), the majority of participants were female (n=342). Parents and guardians represented approximately 475 children with ASD. The majority of children with ASD were male (n=294). Less than half of the included studies (42%; n = 15) reported ethnic and cultural backgrounds of the participants. When participants' racial, ethnic and cultural backgrounds were recorded, the most commonly identified was White. Other racial, ethnic and cultural backgrounds were Hispanic, Black, Arab, Arab American, Jewish, Iranian, Indigenous, and Chinese. When participant language was recorded, it was most commonly English. Other participant languages were Spanish, Arabic, and Chinese.

Review findings

The 36 included studies resulted in a total of 55 qualitative research findings. Of those, 20 were appraised as credible and 35 as unequivocal. There were no unsupported findings. See Appendix

5.V for the research findings from each study. Findings were aggregated into 6 categories and the categories were further aggregated into 3 synthesized findings.

In general, it is apparent that parents' and guardians' experiences during the process of accessing ASD diagnostic services for their children in a timely manner was challenging. Notably, contextual factors, including cultural and socioeconomic disparities, were threaded throughout the findings. More specifically, synthesized finding 1 (category 1: Encountering HCPs who dismissed parents' and guardians' concerns; category 2: Encountering HCPs who acted on parents' and guardians' concerns) indicates that parents' and guardians' ability to access ASD diagnostic services was affected by the amount of perceived support received during parent interactions with HCPs. Synthesized finding 2 (category 1: Encountering delays in the assessment and diagnostic process; category 2: Facing systemic barriers in navigating the pathway to ASD assessment and diagnosis) indicates parents' and guardians' ability to access ASD diagnostic services was affected by encountering delays in the assessment and diagnostic process and facing systemic barriers in navigating the pathway to ASD assessment and diagnosis. Lastly, synthesized finding 3 (category 1: Encountering HCPs with a lack of specialized knowledge about ASD; category 2: Experiencing confusion surrounding inaccurate or mixed diagnoses related to ASD comorbidities) indicates parents' and guardians' ability to access ASD diagnostic services for their children was challenged by encountering HCPs with a lack of specialized knowledge about ASD and experiencing confusion surrounding inaccurate or mixed diagnoses related to ASD comorbidities. See Figure 5.2 for an overview of the meta-aggregative process and synthesized findings, adapted from Davis and colleagues.[99]

Synthesized finding 1: Parents' and guardians' ability to access ASD diagnostic Services for their children is affected by encountering HCPs who actively listened to and addressed

parents' and guardians' concerns instead of dismissing them, providing a sense of support and validation

Parents' and guardians' experiences in their ability to access ASD diagnostic service were affected by the amount of perceived support received from HCPs when they brought concerns to them about their child's developmental progress. Parents and guardians expressed relief when HCPs validated their concerns and conveyed dissatisfaction when HCPs dismissed their concerns. This synthesized finding is composed of 2 categories derived from 18 study findings (13 unequivocal, 5 credible). See Table 5.2.

Category 1: Encountering HCPs who dismissed parents' and guardians' concerns

Parents and guardians experienced barriers in accessing ASD diagnostic services for their children, such as encountering HCPs who dismissed their concerns.[47,68] Early on, they would notice differences in their children's social, communication and interaction skills and bring these concerns to their HCPs who appeared dismissive: "So I was a little concerned that she wasn't doing things as fast as [developmentally] as [my other child]. But every time I mentioned to the doctor… [He said,] 'Oh she's fine, don't worry about [it]'" [57(p.121)] or provided false reassurance to parents, telling them, "everything's fine." [61(p.157)] or assuring them "she was fine, that she would be social and she would talk when she wants to." [46(p.107)] Parents' and guardians' concerns were dismissed telling them they were making too much of their children's behaviors.

> *I would tell [our pediatrician] these things, like little milestones that my son should be hitting. And he's just like, "No, don't worry about it. Boys are late. You overthink everything, you over-analyze everything. Just relax, he'll get there." And my mothers' intuition was like, "This is not good"*[58(p.277)]

I did not like how her doctor dismissed her very quickly and kept saying you are over-analyzing, you are over-analyzing. To me, as a pediatrician he made me feel that he always knew more than me.[40(p.69)]

Then, when I went back to our pediatrician, he is like, well, I didn't think anything was wrong with her… I think at that point he kind of wrote off me and my husband as being overanxious parents.[60(p.76)]

Although parents and guardians became suspicious about signs and symptoms of ASD in their children, their concerns were dismissed. They felt they did not obtain satisfactory answers and explanations to their questions and concerns but rather "just blown off" [72(p.111)] or told to "wait and see" [62(p.71); 69(p.4); 70(p.5, 7-8)] whether or not their child would be able to "catch up" [62(p.71)] or "snap out of it." [46(p.106)] HCPs provided parents and guardians with plausible justifications for their child's behaviors that included gender-specific trends such as, "boys don't develop as quickly as girls," [70(p.7-8)] or "boys are more delayed." [57(p.121)] Other HCPs placed blame on family dynamics, "well he is jealous, he has a new little sister and he is still a little guy himself." [66(p.52)]

Category 2: Encountering HCPs who acted on parents' and guardians' concerns

Parents' and guardians' experienced facilitators in accessing ASD diagnostic services such as, encountering supportive and encouraging HCPs who acted on their concerns and provided them with practical information and referrals for further evaluations.

*My pediatrician was very supportive, and we got him to [*the center*] right away, and we were so lucky.* [60(p.76)]

> *And that pediatrician did send me all the surveys concerning 18-mo behavior. And I obviously, when I started filling it out, I saw that there were a lot of other things. And then she referred me to an evaluation for hearing and a general evaluation at [*the agency*].*[60(p.76)]

Parents acknowledged symptoms of relief when HCPs were able to recognize autism in their children and expressed that not all HCPs possessed that knowledge.

> *Our GP was incredible as well, and his son was also on the spectrum, so I had two very knowledgeable people that I trusted who were giving me referrals and names.*[49(p.1072)]

> *We had these medical professionals who were really aware of what autism looks like in girls that we were able to get the diagnosis.*[49(p.1072)]

Synthesized finding 2: Parents' and guardians' ability to access ASD diagnostic services for their children is affected by extended waiting times and associated financial burdens, and resulted in frustration and associated financial impact when delays occurred

Parents and guardians experienced frustration related to long delays and lengthy waitlists in attempting to access ASD assessment and diagnostic services for their children. In their attempts to expedite ASD service access, parents and guardians would often opt for private services rather than wait for public services which had a financial impact. Navigating the journey to assessment and diagnosis resulted in frustration for parents and guardians as they faced systemic barriers and service inequities. This synthesized finding is composed of 2 categories derived from 18 study findings (13 unequivocal, 5 credible); see Table 5.3.

Category 1: Encountering delays in the assessment and diagnostic process

Parents and guardians encountered delays in the assessment and diagnostic process. A common challenge was the length of time parents had to wait to be assessed for ASD.[43,51]

> *He was on the pathway to being assessed, but still fifteen or eighteen months down the line, nobody had seen him; there was nothing happening.*[67(p.405)]

Parents and guardians described facing lengthy waitlists for ASD assessment and diagnosis for their children.

> *We'd been on the waiting lists forever…to get a diagnosis."* [63(p.317)]

> *At 2 [years old], when he still wasn't saying anything, the doctor said, "Maybe we should refer him to a pediatrician."- which has not yet happened…We're still on the waiting list 2 years later.*[64(p.72)]

> *I started being on the waitlist, and I'm like, 'What am I doing in like the next year?' because the waitlist is, like, a year.*[60(p.76)]

Category 2: Facing systemic barriers in navigating the pathway to ASD assessment and diagnosis

Parents and guardians experienced frustration with the long cumbersome bureaucratic process in accessing ASD diagnostic services for their children, a process that could range anywhere from a few months to several years from the time they first presented their concerns to HCPs. This involved waiting for referrals to be processed and attending multiple appointments with a variety of specialists, such as a child developmental specialist, speech therapist, occupational therapist, and others. The process included a large amount of paperwork required to obtain diagnostic and assessment services, which would delay the process.

[We] waited 8 months to get into speech…the speech language pathologist was the first one that even hinted that there could be something. She suggested that we go to get tested for autism…it was 19 months [on the wait list] from the time we started; [it] was 36 months when he got his diagnosis. [69(p.4)]

We noticed it when he was around 19 months…We got him referred when he was around 24 months…it took about eight months to get in for testing. We went three times for testing…He was almost four years old when he got diagnosed.[69(p.4)]

First, you need to go to your pediatrician and the pediatrician has to make the referral to a specialist, and after you see the specialist, that's when you get the diagnosis added. But that takes a while. The only thing I get very, very mad [about] is the process to get everything done takes so long. Like for my son, I had to wait months to get just an evaluation and I think it's just wasting time…you can't get the services during that time, because you don't have the evaluations yet. [58(p.277)]

Parents and guardians experienced systemic barriers in navigating the pathway to assessment and diagnosis for their children related to a lack of available ASD diagnostic services in their communities.

I think around the reservation it's harder for Native Americans to get services and to get diagnosis and stuff. [59(p.9)]

Those who could afford to pay for private assessment and diagnostic services were able to avoid lengthy wait times.

I went to ask for prices at [Centre A] and I queued for the government one as well. But the government one was very long. It was very hopeless. For [Centre A], the waiting list was half a year. For a private one, [Centre A] is the cheapest one. Then for [Centre B], it was only a 2-week waiting list, so I chose [Centre B].[53(p.837)]

Parents and guardians explored financial options in attempting to expedite access to ASD assessment and diagnostic services that would result in financial inequities. Although some countries provided universal or medical insurance coverage, parents who could afford to do so would choose to pay-out-of-pocket to avoid long waiting times for needed services.

"Like, if you have the money, you can kind of skip ahead of the lines." [60(p.76)]

We're fortunate that we have funds but I know people who want to get diagnosed but they just don't have the money…it's definitely a barrier, so there's real equity issues there. [49(p.1072-73)]

Parents and guardians spoke about challenges and inequities related to language barriers in attempting to access ASD assessment and diagnostic services.

Regarding the language, you have even more barrier. Like you would like to understand more but you can't. [50(p.78)]

Synthesized finding 3: Parents' and guardians' ability to access ASD diagnostic services for their children is affected by encountering HCPs lacking specialized knowledge about ASD, contributing to parents' and guardians' confusion surrounding inaccurate or conflicting diagnoses related to ASD comorbidities

Parents and guardians faced uncertainties as they encountered HCPs with a lack of specialized knowledge about ASD offering them vague and contradictory diagnoses for their children.

Parents and guardians would face further delays as they sought out second opinions or further diagnostic assessments for their children from other HCPs. ASD comorbidities would also pose a challenge in parents' and guardians' experiences in attempting to access an accurate diagnosis for their children. This synthesized finding is composed of 2 categories derived from 19 study findings (9 unequivocal, 10 credible). See Table 5.4.

Category 1: Encountering HCPs with a lack of specialized knowledge about ASD

Parents and guardians experienced barriers in accessing ASD diagnostic services for their children attributed to HCP's lack of specialized knowledge or training about ASD and a lack of understanding about how ASD presents in girls.

> *…she doesn't look like she's got autism, girls don't have autism."* [42(p.1550)]

Lack of knowledge and awareness about ASD hindered timely access to ASD diagnostic services for children.

> *When I had my experience, there was no awareness as to what autism was. I took him to the hospital to see the pediatrician but at the time nobody knew anything about autism, they thought it was a nervous problem. We went to a psychiatric hospital, nobody knew it was autism, even there.* [74(p.78-79)]

> *I was asking so many questions that the doctor couldn't answer. It didn't even seem like the doctors knew much about autism because the first time it was from a book that the doctor tried to find the word autism to explain to me.* [74(p.78-79)]

Parents and guardians travelled to other countries when possible to access diagnostic services for their children that were lacking in their own countries, or where HCPs were not knowledgeable about ASD.

At first, I thought he couldn't hear well, so I went for audiology test, on getting there after checking it they said he might be autistic. On visiting the neurologist, he said, he[son] doesn't look autistic to him. In fact, I had very conflicting results, so I had to take my son to the US. On getting to the US it was confirmed that he is autistic. [74(p.80)]

Parents and guardians experienced uncertainty and disillusionment in HCPs lack of knowledge.

He went for brain scans. He was 100% fine. His EEGs showed no epilepsy, nothing. So, I sat with this child who looked so healthy and normal and the doctors did not know what was going on.[52(p.57)]

Parents and guardians stressed the importance of HCPs having specialized knowledge in ASD, especially when children were affected by visual impairments.

These assessments should never be carried out by people who are inexperienced with blind children. That involves too many risks of misconceptions and is not fair, either to us or to the child. [44(p.1926)]

Category 2: Experiencing confusion surrounding inaccurate or mixed diagnoses related to ASD comorbidities

Parents and guardians experienced barriers in accessing ASD diagnostic services for their children, such as receiving inaccurate or mixed diagnoses from HCPs often related to ASD comorbidities that caused confusion for parents and guardians. A variety of diagnoses, including ADHD, oppositional defiant disorder, anxiety disorder, dysgraphia, OCD, and language delays, were listed by parents prior to obtaining a suspected ASD diagnosis.

He was diagnosed with ADHD [Attention Deficit Hyper-Activity Disorder], OCD [Obsessive Compulsive Disorder], sensory integration, and language delays. Still in my

gut I felt it was Asperger's…The psychologist that we took him confirmed the diagnosis of Asperger's.[56(p.50)]

She had her down with having anxiety, and she diagnosed dysgraphia…ADHD, everything bar the word autism…you get answers, but they're not the right ones.[48(p.279)]

HCPs' opinions expressed when parents and guardians were obtaining a diagnosis for their children were vague, confusing, and contradictory.

It is really easy to get confused […] Even if you get to see a psychiatrist, it is not given that s/he will tell you the right thing. In the mental health centre I was told, 'why are you slandering your own child? He doesn't have autism.' As if I want to get this diagnosis. […] Then we went to another psychiatrist, he said that autism is a dumping ground, anything can qualify as autism. Basically, everyone has [something that can qualify as] an autistic syndrome, and it is easy to get confused, because you don't know what the truth is. […] No, we don't have any system of detection [of ASD] yet. [41(p.6)]

We started walking from specialist to [another] specialist […] so we took [the child] to a doctor who examines hearing, then to a psychiatrist, who says that this is schizophrenia. Every specialist we see gives us their own 'two cents'. [A specialist] is not 100 percent sure [in the diagnosis] […]. We spent so much time to figure out what to do […] it took us almost a year to get this diagnosis.[41(p.7)]

I went to hospitals to get him checked and I went to centers for diagnosis. However, I got different and contradicting diagnoses. [71(p.92)]

He said that it wasn't autism but ADHD [attention deficit hyperactivity disorder] but I didn't believe him. Then I took him to a hospital and 2 of the doctors said that he has autism, not ADHD.[71(p.92)]

So, then we went for a second opinion, we went to [local university clinic]. [Local university clinic] was like, 'No, I don't think he is on the spectrum, I think he has apraxia.' So he had two different diagnoses. And then we went to [other] hospital in [Indiana] where they did have a multidisciplinary team, and they said, 'They are both right, he does have apraxia and he does have autism, but this is what you need to do.[75(p.255,257)]

Discussion

The evidence in this systematic review provided sufficient research findings from among the 36 included studies to generate 55 unequivocal and credible research findings. Overall, aggregation yielded 6 categories and 3 synthesized findings.

The synthesized findings for this review indicate that parents and guardians perceived both barriers to and facilitators in accessing ASD diagnostic services for their children. The barriers and facilitators perceived were in relation to the amount of support received during their interactions with HCPs, encountering delays in the assessment and diagnostic process, facing systemic barriers in navigating the pathway to ASD assessment and diagnosis, perceived lack of HCP specialized knowledge of ASD and confusion surrounding inaccurate or mixed diagnoses related to ASD comorbidities.

This review corroborates other research findings that parents and guardians are often among the first persons to express concerns about atypical behaviors early on in their children's development that are consistent with an ASD diagnosis (ie, difficulties in communication and social interactions and displaying restrictive and/or repetitive behaviors and interests) consistent with an ASD diagnosis.[31,76,86,89,100-102] Parents and guardians then bring those early concerns to their HCPs, such as their children's pediatrician or their family physicians. Results of this review found that parents and guardians viewed HCPS as supportive when they acted promptly on their concerns and provided them with information and referrals for ASD assessment and diagnostic services. In contrast, parents and guardians perceived HCPs who dismissed their early concerns as unsupportive. This lack of recognition or dismissal of concerns is worrisome because it can result in a delay in the start of intervention programs, which research indicates are more effective when implemented at earlier stages.[103] Among parents of children with ASD, those with more proactive HCP responses to parent and guardian concerns regarding ASD experienced shorter delays in obtaining an ASD diagnosis.[104]

There is evidence in the literature that some HCPs may have limited knowledge about ASD or lack training concerning ASD assessment and diagnosis[20,86,101] which is consistent with the perspectives of parents and guardians in this review. Provider knowledge is critical in determining a diagnosis as early as possible because early intervention is associated with better social and communication outcomes, and lower need for costly services as the child develops.[105] Findings from this review highlight the important role of first-line HCPs during the diagnosis process in taking parents' and guardians' concerns, perspectives and observations seriously.

Study findings from this review indicate children are seen by multiple specialists and tested for a multitude of disorders before receiving an ASD diagnosis. Evidence indicates that

the process in accessing an ASD diagnosis is complicated by overlapping ASD comorbidities and co-occurring diagnosis.[78,81,106] This review highlighted the confusion parents and guardians experienced as they attempted to confirm a diagnosis amidst the competing comorbidities and lack of HCPs' knowledge about ASD. As reported elsewhere, parents and guardians recounted how they were given incorrect diagnoses, alternative explanations, and multiple consultations with a variety of HCPs laden with contradictory information and mixed diagnoses that contributed to delays in timely access to ASD services and supports. [31,82,83,104] Findings from this review support existing evidence that demonstrates the process along the ASD journey is arduous and complex for parents and guardians that included lengthy wait times for acquiring evaluations, diagnosis and services.[20,31,32,80,82,83,85,103,104] In this review, the wait times for referral and completion of the assessment and diagnostic process was considered to be too long for parents and guardians. Lack of availability in accessing ASD diagnostic services and specialists have been reported elsewhere.[20,80,81,85,104,105]

Similar to parents' and guardians' reports in this review, it is evident that multiple barriers exist for parents and guardians attempting to access ASD diagnostic services for their children. In addition, countries vary in the extent to which ASD is recognized and accepted, which presents an additional barrier related to cultural beliefs, language, and stigma related to ASD diagnosis.[77,78,84,88,90,91,107,108] Barriers to accessing ASD assessment and diagnostic services presented in this review and in extensive other sources include reluctance from health professionals to provide a diagnosis of ASD (ie, dismissal of parent concerns)[30,32,76,79,80,86,101,103,106,108]; gender bias (i.e., gendering of ASD)[87,106,109]; HCPS taking a "wait and see" approach before providing referrals for assessment and diagnosis[79,82,85,87]; and enduring multiple consultations or receiving multiple and mixed diagnoses for their children

before an ASD diagnosis is confirmed.[104] Corresponding facilitators for parents in accessing ASD diagnostic services in a timely manner include higher economic status and education[81,105] and effective communication between HCPs and parents and guardians.[104]

Findings from this review indicate that parents need quicker and easier access to ASD assessment and diagnostic services. In addition, HCPs need to monitor child development over time to assess ASD risk given the heterogeneity of ASD expression and presentation in children. It is important for HCPs to integrate all sources of information to inform clinical judgement, including listening to parents' and guardians' child development concerns and through systematic surveillance during routine check-ups and appointments.

Strengths and Limitations of the Review

This review has several strengths:

- The review is based on a large group of eligible studies (n=36) and a large number of research findings (n=55), with the majority of findings (64%) being unequivocal.
- The studies included in this review scored 80 to 100% on critical appraisal.
- The included studies originated in a number of different countries and involved varied ethnicities and cultures.
- The review team members have practice, policy, and research experience in chronic conditions, including expertise in qualitative research methodology (JSY, AP, RC) and literature search and management strategies (MS); and experience conducting JBI qualitative systematic reviews (AP, MS). The synthesized findings were corroborated by feedback provided by an experienced researcher in the field of pediatrics (RC).

This review also has several limitations, which should be accounted for when considering the veracity of the synthesized findings:

- Every effort was made to locate and include all eligible studies and to extract all relevant research findings; however, it is possible that studies were missed during the screening process. Studies that did not have available English translation were not included that may be considered a limitation. Because of limitations in research findings (ie, lack of depth, detail, or full researcher analytic interpretation making it difficult to determine the applicability of the research findings), it is possible that pertinent findings were inadvertently omitted.
- Missing distinguishing details about participants and limitations in research findings (i.e., lack of depth, detail, or full researcher analytic interpretation; lack of good fit between particular research findings and the assigned themes or categories) made it difficult to categorize some research findings with complete certainty.
- The majority of the included studies (58%) originated in high income countries and the remainder originated in upper-middle income countries, with few studies from lower-middle-income or low-income countries.

Conclusions

The research findings from the studies included in this review yielded 3 synthesized findings and 6 categories about parents' and guardians' experiences in accessing ASD assessment and diagnostic services for their children. It is apparent from the findings of this review that parents and guardians face barriers and facilitators in accessing ASD diagnostic services for their children. HCPs who work with parents and guardians of children with ASD need the pre-requisite knowledge and skills for assessment and diagnosis. HCPs also need to be aware of contextual and systemic disparities that may arise as parents and guardians seek ASD assessment and diagnostic services for their children.

Recommendations for practice and policy

A number of recommendations for practice and policy are derived from the synthesized findings. The use of qualitative research reviews for practice recommendations is well supported.[110] Although similar recommendations have been documented in the literature, because of the moderate confidence in the synthesized findings, the following recommendations are assigned Grade B, in accordance with the JBI approach to grading recommendations.[1] It is recommended that:

- Health care providers (HCPs) should support and provide guidance for parents and guardians during the autism spectrum disorder (ASD) assessment and diagnosis. (Grade B)
- Providers of health care services develop and employ strategies to reduce wait times in accessing ASD assessment and diagnostic services. (Grade B)
- ASD-specific education and training should be provided to medical health care professionals including but not limited to primary care physicians and pediatricians. (Grade B)

Recommendations for Research

Several recommendations are indicated for future research based on limitations in the methodologies, reporting, and findings of studies located for this review and on the need for further understanding of the barriers and facilitators in accessing ASD diagnostic services.

- It is recommended that in qualitative studies concerning parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for children, robust methodologies (including philosophical or theoretical premise or guiding framework and research paradigm), methods (including researcher characteristics and reflexivity), and samples (including characteristics, such as age and gender); as well as

relevant contextual information, such as socio-economic background, setting, ethnicity, and culture are fully described.

- It is recommended that in studies of mixed samples, participant characteristics are assigned to participant voice to identify relevant findings.
- It is recommended that research is conducted worldwide, including focusing on middle- to low-income countries regarding parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for children.
- It is recommended that research is conducted to understand the needs of HCPs working with parents and guardians of children with ASD.

Declarations

The authors acknowledge that 2 of the studies[69,70] included in this review were authored by the first reviewer (JSY) on this report. To mitigate potential conflict of interest in the review process,[111] JSY and RC abstained from study selection and appraisal, extraction and synthesis processes of these 2 studies; hence, AP and MS were the only reviewers for these 2 studies.

Funding

There was no funding received for this review.

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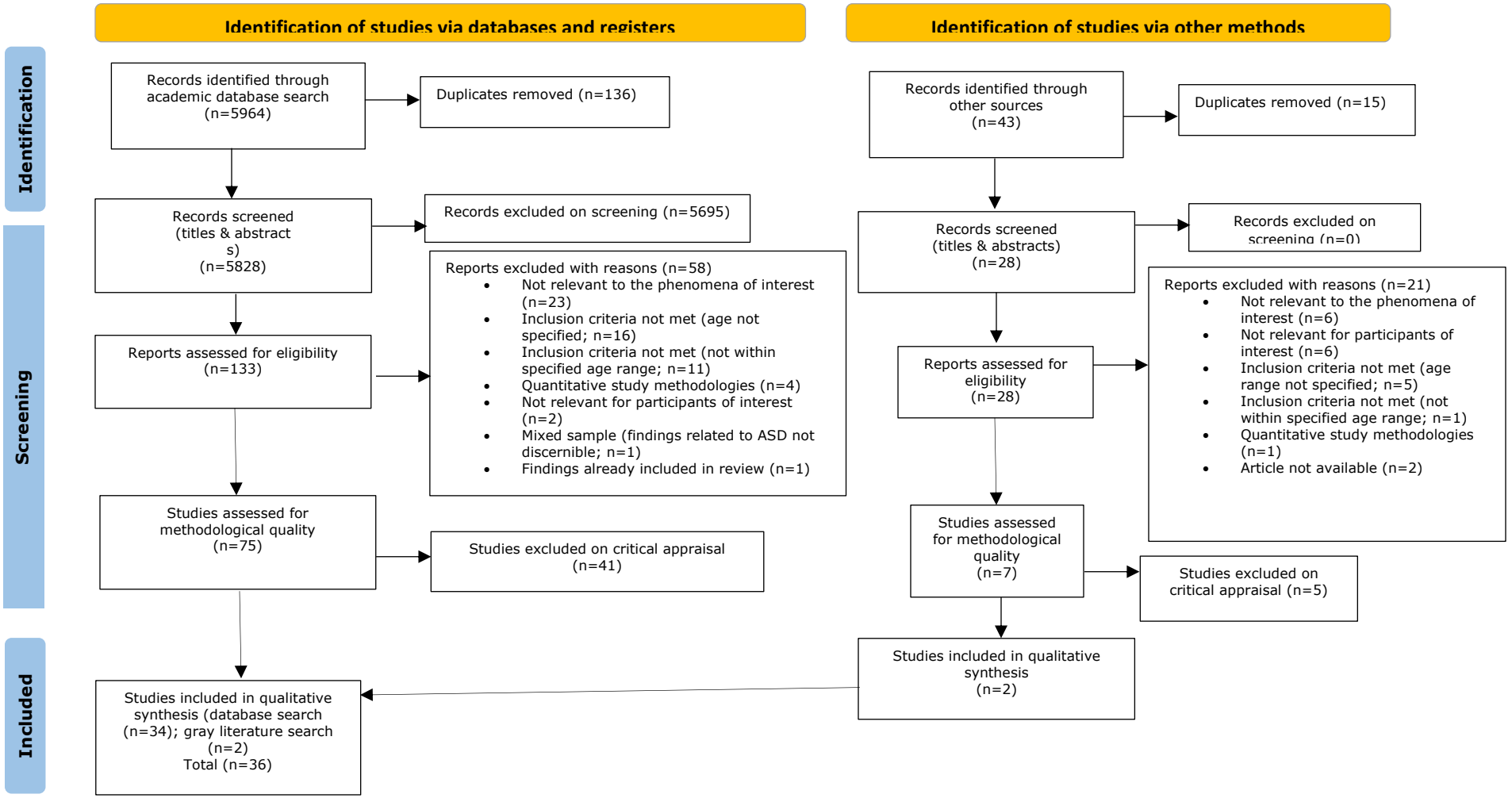

Figure 5.1: Search results and study selection and inclusion process

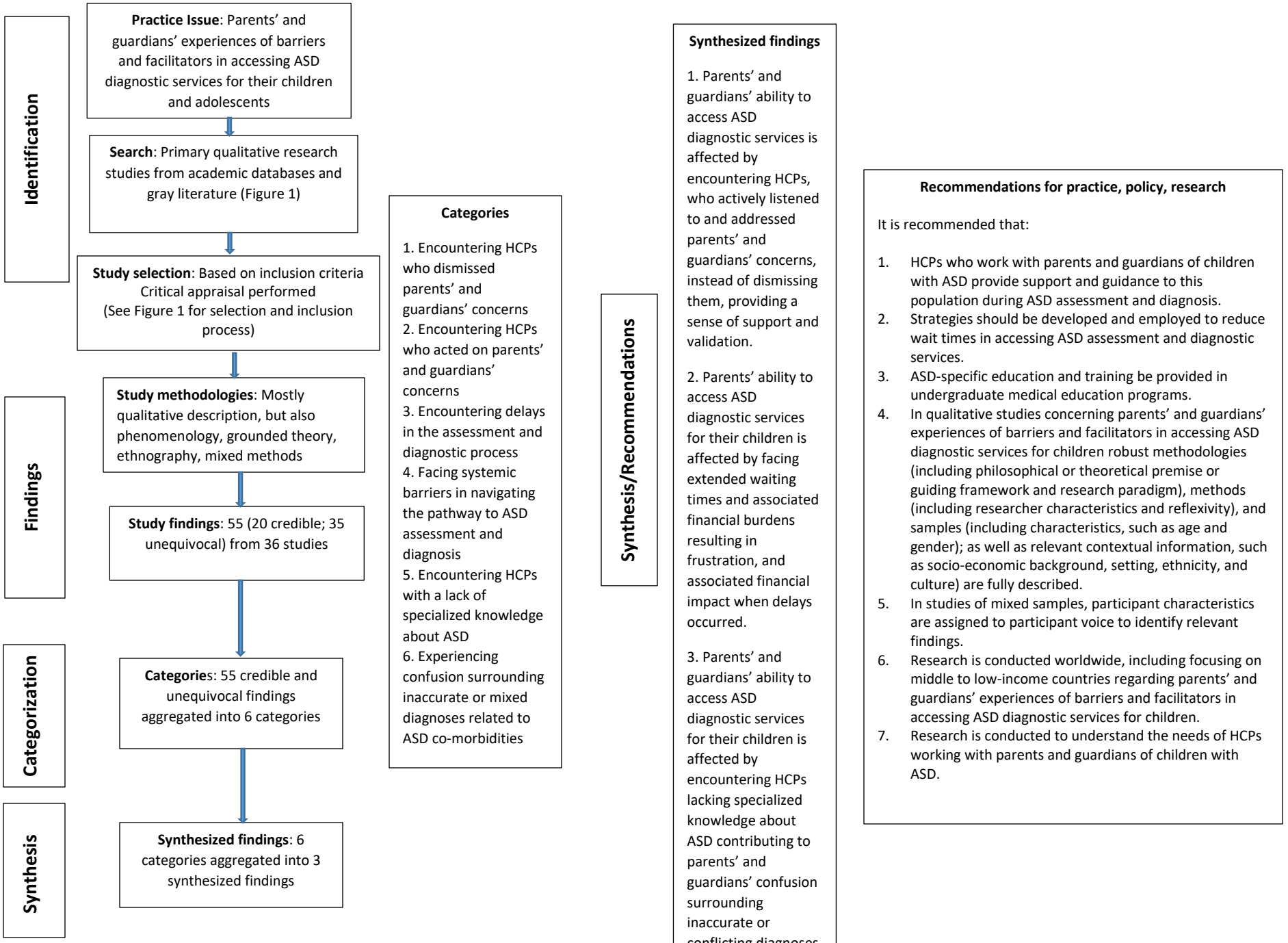

Figure 5.2. Meta-aggregative process and synthesized findings.
ASD, autism spectrum disorder; HCP, health care provider
Flow chart adapted from Davis, White, Stephenson, 2016[83]

Table 5.2: Synthesized finding 1

Study findings	Categories	Synthesized finding
Parents' journeys toward the acceptance of the diagnosis of ASD: Period of uncertainty (U)	Encountering HCPs who dismissed parents' and guardians' concerns	Parents' and guardians' ability to access ASD diagnostic services for their children is affected by encountering HCPs, who actively listened to and addressed parents' and guardians' concerns, instead of dismissing them, providing a sense of support and validation.
Reassurance and denial: Reassurance from pediatricians and family members (U)		
Diagnostic experiences: Difficulties obtaining a diagnosis (U)		
Timing is almost everything: parental critique of themselves and others (U)		
Timing is almost everything: parental critique of themselves and others (C)		
The social construction of Anglo parenting in relation to the diagnosis of autism (C)		
Making sense of child differences (U)		
Response of others when the parent brought up concerns (U)		
Barriers to Receiving a Diagnosis (U)		
Barriers to Receiving a Diagnosis (C)		
Barriers to Identification: Professional dismissed parent concerns (U)		
The Diagnostic Experience (C)		
Orientation Phase: Journey to diagnosis (U)		
Engagement in parental advocacy: Seeking help, assessment, and diagnosis (U)		

Perceived provider disregard: Disregard perceived at time of ASD diagnosis (U)		
Access to and barriers to ASD diagnosis (U)		
Something's not right. The process of getting their daughter diagnosed (C)	Encountering HCPs who acted on parents' and guardians' concerns	
Facilitators to acting on concerns. (U)		

ASD, autism spectrum disorder; HCP, healthcare provider

Table 5.3: Synthesized finding 2

Study findings	Categories	Synthesized finding
Evaluation process and diagnosis: A long process with a lot of paperwork (U)	Encountering delays in the assessment and diagnostic process	Parents' and guardians' ability to access ASD diagnostic services for their children is affected by extended waiting times and associated financial burdens, and resulted in frustration, and associated financial impact when delays occurred.
Orienting themselves: Evaluation for formal diagnosis (U)		
Negative experiences accessing mental health services: The waiting game (U)		
Barriers to acting on concerns (U)		
Pursuing a diagnosis: Waiting, worrying, and uncertainty (U)		
Pre-ASD diagnosis: Waiting lists (U)		
Delays and difficulties regarding diagnosis (U)		
Accessing resources (U)		
Getting to diagnosis (C)		
So many barriers (U)	Facing systemic barriers in navigating the pathway to ASD assessment and diagnosis	
Language barriers: Understanding (U)		
Access to ASC (Autism spectrum conditions) assessment and diagnosis (C)		
Problems with the diagnosis and treatment (C)		
Navigating the diagnosis (U)		
Factors affecting access to autism diagnostic services for Diné parents (U)		
Barriers to acting on concerns (C)		

Watchful waiting: Searching for assessment and diagnosis (U)		
Interactions and diagnosis (C)		

ASD, autism spectrum disorder

Table 5.4: Synthesized finding 3

Study findings	Categories	Synthesized finding
Girls have autism too: Girls don't have autism (U)	Encountering HCPs with a lack of specialized knowledge about ASD	Parents' and guardians' ability to access ASD diagnostic services for their children is affected by encountering HCPs lacking specialized knowledge about ASD, contributing to parents' and guardians' confusion surrounding inaccurate or conflicting diagnoses related to ASD comorbidities.
Inadequate formal screening, assessment, and psychoeducational procedures (U)		
Finding the missing piece of the puzzle (U)		
Responsibility and blame: Confusion and disillusionment during early experiences with helping professionals (C)		
Factors affecting access to autism diagnostic services for Diné parents (C)		
Barriers to identification: Professional lack of knowledge about ASDs (U)		
Pre-ASD diagnosis: Knowledge of ASD (C)		
Low societal awareness about ASD: Medical awareness (U)		
Resources and supports (C)		
The mothers' journey with the diagnosis: Delay in diagnosis and initiation of treatment (C)		
Interactions and diagnosis (C)		
Early signs and diagnostic struggles (C)		
Delayed detection of ASD and multiple pathways to the diagnosis: Mixed messages from multiple specialists (U)	Experiencing confusion surrounding inaccurate and, or mixed diagnoses related to ASD comorbidities	
What's going on? Challenges to securing a diagnosis (U)		

So many barriers. Factors that delayed assessment and diagnosis - co-occurring diagnosis. (C)		
Early signs and diagnostic struggle (U)		
Watchful waiting: Inaccurate or missed diagnoses. (U)		
Accessing resources (C)		
Access to and barriers to ASD diagnosis. (C)		

ASD, autism spectrum disorder; HCP, healthcare provider

Chapter 6

General Discussion and Overview

In this chapter, I provide a general discussion and overview of the thesis; a brief reflection on how my research aligned with my ontological and epistemological assumptions; strengths, impacts and limitations of the research; a comparison of study findings with current literature; practice, policy and research implications; and conclusions.

There is a scarcity of academic literature exploring parents' and guardians' experiences in accessing ASD diagnostic services for children, specifically in NL, Canada. The objectives of this thesis were five-fold. The first objective was to examine parents' experiences of accessing ASD diagnostic services for their children in one Canadian province, namely NL and secondly, I wanted to explore the extent to which families' self-described SES affected accessing these services.

To achieve the first two objectives, a research study was conducted using a qualitative research design guided by grounded theory methodology. As a result of the findings from this study, I developed a process model that included three phases that explained parents' experiences of accessing ASD diagnostic services for their children. 'Managing the Wait' was found to be the core strategy parents used throughout the entire process. As presented in Chapter 3, the findings also revealed how SES, parental self-advocacy, and severity of ASD symptoms impacted the overall process of managing the wait, with families having different capacities for managing or shortening the wait depending on these factors.

The third objective was to explore advocacy in parents and caregivers of children and youth diagnosed with ASD. A descriptive exploratory methodology was used to explore and describe parents' experiences in raising a child diagnosed with ASD in relation to advocacy. This

research was extended to include parents living in the four Atlantic Canadian provinces. The specific aim of this study was to understand when, how, and why parents of children and youth diagnosed with ASD engage in parental advocacy and what barriers, if any, they encountered. A thematic representation of findings was developed that illustrates the pathway in parents' advocacy journey as they navigate barriers and supports in medical, educational, and social contexts of their child's environment. Study findings presented in Chapter 4 reveal the barriers faced and the strategies used to overcome some of these challenges in the process of advocating for their children with ASD.

The final two objectives of this thesis were to comprehensively review the best available qualitative evidence about parents' and guardians' experiences accessing ASD diagnostic services and develop recommendations based on this evidence. To achieve these aims, I conducted an extensive review of qualitative evidence following JBI methodology for systematic reviews. Results of this review confirmed findings from the first two studies that were conducted as part of this thesis. Indications were that parents described their journey in accessing ASD assessment and diagnostic services for children as cumbersome. Their journey was impacted by lengthy delays affected by the amount of perceived support and knowledge of HCPs, confusion surrounding inaccurate or mixed diagnoses related to ASD, as well as systemic and contextual barriers in navigating the pathway to ASD assessment and diagnosis that included socioeconomic and cultural disparities.

This thesis is an important academic contribution to the research literature on parents' and guardians' experiences in accessing ASD diagnostic services and supports for children. I was able to capture the complex reality and dynamics in those experiences and provided understanding into the actions and behaviors of parents and guardians in their journey to

accessing ASD services and supports. I have met the objectives of my thesis and produced in-depth and illustrative examples using participants' own words to ensure their voices are heard.

In this thesis, I provided evidence that the intricacy of parents' and guardians' journeys was compounded by the complex and heterogeneous nature of ASD and the pathway to acquiring timely access to ASD assessment and diagnostic services and supports was fraught with challenges. Parents and guardians underwent emotional reactions throughout their journey as they acted on their child's behalf and interacted with others that included HCPs in acquiring necessary ASD services and supports for their children. They took action on their child's behalf, at the same time developing parental advocacy skills as they began to realize the impact of ASD on every part of their lives. See Figure 6.1 for an illustration on my reflections on the interconnectedness of the study findings.

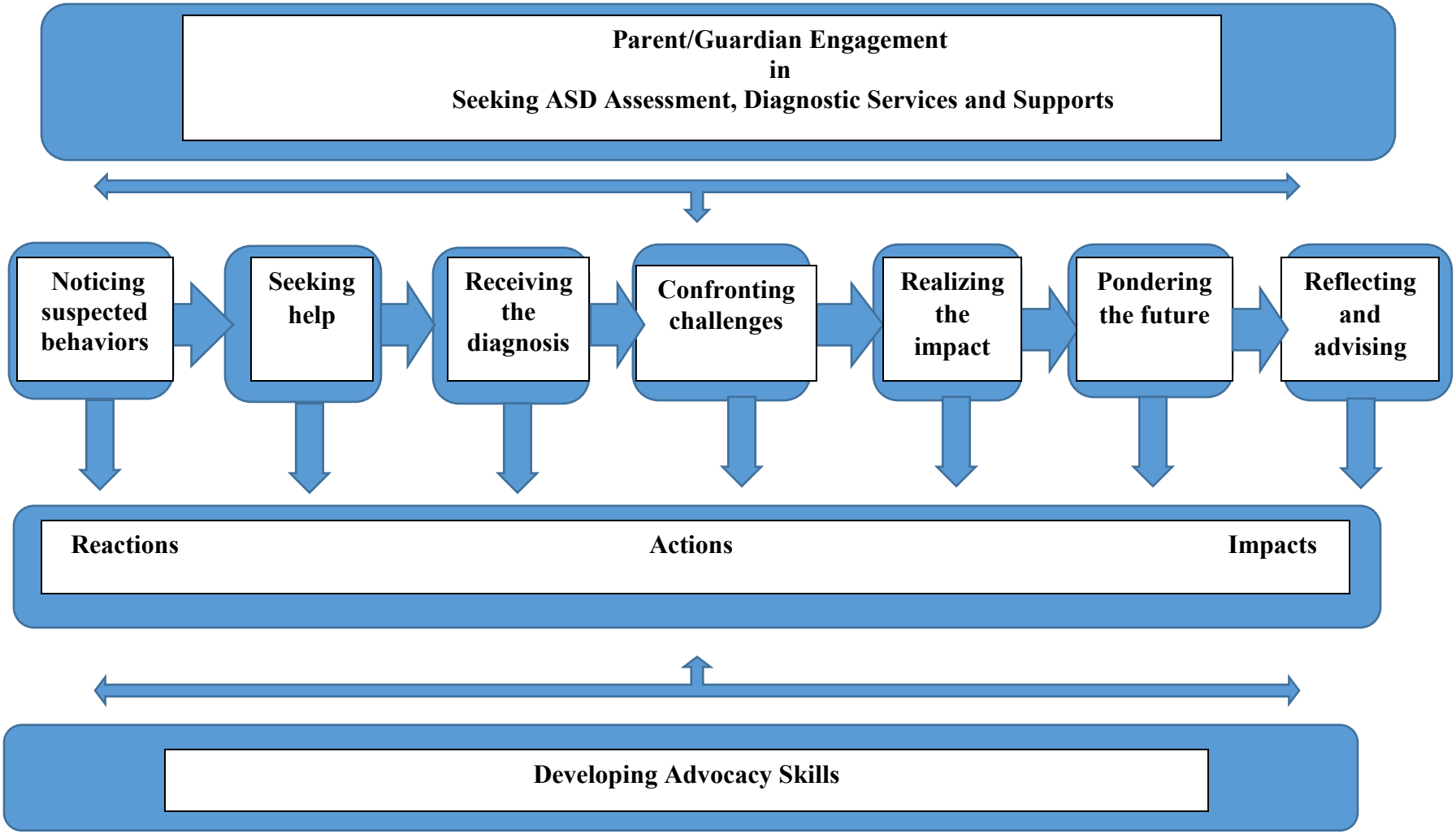

Figure 6.1. Parents' and guardians' journey in seeking ASD assessment, diagnostic services and supports for their children

Research results indicate how wait times play a key role in parents' and guardians' journeys in accessing ASD services and supports for their children. In many jurisdictions around the world, including Canada, a medically confirmed ASD diagnosis opens the door for children to receive tailored interventions and supports that are important for them. However, the demand for ASD diagnostic assessment seems to be outpacing the supply of qualified HCPs and other interdisciplinary team members to perform these assessments, leading to lengthy wait times.

Accessing timely healthcare in general has become increasingly problematic in NL and elsewhere in Canada. According to recent news reports, in Canada, timely access to care continues to be the biggest challenge our healthcare system faces, with perceptions of this problem worsening each year[1,2] and that also includes families waiting for timely ASD assessment and diagnosis.[3,4] The results of the two qualitative studies and the systematic review that were conducted provide evidence that service gaps exist and lengthy waitlists for ASD services are typical both locally and globally.

The complex and often fragmented structure of the health and social service systems in Canada and elsewhere can have unintended negative consequences and costs for families of children with ASD who must navigate them to access appropriate services and supports. Although two of the studies were conducted in local jurisdictions in Atlantic Canada and may be viewed as unique in their sociocultural context, findings from these studies are consistent with the systematic review findings. Apparent from the qualitative systematic review findings in this thesis work is that ASD assessment and diagnostic services are difficult to access in many countries that may be further hindered by the lack of culturally and linguistically appropriate diagnostic tools. This hinders timely access to supportive services for children with ASD. The challenges in accessing ASD services and supports also impede certain cultural and ethnic

groups from acquiring services. It is clear from the findings of this thesis work that the intersection of environmental contexts, such as family, systems, and society influence the journey in accessing ASD services and supports for those affected by ASD. I chose the rainbow symbol to reflect the spectrum of complexity and neurodiversity of ASD as well as the allusion to environmental contexts involved in the journey to ASD assessment and diagnosis that includes family, systems and society (See Figure 6.2).

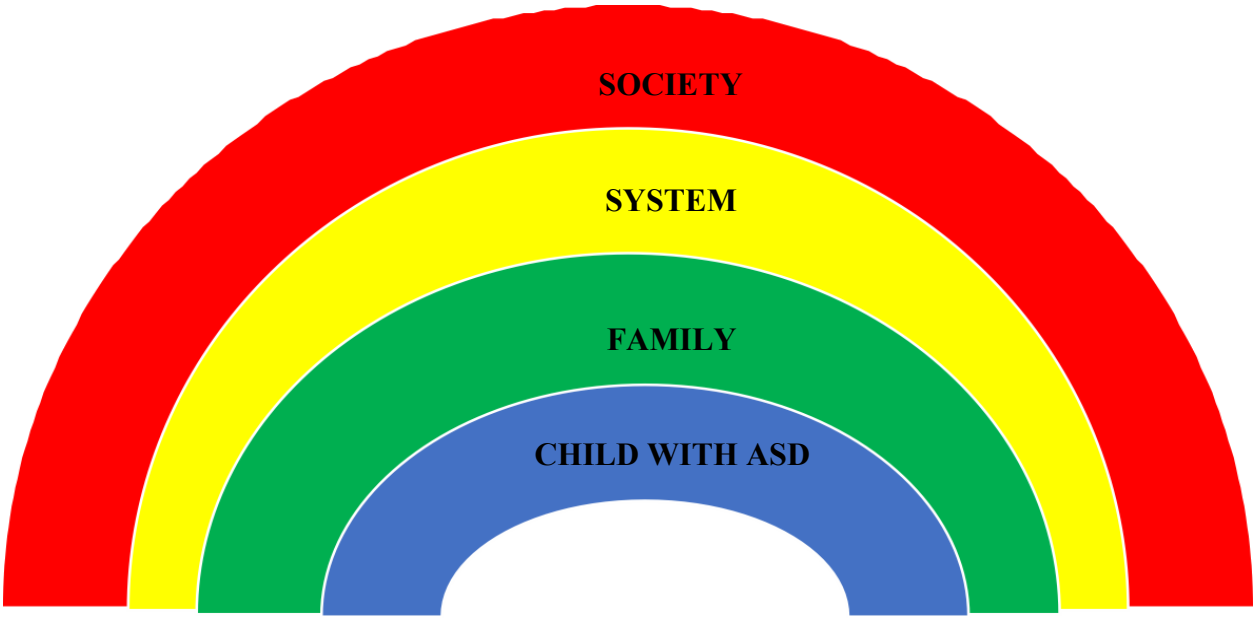

Figure 6.2. The environmental context of parents' and guardians' lifelong journey in accessing ASD assessment, diagnostic services, and supports for their children.

Reflections

My philosophical assumptions as outlined in Chapter 1 were explicit in this thesis. My conceptualization of the research process began with examining the research in the context of my positionality and providing a brief background of my personal history. My educational background and work experience provided valuable insight in understanding and interpreting the

results of this thesis. I provided my stance in relation to my ontological and epistemological assumptions. By using qualitative methodologies in this thesis, I ensured methodological congruence with my philosophical stance. To reflect the multiple realities of the study participants, I used multiple forms of evidence in themes using the actual words of different individuals and presented different perspectives on the topic of interest. This thesis provides a broad understanding of parents' and guardians' experiences in accessing ASD assessment and diagnostic services for their children. In this thesis, I illustrated how my research aligns with my philosophical assumptions by demonstrating how parents and guardians 1) take an active role in responding to challenges they confront; 2) negotiate their social realities by using strategies such as, parental advocacy; 3) make sense of their experiences and provide meaning; and 4) act within an ever-changing environment.

Strengths of the Research

Several strengths can be identified regarding the overall project. The diversity of the methods used to compare the findings and the richness of the data available are the clear strengths. The thematic representations developed is also a strength; for example, the process model of findings developed in the first study, "Managing the Wait" can provide opportunities for researchers to build on that model and develop interventions at pivotal points in that process. Another important strength is that the project provides a comprehensive and meaningful insight of parents' experiences in using their own words to describe their experiences.

Impact of the Research

There is an identified impact of the research conducted in this thesis. The two research studies, published up to this point in time, have been cited extensively. A recent search in Google Scholar revealed 87 citations resulted from the publication of the first study and 36 citations

resulted from publication of the second study. I anticipate the publication of the systematic review publication will provide additional impact to this field of research.

During my PhD program, I presented findings from this thesis on several occasions. By invitation, I presented an overview of the methodologies and findings from the two published research studies conducted in this thesis to 3rd year nursing students in the Faculty of Nursing, Memorial University. I presented findings to the NL Centre for Applied Health Research (NLCAHR) Research and Knowledge Exchange Group on Autism. I provided an online oral presentation of the findings at the Nursing World Conference (5th edition) and an in-person oral presentation at the Canadian Association for Health Services and Policy Research (CAHSPR) Conference. I am presently seeking other opportunities to present my thesis research at local and international conferences.

Limitations of the Research

The research has some limitations. Findings from these studies may not be generalizable to the general population because of the nature of qualitative research design. Our sample for the two qualitative studies was restricted to parents living in Atlantic Canada that may limit the transferability of findings. Although every effort was made to locate and include all eligible studies in the qualitative systematic review, it is possible that studies were missed during the screening process. In addition, a little over half of the included studies originated in high income countries, with the remainder originating in upper-middle income countries and few studies from lower-middle-income or low-income countries, which may be considered a limitation in the available literature.

Comparison of Study Findings with Current Literature

It is important to mention that the systematic review findings from the review conducted as part of this thesis work is the most recent work that looks specifically at parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children. In 2021, an international scoping review of existing evidence about parent or caregiver perceptions of the ASD diagnostic experience was conducted.[5] The findings from this review revealed that more than half the studies used qualitative methodologies and one-quarter of the studies were quantitative questionnaire-based studies.[5] Mixed method studies made up the remaining literature that was reviewed.[5] In addition, there were four qualitative meta-syntheses that were conducted. One of these looked at parental perceptions of caring for a child with ASD,[6] two of these were conducted by the same author and looked at parental perceptions of advocating for their child with ASD[7,8] and another looked at parental experiences of a child receiving a diagnosis of ASD, specifically in the UK.[9]

The findings from this thesis work reveal the journey to ASD assessment and diagnosis was perceived by parents as fraught with delays. Barriers that decreased timely diagnosis included false reassurances or dismissal of concerns as well as missed or inaccurate diagnoses by HCPs are similar to what was indicated in the aforementioned scoping review findings[5] (Note: this review also cited findings from our study conducted in 2020 that is part of this thesis.) Wait times for ASD diagnostic assessment were perceived by parents as a concern in this thesis that has also been evidenced elsewhere.[5]

This thesis provides insight into parents' perceptions of waiting to access timely ASD diagnostic services and supports. Waiting was recognized as a key feature in parents' experiences. The process model of 'Managing the Wait' provides a unique illustration of the

process parents go through in navigating access to ASD diagnostic services for their children. The 2 x 2 typology provides the context of their experiences that illustrates parental strategies in the process of "Managing the Wait". This is also a distinct addition to the research literature on this topic. It illustrates how SES, parental self-advocacy, and severity of ASD symptoms impacts the overall process of managing the wait, with families having different capacities for managing or shortening the waiting depending on these factors.

The concept of 'waiting' for ASD diagnostic services and supports is not new. Autism Alliance of Canada recently reported that "one of the most pressing challenges in ASD assessment and diagnosis in Canada is lengthy wait times".[10] A strategy to reduce wait times was suggested by the Alliance, "reducing wait times should begin with accurate measurements so that data can be compared across regions and various jurisdictions as a means to establish benchmarks, monitor progress, allocate resources effectively. In this way, data findings will highlight barriers and challenges to ultimately improve the efficiency of the healthcare system".[10] Efficiency of the health care system includes society's perceptions of quality of care. According to Donabedian from a health systems perspective, health care needs depend on a match between a clinical assessment as something being medically warranted, what patients want and their willingness to receive care.[11] As HCPs and researchers, we also seek to understand how diagnostic pathways can be improved to improve the quality and efficiency of patient care.

What is clear from this thesis is that parents were often the first to recognize and identify behavioral concerns, that is also reflected in the literature.[12] What was noticeable from the findings is that many parents expressed an overall dissatisfaction with the healthcare system and felt it necessary to become advocates for their children and others. Other researchers have

described how parents of children with disabilities move from being an "advocate" for their own child to becoming an "activist" for all children.[13]

What was obvious from this thesis is that parents reacted to their children's ASD diagnosis with shock, confusion, anger, sadness, and worry. A recent metasynthesis[14] showed similar results where parents have mostly negative emotional responses on receiving an ASD diagnosis for their children. However, findings from this research also indicated that parents have a sense of relief about the ASD diagnosis because they finally have a label for what was going on with their child's development and viewed the diagnosis as a means to obtain interventions and supports for their children in an attempt to reduce problematic behaviors and increase communication skills, comparable to what other researchers have found in other settings.[15]

Social and recreational activities specifically designed to benefit children affected by ASD can be costly.[16] The findings from this research revealed that families often struggle to meet these types of financial challenges, often paying out-of-pocket for activities considered a benefit for their child, that was evidenced elsewhere. [6,14,17,18] Socioeconomic status, environment, and geography have reportedly led to disadvantages for parents of children with ASD.[19] This thesis also highlights that families living in rural communities and single parent families face geographical challenges requiring them to travel long distances to access ASD services only available in urban centers.

This thesis offers a unique thematic representation of the pathway in parental advocacy efforts for children and youth diagnosed with ASD that illustrates when, how, and why parents advocate on behalf of their children as they navigate barriers and supports in health, educational, and social contexts of their child's environment. Through various challenges and uncertainties

faced, they continued their advocacy efforts to acquire services and supports for their children. Parents used their roles as parent advocates as a means to gain access to services in the healthcare and education systems as well as in the community. It is well recognized that parents and guardians of children with ASD and other chronic conditions or disabilities employ advocacy as a management or coping strategy that provides them with a sense of control over the various uncertainties faced.[7-8,20] Evidence from this thesis demonstrates that parents and guardians identified barriers faced in their advocacy work such as, time commitments involved parenting a child with ASD, financial challenges, lack of knowledge and support from service providers, lack of availability of services and system bureaucracies, and perceived stigma related to their child's ASD diagnosis that is consistent with previous findings.[7-8,20-22]

Consistent with the existing literature on this topic, these study findings revealed how parents and guardians are among the first people to notice atypical behaviors early on in a child's development that are consistent with an ASD diagnosis[23-28] and some HCPs may have limited knowledge about ASD or lack training concerning ASD assessment and diagnosis.[23-24,29] Data from this thesis also indicates the confusion parents and guardians experience as they attempt to confirm an ASD diagnosis amidst the competing co-morbidities and lack of HCPs knowledge about ASD that is also reported in other research findings.[6,8,30,31] Several barriers to accessing ASD assessment and diagnostic services that are reflected in our findings that are consistent in the research literature including dismissal of parents' concerns,[8,9,23,25,26,32-37] gender bias,[34,38,39] HCPs taking a 'wait and see' approach before providing referrals for assessment and diagnosis,[30,37,39,40] and enduring multiple consultations and, or receiving multiple and mixed diagnoses for their children before an ASD diagnosis is confirmed.[31]

Practice Implications/Recommendations

There are several practice implications and recommendations from this thesis. It is apparent that parents noticed early signs and symptoms of ASD in their children and identified subtle clues such as limited eye contact, sleep problems, unusual diet, delayed speech, and other related symptoms. HCPs need to recognize parents' expertise in identifying early signs and involve them in the diagnostic process as early as possible.

It is clear from this thesis work that the entire pediatric health workforce needs a good understanding of ASD and how to work with families and children to make each health experience a good one. Receiving the news that a child has ASD can have a profound effect on the family. HCPs need to provide an adequate amount of time to deliver the diagnosis and provide support for parents at the time of diagnosis and afterward. HCPs must also consider parents' financial resources when providing information about treatment and intervention services and provide information to parents about any financial resources that may be available for those who need them.

This thesis highlights the importance of HCPs recognizing parent's input and encouraging their advocacy efforts by including them in the decision-making process and link families to supportive ASD services. For example, family physicians can refer parents to their local or provincial ASD advocacy group (e.g. The Autism Society of Newfoundland and Labrador) to provide information about ASD and assist parents to navigate the ASD delivery system and resources to which they are entitled (e.g., information about provincial or local government programs and services that are available for families). There is a need to provide free community-based programs and services for parents, including ABA therapy, respite care, self-

care services, and parent counseling. Services and supports need to be offered to parents as soon as they suspect symptoms of developmental delays while they are waiting for ASD diagnosis.

Policy Implications/Recommendations

There are several implications/recommendations for policy makers from this thesis. Parents and guardians of children with suspected ASD need improved access to services like physical, speech, and occupational therapy prior to diagnosis to help families get better help sooner. Governments and other funding agencies need to provide more funding to allocate adequate resources to reduce wait times in accessing ASD assessment and diagnostic services. Public and private health insurance providers need to include access to comprehensive ASD services at low or no cost. It is recommended that low-cost in-person and, or online programs be provided for families on waiting lists, such as informational workshops about ASD as well as training and coaching sessions so that effective strategies to help children affected by ASD can be implemented sooner. Government can set up a 1-800 number with qualified and trained professionals to answer questions and concerns about ASD. Finally, there is a need to develop a health monitoring network database to accurately record wait times and service access for individuals with ASD as a means of improving service delivery.

Policies directed at addressing health inequities are in alignment with recent recommendations outlined in the NL Health Accord.[41] Policies arising from this thesis work directly align with the sentiment expressed in the NL Health Accord, that is, "ensuring the voice of lived experience is recognized as essential in all initiatives to bring about a rebalanced health system."[41(p.20)]

Research Implications/Recommendations

As a result of this thesis, it is recommended that further study be conducted to explore the processes by which children with ASD transition into adolescence and adulthood to understand the full impact on families throughout the entire life course of this condition. It is important to address the barriers and challenges that were evidenced in this thesis work. An intervention study might include introducing a patient navigator to assist parents as they move through the ASD assessment, diagnostic and service delivery phases to address any challenges they may face. Since this thesis was focused on the recipients of healthcare, it would also be important to examine the experiences of providers, and policy makers to understand their perspectives on the strengths and limitations of the ASD service delivery system.

Conclusions

This thesis is timely providing a comprehensive view of the topic under study. With increasing ASD prevalence rates, not only in Canada but also around the world, it is important for parents and guardians to obtain timely access to diagnostic and treatment services for affected children, Evidence is clear that early interventions are most effective for the child and their caregivers. It is also important to address the social justice issues faced by these families. The findings from this research highlight many of the barriers families face during their journey in accessing ASD diagnostic services. HCPs who work with parents and guardians of children with ASD need the pre-requisite knowledge and skills for assessment and diagnosis. HCPs also need to be aware of contextual and systemic disparities that may arise as parents and guardians seek ASD assessment and diagnostic services for their children. Advocacy work includes providing a future to make things better for their child as they progress in their ASD journey. Parents and guardians need to be encouraged in their advocacy efforts to support other parents and guardians

navigating the ASD diagnostic process to avoid some of these barriers and have a more positive experience.

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Appendix 1.I: Systematic Review Protocol

Parents' and guardians' experiences of barriers and facilitators in accessing autism spectrum disorder diagnostic services for their children: a systematic review protocol of qualitative evidence

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There is no conflict of interest in this project. *JBI Database of Systematic Reviews and Implementation Reports* 16(5):p 1141-1146, May 2018. | *DOI:* 10.11124/JBISRIR-2017-003437

Abstract

Keywords: Autism spectrum disorder; barriers and facilitators; children; diagnostic services; parents

Review question:

What are parents' and guardians' experiences of barriers and facilitators in accessing autism spectrum disorder diagnostic services for their children?

Introduction

Autism Spectrum Disorder (ASD) is a range of neurodevelopmental disorders identified by the presence of persistent deficits in social interactions and communication, as well as restricted repetitive patterns of behaviors.[1] Autism spectrum disorder is an umbrella term that covers conditions such as childhood autism, atypical autism and Asperger syndrome.[1] The

etiology of ASD is multifactorial.[2] There is a genetic basis for ASD and it is associated with immune dysregulation and inflammation, oxidative stress, environmental toxicant exposures and mitochondrial dysfunction.[3] Older paternal age, complications during pregnancy, premature birth, low birth weight and jaundice in neonates are associated with ASD.[2] Individuals with ASD are at higher risk for other disorders, including fragile X syndrome, allergies, asthma, epilepsy, gastrointestinal disorders, persistent viral infections, feeding disorders, anxiety disorder, bipolar disorder, attention deficit hyperactivity disorder (ADHD), Tourette syndrome, obsessive-compulsive disorder, sensory integration dysfunction, sleeping disorders, immune disorders, autoimmune disorders, neuroinflammation, and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infection.[4]

The economic and social burden of ASD is high. For example, in the United States (US) it was estimated that the total annual direct medical, direct non-medical and productivity costs for ASD in 2015 were US$268 billion, and it is projected that those costs will balloon to US$461 billion by 2025.[5] The most recent published data from the United States indicate that ASD affects one in 66 children in that country.[6] Other developed countries have reported a rising prevalence in autism cases: 65 cases per 10,000 children in Canada, 72 cases per 10,000 children in Sweden, 94 cases per 10,000 children in the United Kingdom, and an alarming 161 cases per 10,000 children in Japan.[6] In developing countries, ASD rates are often underestimated because of under-reporting and under-diagnosis; for example, a recent pilot study indicated that the prevalence of pervasive developmental disorder, which includes ASD, is 27 cases per 10,000 children in Brazil.[7] Globally, in 2010, there were an estimated 52 million cases of ASD or one in 132 persons diagnosed with this disorder.[8]

Diagnostic services are those services organized and provided by physicians for the purpose of providing a diagnosis. Since there is no specific medical test to diagnose ASD, specially trained physicians and psychologists administer ASD-specific behavioral evaluations that may include evaluations from a pediatrician, psychologist, speech and language pathologist, occupational therapist, and geneticist.[9]

ASD is usually detected in early childhood and it can be reliably diagnosed by 18 months of age.[10] However, later diagnosis occurs, especially in children and adolescents who have lower socioeconomic status, are non-White, and exhibit less severe symptoms.[10] Four to five times as many boys are diagnosed with ASD in comparison to girls.[4] This disorder is a lifelong developmental disability that can negatively influence a person's educational and social attainments, as well as employment opportunities. While some people with ASD are able to live independent and productive lives, others have severe dysfunctions and require lifelong care and supportive services. The level of intellectual functioning is extremely variable, extending from profound impairment to superior cognitive skills. Experts agree that early intensive behavioral interventions can positively affect overall health outcomes.[11,12] Earlier diagnosis means more intensive therapy can begin sooner, resulting in improvements in cognitive, language and adaptive skills.[13,14] Despite this, most countries report the median age of ASD diagnosis to be more than 24 months. Canadian data indicate a median age in ASD diagnosis between 39 and 55 months.[15] A study in the United Kingdom reported a median age of diagnosis of 55 months.[16]

A number of barriers in accessing ASD diagnosis have been identified in several primary studies (e.g. stigma;[17,18] living in a rural community;[17,19] transportation issues;[20,21] ineffective screening tools;[18] dismissive, hesitant or unskilled health professionals;[17,22] inadequate insurance coverage;[17,18] cultural/immigrant status;[10,19,23] and difficulty navigating the system[20,21]). Some of

the facilitators in accessing ASD diagnostic services that were identified in primary studies include higher levels of parental education[10,24] and higher socioeconomic status.[10,18,21,24] A good understanding of the barriers and facilitators in accessing ASD diagnostic services gained from a systematic review of the literature could assist healthcare professionals and policy makers in breaking down the barriers to timely diagnosis and early intervention. We completed a preliminary search of databases (PubMed, CINAHL, the *JBI Database of Systematic Reviews and Implementation Reports*, the Cochrane Library, the Campbell Library and PROSPERO) and found that to date, no reviews have been conducted on our phenomenon of interest to our knowledge. Instead, other reviews focused on: barriers and facilitators of parenting programmes for childhood behavior problems;[25] the experience of advocating for a child with autism;[26] lived experience of parents of children with ASD;[27] the experience of parenting or caring for a child with autism;[28-30] parenting stress in parents of children with and without ASD;[31] and early interventions for children with ASD.[32] Furthermore, our phenomenon of interest was not addressed as a subtopic within these previously mentioned reviews. Thus, there are primary studies[17-24] in the literature that have investigated our phenomenon of interest that have yet to be synthesized, which justifies this proposed systematic review.

Inclusion criteria

Participants

The review will consider studies conducted worldwide that include parents and guardians of children up to 18 years of age and who have accessed or who are attempting to access ASD diagnostic services for their children and adolescents on an inpatient or outpatient basis. In some countries, pediatric services go up to the age of 18. The diagnosis of ASD is considered to be a significant life event for families;[33] therefore, we anticipate that their experiences can be

recalled. The studies may also include other participants as well as parents or guardians if the data from the parents or guardians can be separated from the larger sample.

Exclusion criteria

We will exclude all studies that are not written in English or do not have an English translation; studies that include parents/guardians of children over 18 years of age; studies where the parents'/guardians' voices cannot be distinguished from other study participants; and studies where the voices of parents/guardians of children cannot be distinguished from the voices of parents/guardians of children with other diagnoses. Purely quantitative studies will also be excluded.

Phenomena of interest

The phenomenon of interest is parents' and guardians' experiences of barriers and facilitators in accessing ASD diagnostic services for their children and adolescents.

Context

The context for this systematic review is inpatient and outpatient settings in any country worldwide. Regions/countries may have different health system contexts; however, the barriers and facilitators in accessing ASD diagnostic services for parents/guardians of children with ASD could be similar. We will report any differences in parents'/guardians' experiences of barriers and facilitators that can be attributed to dissimilarities in health system contexts (e.g. developed and underdeveloped countries).

Types of studies

This review will consider studies that focus on qualitative data about the experiences of barriers and facilitators for parents and guardians in accessing ASD diagnostic services for their

children and adolescents. These studies include, but are not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Methods

Search strategy

The search strategy will aim to find both published and unpublished studies. An initial limited search of MEDLINE and CINAHL has been undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. This informed the development of a search strategy which will be tailored for each information source. A full search strategy for CINAHL is detailed in Appendix 1.II. The reference list of all studies selected for critical appraisal will be screened for additional studies. Studies published in the English language will be searched and the search will not be limited by publication dates.

Information sources

The databases to be searched include: CINAHL, PubMed, Embase, PsycINFO, Social Services Abstracts and ERIC.

The search for unpublished studies will include: ProQuest Dissertations and Theses, Google Scholar, Google, OpenGrey, and other online resources, including government and organizational websites, such as the International Society for Autism Research and the Centers for Disease Control and Prevention, ASD Research.

Study selection

Following the search, all identified citations will be collated and uploaded into Endnote and duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Studies that meet or could potentially meet the inclusion criteria will be retrieved in full and their details imported into Joanna Briggs

Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI). The full text of selected studies will be retrieved and assessed in detail against the inclusion criteria. Full text studies that do not meet the inclusion criteria will be excluded and reasons for exclusion will be provided in an appendix in the final systematic review report. Studies that meet the inclusion criteria will undergo a process of critical appraisal. The results of the search will be reported in full in the final report and presented in a PRISMA flow diagram. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Assessment of methodological quality

Studies that meet the inclusion criteria will be critically appraised by two independent reviewers at the study level for methodological quality in the review using the JBI Critical Appraisal Checklist for Qualitative Research.[34] Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The results of critical appraisal will be reported in narrative form and in a table.

If there is an insufficient number of high quality studies, then all studies regardless of the results of their methodological quality, will undergo data extraction and synthesis (where possible).

Data extraction

Qualitative data will be extracted by two independent reviewers from papers included in the review using the standardized data extraction tool from JBI SUMARI.[34] The data extracted will include specific details about the populations, context, culture, geographical location, study methods and the phenomena of interest relevant to the review question and specific objectives. Findings, and their illustrations, will be extracted and assigned a level of credibility.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI SUMARI with the meta-aggregation approach.[34] This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning. These categories will then be subjected to a synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Assessing certainty in the findings

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings.[35] The Summary of Findings includes the major elements of the review and details how the ConQual score is developed. Included in the table is the title, population, phenomena of interest and context for the specific review. Each synthesized finding from the review is then presented along with the type of research informing it, a score for dependability, credibility, and the overall ConQual score.

Acknowledgements

We would like to express our sincere thanks to the School of Nursing, Memorial University of Newfoundland for supporting our Joanna Briggs Institute training in systematic reviews.

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Appendix 1.II. Search strategy

CINAHL

(MH "Autistic Disorder" OR MH "Asperger Syndrome" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*)

AND

(MH "Parents" OR MH "Adoptive Parents" OR MH "Foster Parents" OR MH "Fathers" OR MH "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*)

AND

(MH "Diagnosis+" OR MW "di" OR TI diagnos* OR AB diagnos*)

AND

(MH "Qualitative Studies+" OR MH "Phenomenology" OR MH "Audiorecording" OR MH "Focus Groups" OR MH "Interviews+" OR MH "Narratives" OR MH "Observational Methods+" OR MH "Life Experiences" OR MH "Thematic Analysis" OR MH "Parental Attitudes+" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods")

Appendix 5.I: Search strategy

CINAHL Search (EBSCOhost)
Date searched: May 18, 2022

#	Query	Results
S1	MH "Autistic Disorder" OR MH "Asperger Syndrome" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	35,875
S2	MH "Parents" OR MH "Adoptive Parents" OR MH "Foster Parents" OR MH "Fathers" OR MH "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	267,410
S3	MH "Diagnosis+" OR MW "di" OR TI diagnos* OR AB diagnos*	2,538,639
S4	MH "Qualitative Studies+" OR MH "Phenomenology" OR MH "Audiorecording" OR MH "Focus Groups" OR MH "Interviews+" OR MH "Narratives" OR MH "Observational Methods+" OR MH "Life Experiences" OR MH "Thematic Analysis" OR MH "Parental Attitudes+" OR MH "Health Beliefs" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	534,554
S5	S1 AND S2 AND S3 AND S4	1,229

MEDLINE (EBSCOhost)
Date searched: May 18, 2022

#	Query	Results
S1	MH "Asperger Syndrome" OR MH "Autism Spectrum Disorder" OR MH "Autistic Disorder" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	63,441
S2	MH "Parents" OR MH "Fathers" OR MH "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	703,135
S3	MH "Diagnosis" OR MW di OR TI diagnos* OR AB diagnos*	4,372,958
S4	MH "Qualitative Research" OR MH "Grounded Theory" OR MH "Hermeneutics" OR MH "Focus Groups" OR MH "Interviews as Topic" OR MH "Narration" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	645,451
S5	S1 AND S2 AND S3 AND S4	937

Embase
Date searched: May 18, 2022

#	Query	Results
S1	'autism'/de OR 'asperger syndrome'/de OR autism:ab,ti OR autistic:ab,ti OR asperger*:ab,ti	91,828

S2	'parent'/de OR 'adoptive parent'/de OR 'father'/exp OR 'mother'/exp OR parent*:ab,ti OR father*:ab,ti OR mother*:ab,ti OR guardian*:ab,ti	942,254
S3	'diagnosis'/de OR 'delayed diagnosis'/de OR 'early diagnosis'/de OR 'psychiatric diagnosis'/de OR diagnos*:ab,ti	4,760,120
S4	'qualitative research'/exp OR qualitative:ab,ti OR 'interview'/exp OR interview*:ab,ti OR 'grounded theory'/de OR 'attitude to health'/de OR 'focus group':ab,ti OR 'focus groups':ab,ti OR 'mixed method':ab,ti OR 'mixed methods':ab,ti	953,995
S5	S1 AND S2 AND S3 AND S4	1,315

APA PsycINFO (EBSCOhost)

Date searched: May 18, 2022

#	Query	Results
S1	DE "Autism Spectrum Disorders" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	62,052
S2	DE "Parents" OR DE "Adoptive Parents" OR DE "Foster Parents" OR DE "Fathers" OR DE "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	396,508
S3	DE "Diagnosis" OR DE "Differential Diagnosis" OR DE "Medical Diagnosis" OR DE "Psychodiagnosis" OR TI diagnos* OR AB diagnos*	335,779
S4	ZC "qualitative study" OR ZC "focus group" OR ZC "interview" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	665,460
S5	S1 AND S2 AND S3 AND S4	1,544

Eric (EBSCOhost)

Date searched: May 18, 2022

#	Query	Results
S1	DE "Autism" OR DE "Asperger Syndrome" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	17,799
S2	DE "Parents" OR DE "Fathers" OR DE "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	146,561
S3	DE "Clinical Diagnosis" OR TI diagnos* OR AB diagnos*	31,239
S4	DE "Qualitative Research" OR DE "Ethnography" OR DE "Focus Groups" OR DE "Grounded Theory" OR DE "Interviews" OR DE "Semi Structured Interviews" OR DE "Mixed Methods Research" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	206,179
S5	S1 AND S2 AND S3 AND S4	355

Social Services Abstracts (ProQuest)
Date searched: May 18, 2022

#	Query	Results
S1	MAINSUBJECT.EXACT("Autism") OR ti(autism OR austistic OR asperger*) OR ab(autism OR austistic OR asperger*)	877
S2	MAINSUBJECT.EXACT("Parents") OR ti(parent* OR father* OR mother* OR guardian*) OR ab(parent* OR father* OR mother* OR guardian*)	50,886
S3	MAINSUBJECT.EXACT("Diagnosis") OR ti(diagnos*) OR ab(diagnos*)	13,341
S4	MAINSUBJECT.EXACT("Qualitative Methods") OR MAINSUBJECT.EXACT("Grounded Theory") OR ti(qualitative OR interview* OR "mixed method" OR "mixed methods") OR ab(qualitative OR interview* OR "mixed method" OR "mixed methods")	64,957
S5	S1 AND S2 AND S3 AND S4	66

CINAHL Plus (EBSCOhost)
Date searched: June 7, 2023

#	Query	Results
S1	MH "Autistic Disorder" OR MH "Asperger Syndrome" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	37,610
S2	MH "Parents" OR MH "Adoptive Parents" OR MH "Foster Parents" OR MH "Fathers" OR MH "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	281,545
S3	MH "Diagnosis+" OR MW "di" OR TI diagnos* OR AB diagnos*	2,640,007
S4	MH "Qualitative Studies+" OR MH "Phenomenology" OR MH "Audiorecording" OR MH "Focus Groups" OR MH "Interviews+" OR MH "Narratives" OR MH "Observational Methods+" OR MH "Life Experiences" OR MH "Thematic Analysis" OR MH "Parental Attitudes+" OR MH "Health Beliefs" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	567,136
S5	S1 AND S2 AND S3 AND S4	1,333

MEDLINE (EBSCOhost)
Date searched: June 7, 2023

#	Query	Results
S1	MH "Asperger Syndrome" OR MH "Autism Spectrum Disorder" OR MH "Autistic Disorder" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	70,017
S2	MH "Parents" OR MH "Fathers" OR MH "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	746,084
S3	MH "Diagnosis" OR MW di OR TI diagnos* OR AB diagnos*	4,625,940

S4	MH "Qualitative Research" OR MH "Grounded Theory" OR MH "Hermeneutics" OR MH "Focus Groups" OR MH "Interviews as Topic" OR MH "Narration" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	704,540
S5	S1 AND S2 AND S3 AND S4	1,036

Embase

Date searched: June 7, 2023

#	Query	Results
S1	'autism'/de OR 'asperger syndrome'/de OR autism:ab,ti OR autistic:ab,ti OR asperger*:ab,ti	101,543
S2	'parent'/de OR 'adoptive parent'/de OR 'father'/exp OR 'mother'/exp OR parent*:ab,ti OR father*:ab,ti OR mother*:ab,ti OR guardian*:ab,ti	1,002,145
S3	'diagnosis'/de OR 'delayed diagnosis'/de OR 'early diagnosis'/de OR 'psychiatric diagnosis'/de OR diagnos*:ab,ti	5,072,650
S4	'qualitative research'/exp OR qualitative:ab,ti OR 'interview'/exp OR interview*:ab,ti OR 'grounded theory'/de OR 'attitude to health'/de OR 'focus group':ab,ti OR 'focus groups':ab,ti OR 'mixed method':ab,ti OR 'mixed methods':ab,ti	1,037,739
S5	S1 AND S2 AND S3 AND S4	1,459

APA PsycINFO (EBSCOhost)

Date searched: June 7, 2023

#	Query	Results
S1	DE "Autism Spectrum Disorders" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	66,473
S2	DE "Parents" OR DE "Adoptive Parents" OR DE "Foster Parents" OR DE "Fathers" OR DE "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	413,076
S3	DE "Diagnosis" OR DE "Differential Diagnosis" OR DE "Medical Diagnosis" OR DE "Psychodiagnosis" OR TI diagnos* OR AB diagnos*	370,427
S4	ZC "qualitative study" OR ZC "focus group" OR ZC "interview" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	707,729
S5	S1 AND S2 AND S3 AND S4	1,664

Eric (EBSCOhost)
Date searched: June 7, 2023

#	Query	Results
S1	DE "Autism" OR DE "Asperger Syndrome" OR TI autism OR TI autistic OR TI asperger* OR AB autism OR AB autistic OR AB asperger*	18,487
S2	DE "Parents" OR DE "Fathers" OR DE "Mothers" OR TI parent* OR TI father* OR TI mother* OR TI guardian* OR AB parent* OR AB father* OR AB mother* OR AB guardian*	151,924
S3	DE "Clinical Diagnosis" OR TI diagnos* OR AB diagnos*	32,533
S4	DE "Qualitative Research" OR DE "Ethnography" OR DE "Focus Groups" OR DE "Grounded Theory" OR DE "Interviews" OR DE "Semi Structured Interviews" OR DE "Mixed Methods Research" OR TI qualitative OR AB qualitative OR TI interview* OR AB interview* OR TI "mixed method" OR AB "mixed method" OR TI "mixed methods" OR AB "mixed methods"	223,249
S5	S1 AND S2 AND S3 AND S4	391

Social Services Abstracts (ProQuest)
Date searched: June 7, 2023

#	Query	Results
S1	MAINSUBJECT.EXACT("Autism") OR ti(autism OR austistic OR asperger*) OR ab(autism OR austistic OR asperger*)	1,240
S2	MAINSUBJECT.EXACT("Parents") OR ti(parent* OR father* OR mother* OR guardian*) OR ab(parent* OR father* OR mother* OR guardian*)	58,198
S3	MAINSUBJECT.EXACT("Diagnosis") OR ti(diagnos*) OR ab(diagnos*)	16,149
S4	MAINSUBJECT.EXACT("Qualitative Methods") OR MAINSUBJECT.EXACT("Grounded Theory") OR ti(qualitative OR interview* OR "mixed method" OR "mixed methods") OR ab(qualitative OR interview* OR "mixed method" OR "mixed methods")	77,560
S5	S1 AND S2 AND S3 AND S4	81

ProQuest Dissertations and Theses
Date searched: June 7, 2023
Search: (ti(autism OR autistic OR asperger*) OR ab(autism OR autistic OR asperger*)) AND (ti(parent* OR father* OR mother* OR guardian*) OR ab(parent* OR father* OR mother* OR guardian*)) AND (ti(diagnos*) OR ab(diagnos*)) AND (ti(qualitative OR interview* OR "mixed method" OR "mixed methods") OR ab(qualitative OR interview* OR "mixed method" OR "mixed methods"))
406 results

Google Scholar
Date searched: June 8, 2023
Search 1: allintitle: diagnosis autism OR asperger parent OR guardian OR mother OR father -site:.com
40 results

Search 2: diagnosis autism OR asperger parent OR guardian OR mother OR father qualitative -site:.com -site:.gov -site:.org
948 results

Google
Date searched: June 8, 2023
Search: diagnosis autism OR asperger parent OR guardian OR mother OR father qualitative -site:.com filetype:pdf
212 results

OpenGrey
Date searched: June 8, 2023
Not available at time of search run

Government and organizational websites
- National Autism Association: https://nationalautismassociation.org/
- Autism Society of America: https://autismsociety.org/
- Autism Speaks: https://www.autismspeaks.org/
- Autism Canada: https://autismcanada.org/
- Aspect Australia: https://www.autismspectrum.org.au/
- Autism Awareness Australia: https://www.autismawareness.com.au/
- AMAZE: https://www.amaze.org.au/
- Autism CRC: https://www.autismcrc.com.au/
- Asperger/Autism Network (AANE): https://www.aane.org/
- National Autistic Society: https://www.autism.org.uk/

No potentially relevant results

Appendix 5.II: Studies ineligible following full-text review (n=79)

1. Aandersson GW, Miniscalco C, Gillberg N. A 6-year follow-up of children assessed for suspected autism spectrum disorder: parents' experiences of society's support. Neuropsychiatr Dis Treat 2017;13():1783-96.

   Reason for exclusion: No findings relevant to the phenomena of interest.

2. Agnello BA. Coping with autism: The parental journey of adjustment [dissertation]. Minneapolis (MN): Capella University; 2010. 133 p.

   Reason for exclusion: No relevant findings discernible for participants of interest.

3. Acharya S, Sharma K. Lived experiences of mothers raising children with autism in Chitwan District, Nepal. Autism Res Treat 2021. 12 p. Open Access. [cited 2022 Apr 27]. Available at: https://doi.org/10.1155/2021/6614490

   Reason for exclusion: No findings relevant to the phenomena of interest.

4. Anderberg EI. Factors associated with parent reactions to the diagnosis of an autism spectrum disorder [dissertation]. Provo (Utah): Brigham Young University; 2019. 119 p.

   Reason for exclusion: No relevant findings discernible for participants of interest.

5. Bressi RA. Analysis of parental perspectives regarding the diagnostic process for their child with autism. Master of Science [thesis]. Oklahoma City (OK): The University of Oklahoma Health Sciences Center; 2017. 114 p.

   Reason for exclusion: Inclusion criteria not met (age range of children with ASD not specified).

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   Reason for exclusion: No findings relevant to the phenomena of interest.

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   Reason for exclusion: No relevant findings discernible for participants of interest

9. Cane FE. Late(r) diagnosis of ASC: Using parent narratives to understand the contextual factors associated with later diagnosis and its impact on children and families [dissertation]. Birmingham (UK): University of Birmingham; 2015. 221 p.

   Reason for exclusion: No relevant findings discernible for participants of interest.

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    Reason for exclusion: Inclusion criteria not met (not within specified age range of children with autism).

11. Cordy GR. African American parents' experiences with getting their children evaluated for autism spectrum disorder (ASD) [dissertation]. Minneapolis (MN): Capella University; 2022. 162 p.

    Reason for exclusion: No relevant findings discernible for participants of interest.

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    Reason for exclusion: Study methodologies were quantitative.

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    Reason for exclusion: No findings relevant to the phenomena of interest.

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    Reason for exclusion: Not available (effort to contact author unsuccessful).

22. Frye LS. Fathers' experience with autism spectrum disorder [dissertation]. Arlington (TX): University of Texas; 2014. 119 p.

    Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

23. Fuss E. Understanding the parent experience of receiving an early childhood autism diagnosis [dissertation]. Keene (NH): Antioch University New England; 2021. 86 p.

    Reason for exclusion: No relevant findings discernible for participants of interest.

24. Gemegah E. An intersectional approach to black parents' experiences of autism in the UK [dissertation]. London (UK): University of Warwick; 2022. n.p.

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Reason for exclusion: No findings relevant to the phenomena of interest.

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Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

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Reason for exclusion: Inclusion criteria not met (not within specified age range of children with autism).

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Reason for exclusion: Study methodologies were quantitative.

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Reason for exclusion: No findings relevant to the phenomena of interest.

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Reason for exclusion: Inclusion criteria not met (not within specified age range of children with autism).

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Reason for exclusion: Inclusion criteria not met (not within specified age range of children with autism).

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Reason for exclusion: Inclusion criteria not met (not within specified age range of children with autism).

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Reason for exclusion: Inclusion criteria not met (age range of children with ASD not specified).

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Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

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Reason for exclusion: Inclusion criteria not met (not within specified age range of children with autism).

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Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

38. Luelmo P, Sandoval Y, Kasari C. Undocumented Mexican mothers of children with autism: navigating the health care and educational service systems. Int J Dev Disabil 2020; 0(0):1-10.

Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

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Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

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Reason for exclusion: No findings relevant to the phenomena of interest.

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Reason for exclusion: No findings relevant to the phenomena of interest.

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Reason for exclusion: No findings relevant to the phenomena of interest.

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Reason for exclusion: Study methodologies were quantitative.

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Reason for exclusion: No findings relevant to the phenomena of interest.

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    Reason for exclusion: No findings relevant to the phenomena of interest.

46. Mora-Lopez M. Undocumented Latino parents' access to services for their children with autism spectrum disorders: A narrative inquiry [dissertation]. Minneapolis (MN): Northcentral University; 2017. 154 p.

    Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

47. Munro E. "The land of unknown": Mothers waiting for their child's autism assessment [dissertation]. London (UK): City University of London; 2018. 193 p.

    Reason for exclusion: No findings relevant to the phenomena of interest.

48. Mycroft J. 'Being an autism parent': Mothers' experiences from initial concerns about their daughters to a diagnosis of autism spectrum disorder: An interpretative phenomenological analysis [dissertation]. Cardiff (UK): Cardiff University; 2017. 155 p.

    Reason for exclusion: No relevant findings discernible for participants of interest.

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    Reason for exclusion: No findings relevant to the phenomena of interest.

50. Nicolas DB, MacCulloch R, Roberts W, Zwaigenbaum L, McKeever P. Tensions in maternal care for children, youth, and adults with autism spectrum disorder. Glob Qual Nurs Res 2020;7():1-10.

Reason for exclusion: Inclusion criteria not met (not within specified age range for children with autism).

51. Nissenbaum MS. Families' and professionals' perceptions of the interpretive conference when hearing the diagnosis of autism [dissertation]. Lawrence (KS): University of Kansas; 2000. 99 p.

    Reason for exclusion: No findings relevant to the phenomena of interest.

52. Ortiz JL. A generic qualitative inquiry of Hispanic families with a child with autism. [dissertation]. Minneapolis (MN): Capella University; 2023. 144 p.

    Reason for exclusion: Inclusion criteria not met (age range of children with ASD not specified).

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    Reason for exclusion: Inclusion criteria not met (age range of children with ASD not specified).

54. Prasad RC. Fathers' experience of fatherhood when having a child clinically diagnosed with autism: A phenomenological study [dissertation]. San Francisco (CA): California Institute of Integral Studies; 2016. 176 p.

    Reason for exclusion: No findings relevant to the phenomena of interest.

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    Reason for exclusion: No relevant findings discernible for participants of interest.

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Reason for exclusion: No findings relevant to the phenomena of interest.

57. Riley PG. DSM5, Asperger's syndrome diagnosis, and mothers' experiences with mental health services [dissertation]. Minneapolis (MN): Walden University; 2019. 183 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

58. Roberts C. Diagnosis and treatment of autism spectrum disorders: Experiences of Caribbean immigrant families living in the United States [dissertation]. Denton (TX): University of North Texas; 2022. 92 p.

Reason for exclusion: Inclusion criteria not met (age range of children with ASD not specified).

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Reason for exclusion: Study methodologies were quantitative.

60. Rossello E. 'I have What?' A phenomenological inquiry into disclosing a diagnosis of Asperger's disorder to adolescents [dissertation]. Chicago (IL): Chicago School of Professional Psychology; 2017. 167 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

61. Rossi NT. The production of autism diagnoses within an institutional network: Towards a theory of diagnosis [dissertation]. New York (NY): Columbia University; 2012. 277 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

62. Saggu RK. Parental perceptions of the diagnostic process for autism spectrum disorder in British Columbia [dissertation]. Minneapolis (MN): Walden University; 2015. 133 p.
Reason for exclusion: Study methodologies were quantitative.

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Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

65. Schachter MB. Experiences of Jewish American mothers of children with autism spectrum disorder [dissertation]. New York (NY): Yeshiva University; 2023. 148 p.
Reason for exclusion: Inclusion criteria not met (not within specified age range of children with ASD).

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Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

67. Shacar AJ. Parenting an autistic child: A qualitative analysis of parents' perceived needs [dissertation]. Malibu (CA): Pepperdine University; 2007. 81 p.

Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

68. Shardell AR. Parent experiences with early symptoms and diagnosis of children with mild autism and Asperger's syndrome (dissertation]. Minneapolis (MN): Capella University; 2014. 156 p.

Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

69. Slator L. An exploration of parental narratives in the context of a child's diagnosis of autism spectrum disorder [dissertation]. Kent (UK): Canterbury Christ Church University; 2012. 147 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

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Reason for exclusion: Inclusion criteria not met (not within specified age range for children with autism).

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Reason for exclusion: No findings relevant to the phenomena of interest.

72. Sulaimani MF, Mursi NB. Experiences of mothers in dealing with stigma related to their children with autism spectrum disorder in the Saudi context. Prob Educ 21 Century 2022;80(6):851-63.

Reason for exclusion: The findings from this report are from the dissertation by Sulaimani (2018). The dissertation has more detail and is included in this review.

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Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

74. Tyner SM. From diagnosis to intervention: Charting the path with families of young children with autism spectrum disorder [dissertation]. Amherst (MA): University of Massachusetts; 2013. 111 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

75. Varin-Mignano R. The experiences and perceptions of social support by single mothers of children diagnosed with autism spectrum disorder [dissertation]. Garden City (NY): Adelphi University; 2013. 149 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

76. Weaver LJ. "Searching for an answer to make it all better": A grounded theory exploring parental drive for diagnosis: Is it really autism, or a misinterpretation of behavior? [dissertation]. Colchester Essex (UK): University of Essex; 2020, 329 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

77. Wong KK. The experiences of maternal caregivers of children with autism [dissertation]. Manoa (HI): University of Hawaii; 2019. 225 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

78. Wong V, Yu Y, Keyes ML, McGrew JH. Pre-diagnostic and diagnostic stages of autism spectrum disorder: A parent perspective. Child Care Pract 2017;23(2):195-217.

Reason for exclusion: Inclusion criteria not met (age range of children with autism not specified).

79. Woods A. 'Tell me what you think:' An exploration of the lived experiences and views of 'What matters most' to parents of children with autism spectrum disorders who received early intervention [dissertation]. Pasadena (CA): Saybrook University; 2020. 161 p.

Reason for exclusion: No findings relevant to the phenomena of interest.

Appendix 5.III: Study findings and Illustrations

Alsayyari H. Perceptions of Arab American mothers of children with autism spectrum disorder: an exploratory study [dissertation]. Florida, USA: University of South Florida; 2017. 196 p.[40]	
Findings	**Illustrations**
1. Parents' journeys toward the acceptance of the diagnosis of ASD: Period of uncertainty (U)	I was noticing that he was not responding to his name, he does not respond to anyone talking to him. I went to the doctor, and she told me, he is fine. (p.69) I kept asking something is not there. I did not like how her doctor dismissed her very quickly and kept saying, you are over-analyzing, you are over-analyzing. To me as a pediatrician he made me feel that he always knew more than me. (p.69) Nobody encouraged me. Even her own pediatrician. She does not seem like nothing is wrong. And she was running around his office and he was like, no, she does not have anything, just a little hyper. (p.69)
An S, Chan CK, Kaukenova B. Families in transition: parental perspectives of support and services for children with autism in Kazakhstan. Intl J Disabil Dev Educ 2020;67(1):1-17[41]	
1. Delayed detection of ASD and multiple pathways to the diagnosis: Mixed messages from multiple specialists (U)	It is really easy to get confused […] Even if you get to see a psychiatrist, it is not given that s/he will tell you the right thing. In the mental health center I was told, 'why are you slandering your own child? He doesn't have autism'. As if I want to get this diagnosis. […] Then we went to another psychiatrist, he said that autism is a dumping ground, anything can qualify as autism. Basically, everyone has [something that can qualify as] an autistic syndrome, and it is easy to get confused, because you don't know what the truth is. […] No, we don't have any system of detection [of ASD] yet. (p.6) We started walking from specialist to [another] specialist […] So we took [the

	child] to a doctor who examines hearing, then to a psychiatrist, who says that this is schizophrenia. Every specialist we see gives us their own 'two cents'. [A specialist] is not 100 percent sure [in the diagnosis] […]. We spent so much time to figure out what to do […] It took us almost a year to get this diagnosis. (p.7)
Anderson J, Marley C, Gillespie-Smith K, Carter L, MacMahon K. When the mask comes off: mothers' experiences of parenting a daughter with autism spectrum condition. Autism 2020; 24(6):1546-56.[42]	
1. Girls have autism too: Girls don't have autism (U)	People don't believe you exist in the first place, it's the usual 'you don't look autistic' (…) has she got autism, she doesn't look like she's got autism, girls don't have autism. (p.1550) I just wish there was more awareness out there that girls do have it (ASC) as well that you know get it out there that it's not just boys because everybody thinks it's boys. (p.1550) At first she was diagnosed with ADHD and Oppositional Defiant Disorder none of which were actually right. (p.1550)
Bell KM. A phenomenological study of multiple incidence of autism families and school administrator perspectives [dissertation]. North Carolina, USA: North Carolina State University; 2010. 246 p.[43]	
1. Evaluation process and diagnosis: A long process with a lot of paperwork (U)	It was many months before he got a diagnosis. It was just after his second birthday, so this whole process was like a six to eight month period, but it seemed like six to eight years. Because every day I was seeing him, what I thought, getting worse and worse, and nobody had any answers for us. (p.96-7)
Dababnah S, Bulson K. "On the sidelines": access to autism-related services in the West Bank. J Autism Dev Disord 2015;45(1):4124-34.[44]	
1. Inadequate formal screening, assessment, and psychoeducational procedures (U)	We did a scanning, magnetic imaging that showed the size of the cerebellum is smaller

	than normal. So, [the doctor] told me that proves [my child] is autistic. (p.4129)
de Verdier K, Fernell E, Ek U. Blindness and autism: parents' perspectives on diagnostic challenges, support needs and support provision. J Autism Dev Disord 2019;50(6):1921-30.[45]	
1. Finding the missing piece of the puzzle (U)	They blamed all the difficulties on the notion that blind children develop so differently…but it's quite frustrating when the doctors constantly say 'let's wait a year', when you feel that you've tried everything and nothing works, and time just slips through your fingers…we had to wait until we finally had an assessment performed at RCV [Resource Centre Vision], by people who actually knew something about blindness…and then we found out that [s/he] had both autism and intellectual disability. If only we had known this earlier, maybe we could have helped [him/her] in a much better way. (p.1925) These assessments should never be carried out by people who are unexperienced with blind children. That involves too many risks of misconceptions and is not fair, either to us or to the child. (p. 1926)
Ducey RR. Having a child diagnosed with autism: a phenomenological study of mothers' experiences [dissertation]. Colorado, USA; University of Northern Colorado; 2009. 205 p.[46]	
1. Reassurance and denial: Reassurance from pediatricians and family members (U)	Well, we talked to our pediatrician and we were very concerned at 18 months, we were more concerned when he turned two years old, and he said that we could [call a specialist now] or wait three months [until] his two-year checkup…he thought Adam would snap out of it. (p.106) …at his 18-month checkup…we just wanted to make sure, is he on track or not? He said, 'Well, you can get him into early intervention and have him evaluated, but I wouldn't worry about it.' (p.106)

	There were times between two [years] and the time she was diagnosed, and even maybe before that…I would say things to her pediatrician. I would say, "Yanno, she's just not really social, she is just not talking quite [right]…she wouldn't say the normal [words children say at that age]…she would say "paper," like, weird words…And she would say momma and daddy, but I couldn't get her to wave to anybody or get her to tell anybody anything…she's not really eating, she has her certain foods and she will not vary.' And [the pediatrician] …of course, assured me that she was fine, that she would be social and she would talk when she wants to, this, that and the other. (p.106-107)
Finnegan R, Trimble T, Egan J. Irish parents' lived experience of learning about and adapting to their child's autistic spectrum disorder diagnosis and their process of telling their child about their diagnosis. Ir J Psychol 2014;35(2-3):78-90.[47]	
1. Diagnostic experiences: Difficulties obtaining a diagnosis (U)	We were told by the time they were two years and three months old, they were probably autistic. In fact the first diagnosis we got on (child) was that there was absolutely nothing wrong with him, that he was a very bright child, but the second diagnosis said that he had severe autism. (p.82)
Fowler K, O'Connor C. 'I just rolled up my sleeves': Mothers' perspectives on raising girls on the autism spectrum. Autism 2021;25(1):275-87.[48]	
1. What's going on? Challenges to securing a diagnosis (U)	She had her down with having anxiety, and she diagnosed dysgraphia…ADHD, everything bar the word autism…you get answers, but they're not the right ones. (p.279)
Freeman NC, Paradis P. Parent experiences of obtaining an autism diagnosis for their daughter: An interpretative phenomenological analysis. Autism 2023;27(4):1068-78.[49]	
1. Something's not right. The process of getting their daughter diagnosed (C)	Our GP was incredible as well and his son was also on the spectrum, so I had two very knowledgeable people that I trusted who

	were giving me referrals and names. (p.1071) We had these medical professionals who were really aware of what autism looks like in girls that we were able to get the diagnosis. (p.1072)
2. So many barriers. Factors that delayed assessment and diagnosis - co-occurring diagnosis. (C)	I cried when they said it's social anxiety. I'm going, the last two years have not been – it's just not. I cannot explain all that we went through [misdiagnosed] as social anxiety. (p.1072) Our GP referred us to a pediatrician and he flatly stated that girls could not be autistic. (p.1072) They basically blew me off and made me feel like a complete idiot. [One of them said] Oh my gosh, don't be ridiculous, she makes eye contact, she's fine. (p.1072) We went to this psychologist…and she said she doesn't have autism, she does not have autism and I said, well, if you look at the criteria and I tried to get her to talk about it [but] she was just very much – she does not have autism…if it hadn't been for the psychiatrist and these other psychologists [we saw at another clinic] she still probably would be undiagnosed. (p.1072) I went to see a psychologist just for some ADHD sort of executive function stuff and mentioned to her, 'oh my daughter is – it looks like she might be diagnosed with ASD' and she went off on how don't put that label on her, that label is going to hurt her, it's going to stick to her the rest of her life. (p.1072)
3. So many barriers (U)	We're fortunate that we have funds but I know people who want to get diagnosed but they just don't have the money so it isn't –

	it's definitely a barrier so there's real equity issues there. (p.1072-73).
Gonzalez M. Lived experiences of the diagnostic process and symptom interpretation among Puerto Rican mothers with a child with autism spectrum disorder [dissertation]. Gainesville (FL): University of Florida; 2020. 153 p.[50]	
1. Language barriers: Understanding (U)	Regarding the language, you have even more barrier. Like you would like to understand more but you can't. (p.78) I don't think I had any problems or situations because I'm bilingual, but I know for a fact there's like other moms that don't know English that probably have had some kind of trouble at the beginning even answering the questionnaires about milestones and stuff because they just can't read it because they don't know how to in English. So they couldn't read it. They couldn't answer the questions. I've seen it with my own eyes. (p.79)
2. Getting to diagnosis. Mixed messages (C)	When we started mentioning the speech delay, you know but she was like there's not enough research that says that's it's… because of the two languages. So just keep waiting, keep waiting. (p.83)
Hannon MD, Hannon LV. Fathers' orientation to their children's autism diagnosis: a grounded theory study. J Autism Dev Disord 2017;47(7):2265-74.[51]	
1. Orienting Themselves: Evaluation for formal diagnosis (U)	So we took her to a hearing doctor, and the hearing doctor found her behavior quite bizarre, and he worried us a lot. He said, 'There is something wrong with your daughter but it's not hearing, and we, at that point, still didn't have a clue', and he recommended we see a specialist at the hospital in the audio department and a developmental pediatrician. At that point, we had no idea what a developmental pediatrician was and they scheduled us. I do remember that there was quite a wait, and when your kid has an issue, you know, every day seems life forever. I think we had

	to wait like six weeks. We tried to call everybody we knew to see if someone knew somebody, and we finally got a cancellation a few weeks later. They did a full, what I guess would be called a developmental profile. The developmental pediatrician saw her. A speech person saw her. An occupational therapist saw her, and after a little while of observing my daughter they were pretty sure, you know, they called – she had autism. (p. 2269)
Heslip VC. Hispanic mothers' experiences of raising children with moderate to severe autism: a phenomenological study [dissertation]. Minnesota, USA; Capella University; 2009. 128 p.[52]	
1. Responsibility and Blame: Confusion and disillusionment during early experiences with helping professionals (C)	He (autistic child) went to doctors and speech therapists…It was very difficult for us. His eyes were tested. "He is far sighted", that's all they could tell us. The neurologists did all the scans; brain scans. The neurologist…I almost punched her! I almost hit her, because she told me that the only sure thing was that my child is not autistic, because he is too warm in his way with people and he makes good eye contact…She totally put us on the wrong track! (p. 56) The first doctor said I shouldn't bring such a healthy kid into his clinic, because a healthy kid would only get sick (Laughs). The second doctor said that my child was mentally retarded, which is partially true. He is mentally retarded, but only to a certain extent. Most autistic children are, but that is not his primary diagnosis…He went for brain scans. He was 100% fine. His EEG's showed no epilepsy, nothing. So, I sat with this child who looked so healthy and normal and the doctors did not know what was going on. I became very sad during that time. I tried to read books on autism, listen to shows on TV and trying to figure it but that would just upset me even more. (p.57)

	I took her (autistic child) to a Pediatrician one day and he said (imitates an angry, shouting voice), 'Your child has got irreversible brain damage. She's got a brain tumor. You must take her to the hospital right now!'…That was so ugly. It was so terrible…so I took her to see a neurologist after waiting months to get that appointment approved by the insurance, and he said, 'There's nothing wrong with her…just give her some more vitamins and make sure she eats properly'…He took all the blood tests and X-rays and TB and muscular dystrophy and all the rest…but everything came back normal. So, he said, we should just wait. It was so crazy, 'because this one here said she had irreversible brain damage....he was actually right, but you want to believe the good guy, you want to believe the one with the good news…so we did. You know when you on that level of coping with what is happening around you, you don't think. You can't think, 'Is this right, what he said?' Your emotions are so out of it and they just tend to take over. And your hope lies in the people who are meant to know. Now, no hope lies in the people who are meant to know. Everything they say now, I question. (p.55)
Ho HSW, Yi H, Griffiths S, Chan DFY, Murray S. 'Do it yourself' in the parent-professional partnership for the assessment and diagnosis of children with autism spectrum conditions in Hong Kong: a qualitative study. Autism 2014;18(7):832-44.[53]	
1. Access to ASC (autism spectrum conditions) assessment and diagnosis (C)	I went to ask for prices at [Centre A] and I queued for the government one as well. But the government one was very long. It was very hopeless. For [Centre A], the waiting list was half a year. For a private one, [Centre A] is the cheapest one. Then for [Centre B], it was only a 2-week waiting list, so I chose [Centre B]. (p. 837)

	We went to two or three family doctor…I could not accept a doctor telling me nothing was wrong. (p.837)
Hosseinpour A, Younsesi SJ, Azkhosh M, Safi MH, Biglarian A. Exploring challenges and needs of parents providing care to children with autism spectrum disorders: A qualitative study. Iran J Psychiatry Behav Sci 2022;16(3):e127300.[54]	
1. Problems with the diagnosis and treatment (C)	We sought to diagnose the problem way too long until we found out what the problem was. We went wherever we could. Everyone said same: Take him to a speech therapist! Take him to an audiologist! Take him to a neurologist! To everyone, we took him for three or four sessions, come and go, do this test and that test, spend money for this, for that. (p.3)
Jackson L, Keville S, Ludlow AK. Mothers' experiences of accessing mental health care for their child with an autism spectrum disorder. J Child Fam Stud 2020;29(1):534-45.[55]	
1. Negative experiences accessing mental health services: The waiting game (U)	It was terrifying. I didn't know what to do. And I just had to wait…and then wait some more. (p. 535) We were at a crisis point and the referrals take quite long to come through so your […] kind of really struggling at the time and you've still got this, I can't remember how long the wait was but it was quite a few months and […] I need the help now, it was just like what do I do now? How do I get through these next few months? (p. 535)
Kalash LA. Perspectives of parents who have a child diagnosed with an autism spectrum disorder [dissertation]. North Dakota, USA; University of North Dakota; 2009. 113 p.[56]	
1. Early signs and diagnostic struggles (C)	I think a doctor should have done it, saw the red flags. I think that when I took Brandon in to his appointments, they should have noticed it. I think that missing autism is like missing a train wreck. I think somebody should have said, 'Looks like your child has autism." I would have hated them, but I

	think that is their job. I think they should have told me that. Absolutely. (p.48) We went back to the doctor and I told the doctor that I felt bad about diagnosing my child off the TV and I certainly didn't want to do that, but I said, 'Could our child have autism?" I said that I saw this show on 20/20 and Evan acted just like that. He took his glasses off and put them on the table and set his pen down and then he looked at us and said, "Dave, one thing we know for sure is that your son does not have autism." Then he kind of mumbled about autism being the word this week because he already had two other parents in this week thinking their sons had autism. We felt kind of small and wished we hadn't said anything, and out the door we went. We were very, very disappointed with the local medical system here. We just struggled with it. (p.49-50)
2. Early signs and diagnostic struggles (U)	Tommy was seeing our family physician for "attention," but I had a gut feeling he had Asperger's Syndrome. We requested some testing be done…He was diagnosed with ADHD [Attention Deficit Hyper-Activity Disorder], OCD [Obsessive Compulsive Disorder], sensory integration, and language delays. Still in my gut I felt it was Asperger's. Finally, when going into 2nd grade he still had those repetitive behaviors and he still did some very different things. We knew he was attention deficit, and OCD, and had some sensory integration problems. Even though he had all of these things, something just didn't seem quite right. So, then we took him to another doctor to see if it might be Asperger's. At that point I was reading a lot more and dealing with a lot of kids in the school system with Asperger's. The psychologist

	that we took him to confirmed the diagnosis of Asperger's. (p.50)
Kelly KJT. Comparative and critical analysis of parental accounts regarding delayed diagnosis of autism spectrum disorder [dissertation]. Utah, USA: University of Utah; 2017. 249 p.[57]	
1. Timing is almost everything: parental critique of themselves and others (C)	So I was a little concerned that she wasn't doing things as fast as [developmentally] as [my other child]. But every time I mentioned to the doctor…[he said,] 'Oh she's fine, don't worry about [it].' (p. 121)
2. Timing is almost everything: parental critique of themselves and others (U)	I think he's autistic and [the doctor] stated, "No, boys are more delayed"…but nobody would listen to me…I had three referrals done. (p. 122)
3. The social construction of Anglo parenting in relation to the diagnosis of autism (C)	Um, and I just kept asking the doctors, "I think something is wrong with him. I think something. There is just something. And you know they're like, oh you've read too many Jenny [McCarthy] books or you've watched too many doctor films." (p.136)
Lappé M, Lau L, Dudovitz RN, Nelson BB, Karp EA, Kuo AA. The diagnostic odyssey of autism spectrum disorder. Pediatr 2018;141(suppl 4):S272-79.[58]	
1. Making sense of child differences (U)	I would tell [our pediatrician] these things, like little milestones that my son should be hitting. And he's just like, "No, don't worry about it. Boys are late. You overthink everything, you over analyze everything. Just relax, he'll get there." And my mother's intuition was like, "This is not good."' (p.277)
2. Navigating the diagnosis (U)	First, you need to go to your pediatrician and the pediatrician has to make the referral to a specialist, and after you see the specialist, that's when you get the diagnosis added. But that take a while. The only thing I get very, very mad about is the process to get everything done takes so long. Like for my son, I had to wait months to get just an evaluation and I think it's just wasting time…you can't get the services during that

	time, because you don't have the evaluations yet. (p.277) I felt like…when you say I'll have to wait some months, it's killing me, because that is time that my child could be learning or at least you could be evaluating them. You could be doing more testing, but I have to wait months. It is something that I know he already has, it's torture, that we had to wait months. (p.278) The process took almost a year. (p.278)
Lindly OJ, Henderson DE, Vining CB, Running Bear CL, Nozadi SS. "Know your children, who they are, their weakness, and their strongest point": A qualitative study on Diné parent experiences accessing autism services for their children. Int J Environ Res Public Health 2023;20:1-22.[59]	
1. Factors affecting access to autism diagnostic services for Diné parents (U)	I think around the reservation it's harder for Native Americans to get services and to get diagnosis and stuff. (p. 9) Yeah, they [AHCCCS], again, pretty much covered 100% of the costs. I think even up to now, we haven't paid out of pocket for anything. AHCCS pretty much covers his medical costs. (p.11)
2. Factors affecting access to autism diagnostic services for Diné parents (C)	He showed behaviors when he was one and a half and they couldn't officially diagnose him just because they said he was too young…he's four now and he just got diagnosed officially…if somehow it was diagnosed when he was younger, maybe he could have had a lot more interventions. (p.10) I had already [done] some research on [autism], and she did show traits that I did see on YouTube, how autism kids were, and I did see it in her. And then that's when I took her to IHS (Indian Health Service), and they referred us out to Phoenix, and that's when they gave her, that she was diagnosed with autism. (p. 8)

Locke J, Ibanez LV, Posner E, Frederick L, Carpentier P, Stone WL. Parent perceptions about communicating with providers regarding early autism concerns. Pedriatr 2020;145(s1):72-80.[60]	
1. Response of others when the parent brought up concerns (U)	Then, when I went back to our pediatrician, he is, like, 'Well, I didn't think anything was wrong with her.' He was just…I think at that point, I didn't realize it, but I think at that point, he kind of wrote off me and my husband as being overanxious parents.' (p.76)
2. Barriers to acting on concerns (U)	I started being on the waitlist, and I'm, like, 'What am I doing in like the next year?' because the waitlist is, like, a year. (p.76)
Barriers to acting on concerns (C)	I also agree that my pediatrician, why didn't she refer us or say something? We had to wait until the [city] school district actually said something. To me, there is no harm in sending that referral when a parent is saying, 'I am having developmental concerns about my child.' Then, that way, it gets out, and then the parent can do something about it. (p.76) No, I begged the doctor; I talked to her and told her to get me an appointment. So she told me, 'No, you have to find references and etc.' I told her, 'Well I am concerned'; the doctor told me I was exaggerating. (p.76)
3. Facilitators to acting on concerns (U)	Like, if you have the money, you can kind of skip ahead of the lines. (p.76) I found really making that extra effort to network helped get the resources because everybody seems to be booked. (p.76) My pediatrician was very supportive, and we got him to [the center] right away, and we were so lucky. (p.76) And that pediatrician did send me all the surveys concerning 18-mo behavior. And I obviously, when I started filling it out, I saw that there were a lot of other things. And

	then she referred me to an evaluation for hearing and a general evaluation at [the agency]. (p.76)
Lutz HR. Coping with autism during childhood and adulthood: mothers' journey towards adaptation [dissertation]. Pennsylvania, USA: Widener University; 2008. 161 p.[61]	
1. Barriers to Receiving a Diagnosis (U)	…we went to our pediatrician…and our pediatrician dismissed it…and said it was way too young for us to even be coming up with that kind of diagnosis, and everything's fine. How did the pediatrician NOT know? (Sounds exasperated.) How come he didn't SUGGEST going and getting an evaluation cause right there in black and white are all these signs, this checklist and it was almost everything Tory was doing. (p.157)
2. Barriers to Receiving a Diagnosis (C)	I noticed that he seemed not to understand me and was not speaking. He was hyperactive, hard to manage, had temper tantrums, and was pretty destructive. The doctors did not listen to my concerns. I knew a lot about child development…I knew by the way he looked at me he was different. (p.156)
Mann TL. "We didn't really know what was ahead of us." Family experiences with autism identification, diagnosis, and treatment in the policy context [dissertation]. Delaware, USA: University of Delaware; 2013. 216 p.[62]	
1. Barriers to Identification: Professional dismissed parent concerns (U)	And then the doctor kept blowing me off saying, Oh he'll catch up. Oh he'll catch up.' 'No, he really isn't. Like I know babies, and I think I know my child more than you do, who you see once a year pretty much.' So he just kept saying, 'He'll catch up. He'll catch up. He's just, a shy, timid kid.' No, Joseph is not shy. He's not timid. He's not a shy kid. He's not a timid kid. (p.70-71) …the pediatrician that we first started with when we moved back to [Kent County], we were expressing a lot of concerns about development, about language, about feeding, and we got a lot of, 'He was so

	premature. He's been through so much. Let's wait and see. He'll catch up. (p.71) [The doctor only wanted to ever talk to me because, since I'm [in the medical field]. His, his daughter wanted to be [in the same medical field], and he liked to talk doctor stuff to me. So he wasn't interested in my son because he was…busy talking to me. So he would blow it off. He told me his daughter didn't speak until she was like five or six. (p.71) …when we kind of started thinking that Jacob had something, our pediatrician didn't want to push because at the time he was only like two and a half. She said, "You know it's really too early to start screening for anything at this age, because just being so young, maybe he is just a little bit slower in some things and that's normal." Some kids focus on vocabulary before they focus on their motor skills, so maybe he was just doing that. (p.71)
3. Barriers to identification: Professional lack of knowledge about ASDs(U)	She was very unhelpful, basically kicked me out of her office and told me there was something wrong with me…Literally her words were, because I brought up autism and she said, 'He's talking, so therefore he doesn't have autism. Kids who have autism come into my office when they're three years old and they just say 'Muh'.' Those were her exact words. (p.73)
Mulligan J, MacCulloch R, Good B, Nicholas DB. Transparency, hope, and empowerment: A model for partnering with parents of a child with autism spectrum disorder at diagnosis and beyond. Soc Work Ment Health 2012;10(4):311-30.[63]	
1. Pursuing a diagnosis: Waiting, worrying, and uncertainty (U)	We'd been on waiting lists forever…to get a diagnosis, which I think is one of the biggest problems. (p.317)
Newman KL. Navigating motherhood and the state: mothers of children with autism spectrum disorder [dissertation]. New Brunswick, Canada: University of New Brunswick; 2008. 280 p.[64]	

1. Pre-ASD diagnosis: Waiting lists (U)	At two [years old], when he still wasn't saying anything, the doctor said, "Maybe we should refer him to a pediatrician." - which has not yet happened…We're still on the waiting list two years later. (p.72)
2. Pre-ASD diagnosis: Knowledge of ASD (C)	She [the physician] said, "I can't tell you that he has autism"…Pretty much telling me that I have to wait…because she didn't feel comfortable diagnosing him. (p.72)
Perlman J, Howe N. Mothers' experiences of obtaining a diagnosis and support for their child with autism spectrum disorder. Can J Fam Youth 2022;14(3):1-19.[65]	
1. The Diagnostic Experience (C)	He's like 'oh you young parents, you think you know it all. (p.7) He's so young…maybe a little speech impediment but give it a chance he's still young. (p.7-8)
Piepenbring J. A narrative analysis of motherhood and maternal-efficacy among women raising children with ASD [dissertation]. New York, USA: Fordham University; 2017. 156 p.[66]	
1. Orientation Phase: Journey to diagnosis (U)	But pediatricians were not giving me any red flags…and I'd get the, "well he is jealous he has a new little sister, and he is still a little guy himself,' so there is always like a justification. So then I finally ask our pediatrician and he quickly dismissed me – you know, again he met all the milestones, you know, fine and gross motor skills are fine, he is just a really, smart kid that is why, you know, and he has two siblings close in age and all of it was justifiable. So when I would bring that up our pediatrician they really just chalked it all up to "well most children like the predictability, they are learning the world around them." But I was consistently just kind of dismissed. So I started thinking, I am over thinking this or overanalyzing this? I definitely started thinking that; not thinking that I am looking for something that isn't there, just that I am making more of it than I need to. My

	husband would just tell me that I supersensitive and blah, blah, blah, just let it go. (p.52) I mean it's just that so many little things, and all the doctors were like oh well a lot of kids are sensory, a lot of kinds are sensory and I was just like, okay. They said "Oh! He is so way too verbal and he has a high IQ" and I think they thought the sibling thing – and yeah I mean I was dismissed. (p.52)
Preece D. There isn't really anything around here…": autism, education and the experience of families living in rural coastal England. Educ Sci 2021;11(1):397-411.[67]	
1. Delays and difficulties regarding diagnosis (U)	He was on the pathway to being assessed, but still fifteen or eighteen months down the line, nobody had seen him; there was nothing happening, and things were becoming really bad at home. He was on full school refusal at this point; it was just dreadful. (p.405)
Shattnawi KK. Bani WM, Al-Natour A, Al-Hammouri MM, Al-Azzam M, Joseph RA. Parenting a chld with autism spectrum disorder: perspective of Jordanian mothers. J Transcult Nurs 2021;32(5):474-83.[68]	
1. The mothers' journeys with the diagnosis: Delay in diagnosis and initiation of treatment (C)	I started noticing that there is something wrong when she was a year and a half old. I thought it was a hearing problem. But hearing tests were normal. The nurse who did the test advised me to go to a psychiatric clinic because she thought that it might be a psychiatric problem. I took her to a psychiatrist in the same hospital, but he told me that my daughter is 100% normal. But the problem remained, and we returned after a year to a doctor in Al-Medina hospital, where they finally diagnosed her with autism. (p.478)
Smith-Young J, Chafe R, Audas R. "Managing the wait": parents' experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with autism spectrum disorder. Health Serv Insights 2020;13(1):1-10.[69]	
1. Watchful waiting: Searching for assessment and diagnosis (U)	[We] waited eight months to get into speech…the speech language pathologist was the first one that even hinted that there

	could be something. She suggested that we go to get tested for autism…it was 19 months [on the wait list] from the time we started; [it] was 36 months when he got his diagnosis. (p.4) We noticed it when he was around 19 months…We got him referred when he was around 24 months…It took about eight months to get in for testing. We went three times for testing...He was almost four years old when he got diagnosed. (p.4)
2. Watchful waiting: Inaccurate or missed diagnosis (U)	He wasn't meeting his milestones as a baby…they always said, "He's just a very quiet baby and when he's two years old he'll be perfect just give him some time. He's a bit slower." So I never thought anything of it…Then the pediatrician wanted to check for muscular dystrophy and cerebral palsy…Then we started all these very intrusive diagnostic tests…muscular dystrophy was ruled out, cerebral palsy was ruled out…saw the top pediatric neurologist in Canada and we did genetic counselling…global delay…Now he's diagnosed with autism. (p.4)
Smith-Young J, Chafe R, Audas R, Gustafson DL. "I know how to advocate": parents' experiences in advocating for children and youth diagnosed with autism spectrum disorder. Health Serv Insights 2022;15(1):1-11.[70]	
1. Engagement in parental advocacy: Seeking help, assessment, and diagnosis (U)	He [pediatrician] was like, well, wait and see over the next – because he was so young – over the next three to six months and I was like, 'Are you…kidding me? You just told me you think my kid might have autism, I'm not doing the wait and see approach'…I went home and called [another pediatrician] and she booked us in like two weeks later – so we saw her within two weeks and she did the Autism Diagnostic Observation Schedule on the spot…she did the full testing at the initial visit and gave us the diagnosis…for sure we

	hopped the queue because until you get a diagnosis you don't have access to autism intervention…if I wasn't aggressive, if I hadn't called them, it would probably have taken another 6 to 12 months I would say. (p 5) I have a minor in psychology, so I was familiar with child development, and I just noticed he wasn't hitting his milestones and seeing our General Practitioner you know, it's the typical story – boys don't develop as quickly as girls…a wait and see basis. (p.7-8)
Sulaimani MF. A phenomenological study of mothers' experiences navigating issues of stigma related to autism in the context of Saudi Arabia [dissertation]. Ohio, USA: Ohio University; 2018. 201 p.[71]	
1. Accessing resources (C)	So he diagnosed him with learning difficulties. I wasn't convinced with what he said because at that time I had already started searching extensively about autism. (p.91) They told me different diagnoses and different opinions. (p.91) I went to hospitals to get him checked and I went to centers for diagnosis. However, I got different and contradicting diagnoses. (p.91) He said that it wasn't autism but ADHD [attention deficit hyperactivity disorder] but I didn't believe him. Then I took him to a hospital and two of the doctors said that he has autism, not ADHD. (p.92)
2. Accessing resources (U)	It is difficult to get an appointment or even talk to the doctor. It takes two months or more to get a turn. They are not good with timing. (p.142)
Templeman CP. Parent satisfaction with family professional partnerships and services for children with autism spectrum disorder [dissertation]. Arizona, USA: Northern Arizona University; 2019. 206 p.[72]	

1. Perceived provider disregard: Disregard perceived at time of ASD diagnosis (U)	Our first trip to be diagnosed wasn't very pleasant, as we were just blown off and told that it was normal for her at her age to be acting the way she was. Our concerns were not taken into consideration, and we left absolutely devastated and looking for more answers than we had come in with. (p. 111-112)
Truett AR. "It is difficult, but you experience a beautiful thing"; perspectives of Latina/O parents on autism [dissertation]. New Jersey, USA: Seton Hall University; 2012. 161 p.[73]	
1. Interactions and diagnosis: Culture (C)	The only, the only [laughs]…something we faced was calling [specialist] and she said like "well if you are on AHCCCS (Arizona Health Care Cost Containment System – Medicaid], you are going to wait." She like immediately labeled me, because of my last name. I told her that I don't have AHCCCS and she said "what do you have" and I said "Tricare." And she said, I still have to wait three months and I said…but I was very professional, I said "no, I don't have to wait, I have other options, thank you" and I left it at that. Hum yeah. I feel bad for the parents that have to go through that. (p.74)
2. Interactions and diagnosis (C)	And we were struggling, because I took him to the pediatrician there in the office and I told them about his problems, that he doesn't hear me, all about him not being okay because he didn't speak, he didn't interact with all the other children or with his brother, so he was all by himself…I told the doctor all of that and she told me, 'No there's nothing wrong with him. There's nothing wrong with him.' And I got upset with the doctor and I told her, "I need you to give me a referral'…she told me, I'm going to give you one, but there is nothing wrong with your son.' (p.86-87)

3. Resources and Supports (C)	I think over there. In some places over here in the United States, if they are very…um…we have a saying over there in Spanish, they say "en panelas" like in diapers. It's over there in Mexico, too. It's like that. They are in diapers with autism. They are, they don't have any er that much knowledge and you can see it in the doctors…Doctor er neurologist is the one that give you diagnosis. I mean and he a doctor, but doesn't know anything about psychology so I mean it's hard. I don't know, the people also, they don't have that much knowledge. Like I told you just common, common people and if they heard the word autism you [intake of break] they get scared you know, but because they don't know. (p.96)
Ulofoshio J. Lived experiences of mothers raising children with autism spectrum disorder in Nigeria [dissertation]. Minnesota, USA. Walden University; 2018. 168 p.[74]	
1. Low societal awareness about ASD: Medical awareness (U)	When I had my experience, there was no awareness as to what autism was. I took him to the hospital to see the pediatrician but at the time nobody knew anything about autism, they thought it was nervous problem. We went to a psychiatric hospital, nobody knew it was autism, even there. (p.78-79) Getting to the hospital the big word autism was suggested but not confirmed. From then on, I began really trying to know what actually made her different from the regular child. I was asking so many questions that the doctors couldn't answer. It didn't even seem like the doctors knew much about the autism because the first time it was from a book that the doctor tried to find the word autism to explain to me. Then many hospitals after that, from hospital to hospital, many said she couldn't have autism because she seems to do a lot of things right. Many said it has to be autism,

	if it is not autism what could it be? So most of the early stages I spent trying to find out what is actually wrong. (p.79) At first, I thought he couldn't hear well, so I went for audiology test, on getting there after checking it they said he might be autistic. On visiting the neurologist, he said, he [son] doesn't look autistic to him. In fact, I had very conflicting results, so I had to take my son to the US. On getting to the US it was confirmed that he is autistic. (p.80) We went to see a pediatrician and he said, 'Madam, he is fine. You are just comparing him with your other son that is why you think there is something wrong.' I insisted that I needed to see a neurologist. I needed an evaluation done. He [the neurologist] said everything was fine, it was almost like: what is wrong with you, madam? He said, 'Your child is fine. You can go.' We turned to leave and my son just came down and jumped on the doctor's table and his laptop was on the floor and everything and the doctor said, 'Oh, okay madam, come back, this is ADHD (Attention Deficit Hyperactivity Disorder)'. I said, 'ADHD, there should be at least some level of speech' but at that time there was no speech. So we had to travel with him, we went to the UK and we saw a doctor and the doctor said, 'This is autism.' (p.79) I went to the hospital and I spoke with his doctor and the doctor was like, "no, no, no" That most of the time when a child is on the spectrum, the child is born like that, and he didn't even understand it's autism spectrum. He said: I have been taking care of him for years so obviously, we don't have a problem." (p.80)
Vanegas SB, Xu Y, Magaña S, Heller T. "You had this clean window, but it was glued shut": Identifying the needs of parents and providers of children and youth with	

autism spectrum disorders in rural areas through a life course perspective. J Dev Phys Disabil 2023;35:247-71.[75]	
1. Access to and barriers to ASD diagnoses (C)	So, then we went for a second opinion, we went to [local university clinic]. [Local university clinic] was like, 'No I don't think he is on the spectrum, I think he has apraxia.' So he had two different diagnoses. And then we went to [other] hospital in [Indiana] where they did have a multidisciplinary team, and they said, 'They are both right, he does have apraxia and he does have autism, but this is what you need to do. (p. 255,257)
Access to and barriers to ASD diagnosis (U)	My pediatrician was wait and see. It was like, 'let's just wait and see'. And I am like 'no, let's not wait and see'. (p. 256)

Appendix 5.IV: Studies excluded on methodological quality (n=46)

1. Avdi E, Griffin C, Brough S. Parents' construction of the 'problem' during assessment and diagnosis of their child for an autistic spectrum disorder. J Health Psychol 2000;5(2):241-54.

   Reason for exclusion: Influence of researcher on research and vice-versa not addressed; participant voices not adequately represented; ethical approval not addressed.

2. Bloch JR, Gardner M. Accessing a diagnosis for a child with an autism spectrum disorder: the burden is on the caregiver. Am J Nurse Pract 2007;11(8):10-7.

   Reason for exclusion: Influence of researcher on research and vice-versa not addressed.

3. Braiden H-J, Bothwell J, Duffy J. Parents' experiences of the diagnostic process for autistic spectrum disorders. Child Care Pract 2010;16(4):377-89.

   Reason for exclusion: Participant voices not adequately represented; ethical approval not addressed; lack of flow between conclusions and interpretation of data.

4. Carinci GJ. Experiences of caregivers with an autistic child: Understanding perspectives related to prenatal participation and involvement [dissertation]. San Diego (CA): Alliant International University; 2008. 192 p.

   Reason for exclusion: Influence of researcher on research and vice-versa not addressed; participant voices not adequately represented.

5. Chamak B, Bonniau B. Changes in the diagnosis of autism: How parents and professionals act and react in France. Cult Med Psychiatry 2013;37(3):405-26.

   Reason for exclusion: Influence of research on research and vice-versa not addressed; participant voices not adequately represented; ethical approval not addressed.

6. Chao KY, Chang HL, Chin WC, Li HM, Chen SH. How Taiwanese parents of children with autism spectrum disorder experience the process of obtaining a diagnosis: A descriptive phenomenological analysis. Autism 2018;22(4):388-400.
Reason for exclusion: Influence of research on research and vice-versa not addressed.

7. Chavez AE, Feldman MS, Carter AS, Eisenhower A, Mackie TI, Ramella L, *et al.* Delays in autism diagnosis for U.S. Spanish-speaking families: The contribution of appointment availability. Evid Based Pract Child Adolesc Ment Health 2022;7(2):275-93.
Reason for exclusion: Lack of congruity between research methodology and analysis; Influence of research on research and vice-versa not addressed.

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Appendix 5.V: Characteristics of included studies

Study, year, country	Methods for data collection and analysis	Phenomena of interest	Setting/context/culture	Participants and sample size	Broad research findings relevant to the systematic review question
Alsayyari,[40]2017 United States	Doctoral dissertation The methodology is described as a qualitative interview study using an interpretative approach. Face-to-face semi-structured interviews were conducted and transcribed.	The experiences of Arab American parents of children with ASD with their child's diagnosis and how it affected their reactions and help-seeking behaviors	Participants were described as Arab American from a Muslim religious background currently living in a city in a southeastern US state. Participants' countries of origin included: Palestine, Jordan and Egypt.	Five parents (mothers and fathers) of children with ASD. Out of the 5 children with ASD, there were 3 girls and 2 boys between the ages of 7 to 13 years	Six themes with sub-themes; 2 themes and sub-themes with findings relevant for this review: Parent's journeys toward the acceptance of the diagnosis of ASD (period of uncertainty) and needs (need for improvement in services and therapies).
An S *et al*., [41]2018 Republic of Kazakhstan	The methodology is described as exploratory qualitative research design. Focus group interviews (n=2) using an interview guide conducted in Russian (audio-recorded and transcribed in Russian and English). Open coding and axial coding procedures guided analysis.	Family caregivers' perspectives on the availability and accessibility of health care, educational and social services for children with ASD	Focus groups took place in two major cities of Kazakhstan: Astana and Almaty. These 2 cities were chosen because they have active informal networks of parents who reported having children with ASD, as well as recently established social service centers for children with ASD. In Almaty, study participants were found with the assistance of a parents' autism advocacy NGO. In Astana, participants were invited from an informal parental network of parents of children with ASD.	Seventeen parents (16 mothers and 1 father) who reported having children with ASD, including 9 parents in Almaty and 8 parents in Astana. Out of the 16 children with ASD, there were 3 girls and 13 boys between the ages of 3 and 13 years	Four categories with themes; 1 category and theme with findings relevant for this review: delayed detection of ASD and multiple pathways to the diagnosis (mixed messages from multiple specialists).
Anderson *et al.*[42], 2020. United Kingdom	Phenomenology with face-to face or via Skype open-ended interviews (audio-taped and transcribed) and interpretative phenomenological analysis.	Mothers' lived experiences of parenting a daughter with autism spectrum condition, with a specific focus on female autism spectrum condition presentation and the diagnostic process	Participants were White, British, English-speaking and currently living in the UK.	Ten mothers who had daughters diagnosed with ASD or a variation (autism, Asperger's syndrome). The age range of daughters was between 12 and 18 years	Five super-ordinate themes and various subthemes; 1 super-ordinate theme and 1 subtheme with findings relevant for this review: Girls have autism too ("girls don't have autism").

Bell,[43] 2010 United States	Doctoral dissertation Qualitative approach using hermeneutic phenomenology via face-to-face, semi-structured interviews (audio-recorded and transcribed) and phenomenological analysis. There is a mixed sample of parents and school administrators; only parent interviews are relevant to this review.	The experience of families who have more than 1 child with ASD and perceptions of school administrators (school principals) who have worked with these families	Parent interviews took place in parents' homes in North Carolina's Research Triangle area (consisting of Raleigh, Durham and Chapel Hill), a region that provides diagnostic and treatment services for individuals with autism.	Four families (3 fathers and 4 mothers) of children with ASD Family 1: 3 sons (aged 10-13 years) with ASD Family 2: 4 sons (aged 3 to 7 ½ years) with ASD Family 3: 2 sons (aged 15 and 17 years) with ASD Family 4: 2 sons and 1 daughter (aged 12 to 18 years) with ASD	Eight themes and various subthemes; 1 theme and sub-theme with findings relevant for this review: Evaluation process and diagnosis ("A long process with a lot of paperwork").
Dababnah and Bulson,[44] 2015 Palestine	The methodology is described as qualitative research design using grounded theory approach via face-to-face, semi-structured focus groups (n=4) and individual interviews (n=11) Interviews were audio-recorded, transcribed, and translated from Arabic to English by a native Arabic speaker with complete English fluency.	Parents' experiences of access to ASD-related services for their children	Palestinian parents were living in the West Bank and East Jerusalem in the Middle East (Ramallah, Nablus, Hebron, and nearby refugee camps and villages). Participants spoke Arabic, with the exception of 1 parent who spoke Arabic-English mixture.	Twenty-four parents (20 mothers and 4 fathers) of children between the ages of 4 and 17 years with ASD	Five themes; 1 theme relevant for this review: Inadequate formal screening, assessment, and psychoeducational procedures.
de Verdier *et al.,*[45] 2019. Sweden	The methodology is described as a qualitative interview-based design (audio-recorded and transcribed) and inductive thematic analysis.	Parents' experiences of having a child with blindness in combination with ASD, with or without intellectual disability and the support needs of the parents and support provided to them concerning the child's disabilities	Participants were living in rural and urban areas of Sweden.	8 parents (5 mothers and 3 fathers), representing 6 children with blindness and ASD	Five themes; 1 theme relevant for this review: Finding the missing piece of the puzzle.

Ducey,[46] 2009 United States	Doctoral dissertation Phenomenological approach to data collection and analysis via face-to-face, semi-structured interviews (audio-recorded and transcribed).	The experience of parents prior to and during the diagnostic process for autism	Participants were living in the New England area of the US (n=3) and southeastern region of US (n=1).	4 mothers of children (3 boys and 1 girl) with autism between the ages of 3 and 6 years	Six main themes; 1 theme and 1 sub-theme relevant for this review: reassurance and denial: Reassurance from pediatricians and family members.
Finnegan *et al.,*[47] 2014 United Kingdom	Qualitative approach using interpretative phenomenological analysis using semi-structured interviews (audio-recorded and transcribed).	Parents' experiences of receiving and adjusting to a diagnosis and sharing the diagnosis with their children	Participants were living in Ireland, UK. Interviews took place in participants' homes.	Seven parents (6 mothers and 1 father) of children (all males) between the ages of 8 and 16 years with Asperger's syndrome or high-functioning autism	Three main themes; 1 theme and sub-theme relevant for this review: Diagnostic experiences: Difficulties obtaining diagnosis.
Fowler and O'Connor,[48] 2021 United Kingdom	Phenomenological approach using inductive thematic analysis via semi-structured interviews (audio-recorded and transcribed). Interviews were conducted face-to-face (n=12), by video-call (n=4), and phone (n=3).	Mothers' experiences and perceptions regarding diagnostic processes, autism presentation in girls, and impacts of raising a daughter with autism	Participants were living in urban and rural locations across Ireland, UK.	19 Irish mothers of girls aged between 7 and 18 years with autism	Six main themes; 1 theme and 2 sub-themes relevant for this review: What's going on: Challenges to securing a diagnosis and Diagnostic and service difficulties.
Freeman and Paradis,[49] 2023 Australia	Phenomenological approach using interpretative phenomenological analysis; face-to-face semi-structured interviews (n=5) (audio-recorded and transcribed) were conducted lasting approximately 75 minutes.	To understand the lived experience of parents when their daughter undertakes an autism assessment	Participants were White; ethnic backgrounds included Australian (n=4), German (n=1), Ukrainian (n=1), French (n=1), and English (n=1). Participants were of mid-to high socioeconomic status. Participants were living in Australia in 3 states of Australia. Interviews took place in a quiet meeting room that was convenient for the participant and interviewer.	8 parents (6 mothers and 2 fathers) of daughters (aged between 6 and 18 years) with autism	Three themes; 2 themes and sub-themes relevant for this review: 'Something's not right' the process of getting their daughter diagnosed ('When it comes to health professionals, it's who you know'); 'So many barriers' factors that delayed assessment and diagnosis ('Just please recognize what's going on here'; 'We should avoid that label'; 'It was extremely

					expensive even with Medicare'.
Gonzalez,[50] 2020. United States	Doctoral dissertation Qualitative phenomenological research approach to data collection and analysis; field notes. Interviews (open-ended) took place (in-person (n=1) or via Zoom (=3) (audio-recorded and transcribed).	To understand, interpret, and present Puerto Rican mothers' lived experiences of the diagnostic process and symptom interpretation of their child with autism	Participants were living in North Florida. All participants were born in Puerto Rico and spoke English and Spanish.	Three families (4 mothers; 2 mothers from the same family) of 4 girls (aged 4 years) and 1 boy (aged 5 years) with autism	Five themes: 2 themes relevant for this review: Language barriers (Understanding) and Getting to Diagnosis (Mixed messages).
Hannon and Hannon,[51] 2017 United States	Qualitative approach using grounded theory research design via semi-structured interviews (face-to-face or web-based ie, Skype, Google Hangout).	The process of fathers learning about their children's autism diagnoses	The majority of participants identified themselves as White (n=12) or White and Jewish, White and Spanish, or White and Arab-American; 1 participant identified as Black. All were English-speaking and living in the northeastern region of the United States.	16 fathers of children with autism between the ages of 1.5 years to 36 years. (Only fathers of children [aged up to 18 years] are relevant and included in the findings of this review.)	Two parts: Orienting themselves and orienting others and 5 phases; 1 part and 1 phase relevant for this review: Orienting themselves: Research and education activities.
Heslip,[52] 2009 United States	Doctoral dissertation Phenomenological method of data collection and analysis via semi-structured interviews (face-to-face).	Hispanic mothers' experiences of raising a child with moderate to severe autism before and after diagnosis	Participants were living in a Hispanic community, able to communicate in English and living in southern California in the US.	Five mothers of children (1 girl and 4 boys aged between 5 and 12 years) diagnosed with moderate to severe autism	Eight main themes and various sub-themes; 1 theme and sub-theme relevant for this review: Responsibility and blame: Confusion and disillusionment during early experiences with helping professionals.
Ho *et al.,*[53] 2014 China	Interpretative phenomenological method of data collection and analysis via semi-structured interviews (audio-recorded and transcribed).	Assessment and treatment experiences of Chinese parents of children with autism spectrum condition (ASC) focusing on the contextual factors of parent-professional partnership (PPP) in the region	Participants were living in Hong Kong, China.	Ten parents (7 mothers and 3 fathers) of children (9 boys and 2 girls) with autism (aged between 2 and 11 years)	Five themes; 4 themes relevant for this review: Access to ASC assessment and diagnosis; Multiple procedures of the ASC assessment; Consultation prior to ASC diagnosis and assessment; and the interpretive

					session: communication with doctors about the ASC assessment.
Hosseinpour *et al.,*[54] 2022 Iran	Exploratory qualitative methodology; semi-structured, face-to-face and telephone interviews (lasting between 45 and 90 minutes) (audio-recorded and transcribed); content analysis.	Challenges and needs of parents caring for children with ASD	Participants were living in Tehran, Iran.	18 parents (67% mothers) of children (13 sons and 4 daughters (mean age 7.92 ± 7.8 years) with ASD	Three themes and various sub-themes; 1 theme relevant for this review: Issues and problems related to diagnosis, treatment, and rehabilitation (Problems with the diagnosis and treatment).
Jackson *et al.,*[55] 2019 United Kingdom	Interpretative phenomenological method of data collection and analysis via semi-structured interviews (face-to-face).	Parents' experiences of gaining access to mental health services for their child with ASD and mental health comorbidity	Participants lived in a southeastern county in England in the UK.	7 mothers of children with ASD aged between the ages of 11 and 15 years	Three themes with various sub-themes; 1 theme and sub-theme relevant for this review: Negative experiences accessing mental health services: The waiting game.
Kalash,[56] 2009 United States	Doctoral dissertation Qualitative approach using phenomenology via semi-structured interviews (audio-recorded and transcribed).	Parents' experiences and perceptions of a child newly diagnosed with ASD	Participants were living in 4 separate geographical locations within a rural Midwestern state of the US. Interviews were conducted in the parents' homes.	12 parents (8 mothers and 4 fathers) of children (all boys) with autism. Children included in this review were identified as attending kindergarten and middle school. One child was identified as a recent high school graduate (age undetermined) thus was not included in this review	Six themes; 1 theme relevant for this review: Early signs and diagnostic struggles.
Kelly,[57] 2017 United States	Doctoral dissertation Social constructionist methodology using an interpretative	The parental use of language and discourse and its relation to the ability of parents from diverse linguistic heritages and levels	Anglo (English-speaking) participants were from a more privileged perspective with a sociocultural linguistic heritage from the US and Canada.	Twenty parents (mothers and fathers) of 20 children (10 males and 10 females) with ASD living in 2	Seven organizing themes; 1 theme relevant for this review: Timing is almost everything: Parental critique

	approach informed by critical discourse theory via face-to-face semi-structured interviews (audio-recorded and transcribed) and cross-sectional descriptive and comparative critical discourse analysis.	of privilege to obtain a timely diagnosis for their child with ASD	Hispanic participants were from an overall less privileged perspective had a sociocultural linguistic heritage from Mexico while living in the US. With the exception of 1 participant who was from Wyoming (Uinta county), participants lived in Utah (Salt Lake, Weber, Provo, Carbon and Cashe counties). Participants were Spanish- and English-speaking.	US states (Utah and Wyoming). Children were less than or equal to 16 years old	of themselves and others and 1 category under critical discourse analysis was relevant for this review: Anglo parents constructed themselves as aware of their child's temporal development
Lappé *et al.,*[58] 2018 United States	Qualitative approach following the method of grounded theory via in-person, semi-structured interviews (audio-recorded and transcribed).	Parents' experiences of the process of obtaining an ASD diagnosis and navigating ASD-related services	Participants were living in the greater Los Angeles area of California, US.	44 parents of 25 children (aged between 24 and 45 months) diagnosed with autism	Three phases; 2 phases relevant for this review: Making sense of child differences and navigating the diagnosis
Lindly *et al.,*[59] 2023 United States	Qualitative approach; semi-structured interviews via telephone or videoconference); (audio-recorded and transcribed); directed content analysis; demographic survey. This study was part of a larger study to adapt and pilot a parent education and training program delivered by community health workers for Diné parents of children with autism.	To explore the lived experiences of Navajo (Diné) parents raising a child with autism to identify factors affecting access to services	Participants were living in or around the Navajo Nation in northern Arizona, US. All participants (parents and children) identified as Navajo (Diné).	Fifteen Navajo (Diné) parents (14 mothers and 1 father) of 15 children (12 sons and 3 daughters; aged between 2 and 12 years) with autism	Twelve themes and various sub-themes); 1 theme relevant for this review: Factors affecting access to autism diagnostic services for Diné parents (Despite their resilience and resourcefulness, the diagnostic process was often stressful and emotionally fraught for Diné parents; Once families understood that their child needed autism diagnostic services, they commonly experienced wait times on the magnitude of months or even years; After parents recognized that their child had

					developmental issues and raised these concerns to health professionals, limited clinician training and cultural humility impeded parents' access to autism diagnostic services; Factors helped Diné parents to access autism diagnostic services included adequate health insurance, IHS [Indian Health Service] referrals, care coordination, financial aid to travel, and an efficient evaluation process.
Locke *et al.,*[60] 2020 United States	The methodology is described as qualitative using an iterative and systematic approach to data analysis. Three focus groups were conducted in English (n=2) and Spanish (n=1) (audio-recorded and transcribed).	Parents' experiences in recognizing and communicating about early ASD concerns and identified barriers to and facilitators these concerns	Participants were Hispanic (n=6) and non-Hispanic (n=16) living in or near Washington, DC, US.	Twenty-three parents (1 father and 21 mothers); 1 parent did not provide information regarding parental role) of 29 children (aged between 2 and 8 years) diagnosed with ASD	Eight themes; 3 themes relevant for this review: Response of others when the parent brought up concerns; Barriers to acting on concerns; and Facilitators to acting on concerns.
Lutz,[61] 2008 United States	Doctoral dissertation The methodology is described as a descriptive narrative research design using a constructivist lens via semi-structured face-to-face (n=15) or telephone (n=1) interviews. (All interviews were audio-taped and transcribed with the exception of 3 telephone interviews that were not audio-recorded due to	Mothers' experiences of coping and adapting over time following the autism diagnosis	All participants spoke English and self-identified as Caucasian (n=14) and African American (n=2). Interviews took place in participants' home (n=8) or by telephone (n=8)	Sixteen mothers who had children and/or adults with ASD. (Only 10 mothers of children [12 boys and 1 girl] aged between 5 and 17 years of age with ASD are relevant and were included in the findings of this review.)	A model of findings was developed with various stages of adaptation (responses to stressor and coping strategies. One additional category was relevant for this review: Barriers to receiving a diagnosis.

	technical difficulties.)				
Mann,[62] 2013. United States	Doctoral dissertation Qualitative approach using a case study design. Interviews were conducted with parents of children diagnosed with autism in the past 1 to 5 years and key informants from state and national agencies who serve this population. (Only interviews with parents of children with ASD are relevant and included in the findings of this review.)	Families' experiences with autism identification, diagnosis, and service systems, and how a state's policies and systems influence the identification, diagnosis, and intervention process for families of children with autism	Participants were living in urban and rural areas of the state of Delaware, US.	Seventeen parents (15 mothers and 2 fathers) of children with autism. (One family had 2 children with autism.) Of the 19 children, 14 were male and 5 were female; aged between 3 and 10 years	There were 4 main findings and various categories under each finding. One finding and 1 category relevant for this review: Barriers to identification (professional dismissed parent concerns and professional lack of knowledge about ASD).
Mulligan *et al.,*[63] 2012 Canada	Phenomenological approach to data collection and analysis via face-to-face open-ended interviews (audio-recorded and transcribed).	Parents' experiences of receiving a diagnosis of ASD for their child	Participants were living in the Greater Toronto area in the province of Ontario, Canada.	10 parents (8 mothers, 2 fathers) of boys diagnosed with ASD. The mean age at diagnosis was 4 years and all parents' children had been diagnosed 3 to 24 months prior to recruitment	Five themes; 1 theme relevant for this review: Pursuing a diagnosis: Waiting, worrying, and uncertainty.
Newman,[64] 2008 Canada	Doctor dissertation Institutional ethnography specifically, psychosocial ethnography of the commonplace via face-to-face or telephone semi-structured interviews (audio-recorded and transcribed); thematic analysis.	Mothers' experiences in how the institutions of motherhood and the welfare state constrain the everyday lives of mothers of children with ASD and how they understand and cope with difficulties created by these institutions	Participants were living in the province of New Brunswick, Canada. The majority of participants lived in an urban area.	Thirty-two mothers of children (86% male with a mean age of 8 years (22% were below age 6; 69% were between 6 and 12 years; and 1% were 13 years and older) diagnosed with ASD	Six themes; 1 theme and subtheme relevant for this review; Pre-ASD diagnosis: Waiting lists.
Perlman and Howe,[65] 2022 Canada	Collective case study approach; demographic questionnaire and semi-structured interviews (lasting 1 hour) audio-recorded and	Experiences of parents in the Canadian province of Quebec in obtaining a diagnosis and services for their child with ASD and identify what aspects	Participants were living in the province of Quebec, Canada. Interviews were conducted in the family homes.	Six mothers (5 married; 1 single) of children of 6 sons and 2 daughters (aged between 3 and 11 years)	Three themes; 1 theme relevant for this review: The diagnostic experience.

	transcribed); thematic analysis. This study is part of a larger study focusing on sibling relationships.	were beneficial to them and what challenges they experienced		diagnosed with ASD	
Piepenbring,[66] 2017 United States	Doctoral dissertation Narrative approach via face-to-face semi-structured interviews (audio-recorded and transcribed); structural analysis	Experiences of motherhood of mothers raising children with ASD	Participants were living in the state of Connecticut, US.	Nine mothers of children (aged 14 to 16 years) with ASD	Six phases with several themes in each phase. The second phase and related theme relevant for this review: Orientation: Journey to diagnosis
Preece and Lištiaková,[67] 2021 United Kingdom	Qualitative methodology using thematic content analysis via semi-structured interviews (audio-recorded and transcribed)	Family members' experiences of living with ASD	Participants were living in rural coastal and inland communities of Cornwall and Norfolk, England.	21 mothers (4 were diagnosed with ASD); 9 fathers (2 were diagnosed with ASD); 2 grandparents with caregiver responsibilities of 11 young people (aged 9-22 years) diagnosed with ASD; and 5 typically developing siblings (aged 5-15 years). Age of child with ASD can be identified in quotes.	Two main themes and several sub-themes: 1 sub-theme relevant for this review: Delays and difficulties regarding diagnosis
Shattnawi *et al.,*[68] 2021 Jordan	The methodology is described as a phenomenological descriptive approach using thematic analysis via semi-structured, face-to-face interviews (audio-recorded, transcribed and translated into English). All interviews were conducted in Arabic.	Jordanian mothers' experiences in caring for a child with ASD	Participants were living in the Arab country of Jordan, Western Asia.	Fourteen mothers of children (12 males and 2 females) aged between 4 to 14 years diagnosed with ASD	Three main themes and various sub-themes; 1 theme and sub-theme relevant for this review: The mothers' journeys with the diagnosis: Delay in diagnosis and initiation of treatment
Smith-Young *et al.*[69], 2020 Canada	Qualitative research design guided by	Parents' experiences of accessing diagnostic and	Participants were living in the province of	Seventeen parents (13 mothers and 4	Three phases and various sub-phases; 1 phase

	grounded theory methodology via face-to-face semi-structured interviews (audio-recorded and transcribed) and constant comparative analysis.	treatment services over the life course of ASD and the extent to which a family's self-described socio-economic status affected their access to services	Newfoundland and Labrador, Canada.	fathers) of children and adolescents with ASD aged 3 to 19 years. Out of the 17 children, 15 were male and 2 were female.	and 1 sub-phase relevant for this review: Watchful waiting (Searching for assessment and diagnosis).
Smith-Young *et al.,*[70] 2022 Canada	Descriptive exploratory methodology via face-to-face semi-structured interviews (audio-recorded and transcribed) and reflexive thematic analysis	Parents' experiences in raising a child diagnosed with ASD in relation to advocacy	Participants were living in 4 provinces of Atlantic Canada (Prince Edward Island, New Brunswick, Nova Scotia, and Newfoundland and Labrador)	Fifteen parents (1 father and 14 mothers) of children (12 males and 3 females) aged from 2 years to 14 years diagnosed with ASD	Three themes and various sub-themes; 2 themes and sub-themes relevant for this review: Engagement in parental advocacy: Seeking help, assessment, and diagnosis; and Removing challenges or barriers: Lack of knowledge and support
Sulaimani[71], 2018 Kingdom of Saudi Arabia	Doctoral dissertation Phenomenological approach to data collection and analysis.	Mothers' experiences with stigma directed/associated with their children diagnosed with ASD in the Kingdom of Saudi Arabia	Participants were living in Jeddah, Kingdome of Saudi Arabia who spoke English or Arabic.	15 Saudi mothers of children (13 boys and 2 girls) with autism (aged between 5 and 12 years).	Five themes and various sub-themes; 1 theme and subtheme relevant for this review: Accessing resources (Negative experiences).
Templeman,[72] 2019 United States	Doctoral dissertation Mixed methods design using anonymous on-line surveys via Qualtrics that included open-ended questions. Qualitative questions were analyzed through inductive thematic analysis.	Parents' experiences of using services for their child with ASD	Participants were living in various communities in various states of the US.	One hundred and seventy-one parents of children (119 sons and 52 daughters aged between 4 and 17 years of age) with ASD.	Positive and negative experiences included several themes; Under negative experiences 1 theme and sub-theme relevant for this review: Perceived provider disregard: Disregard perceived at time of ASD diagnosis.
Truett[73], 2012 United States	Doctoral dissertation Qualitative study using multiple-case study design via semi-	Latino parents' perspectives of raising a child with autism	Participants were Latino of Mexican origin residing in the border communities of San Luis and Somerton, South Yuma County, Arizona	Four mothers and 1 couple (mother and father) of 5 children (aged between 3 and	Four themes and several categories of results; 1 category relevant to this review: Interactions and

	structured, face-to-face interviews (audio-recorded and transcribed). Interviews were conducted in English (n=3) and Spanish (n=3). Spanish-language interviews were translated into English by a professional Spanish-speaking transcriptionist; cross-case analysis		in the US. Participants chose to speak English (n=3) or Spanish (n=3) with the help of an interpreter during the interviews. Interviews were conducted in the home (n=5) or another location in Yuma (n=1).	6 years of age) diagnosed with autism.	Diagnosis: Culture.
Ulofoshio,[74] 2017 Nigeria	Doctoral dissertation Qualitative, transcendental phenomenological approach to data collection and analysis via semi-structured, face-to-face interviews (audio-recorded and transcribed)	Perceptions and lived experiences of mothers raising children with autism in Nigeria	Participants were living in Lagos and Port-Harcourt, Nigeria. They were fluent in English. Interviews took place at mutually agreed upon locations.	Ten mothers of children with ASD (Only mothers of children [7 boys and 2 girls] aged between 3 and 17 years) are relevant and were included in the findings of this review.)	Eight themes and various sub-themes; 1 theme and subtheme relevant for this review: Low societal awareness about ASD (Medical awareness).
Vanegas *et al.,*[75] 2023 United States	Qualitative approach; inductive content analysis. Focus group interview (semi-structured) with parents lasting 150 minutes (audio-recorded and transcribed). This study was part of a larger needs assessment project on rural families of children with ASD in a Midwestern state in the US.	Barriers and unmet needs experienced by parents and providers providing support to children with ASD in rural communities in a Midwestern state in US through a life course perspective.	Participants were White (100%) and resided across 3 rural counties in Illinois, US. The focus group interview took place at local community agencies (easy access and free parking).	Eight parents of children and youth with ASD (6 boys and 2 girls aged between 7 and 17 years) are relevant and were included in the findings of this review.	Six themes; 1 theme was relevant for this review: Access and barriers to ASD diagnosis.

ASD, autism spectrum disorder; NGO, non-governmental organization.

Appendix 6. Ethics approval for Manuscript 1.

Health Research Ethics Board of Newfoundland and Labrador

ROMEO - Researcher Portal

Project Info.

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File No: 20150100

Project Title: A needs assessment for the Autism Spectrum Disorder community in Newfoundland and Labrador

Principal Investigator: Dr. Richard Audas (Faculty of Medicine\Division of Community Health and Humanities)

Start Date: 2014/06/01

End Date: 2015/01/31

Keywords: Health and Wellness

Appendix 7. Ethics approval for Manuscript 2.

Health Research Ethics Board of Newfoundland and Labrador

ROMEO - Researcher Portal

Project Info.

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File No: 20131052

Project Title: Barriers and facilitators in access to child/youth mental health services: A mixed methods, inter-sectoral study in Atlantic Canada

Principal Investigator: Dr. Richard Audas (Faculty of Medicine\Division of Community Health and

Humanities)

Start Date: 2013/04/01

End Date: 2023/03/31

Keywords: Health and Wellness