Exploring Communication and Information Processes for Informed Parental Decision-Making in the Context of Autism Diagnosis

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Preface

This thesis is presented in a thesis-by-articles format. Three empirical articles form the basis of Chapters 3, 4, and 5. A general introduction and comprehensive literature review establish the research problem and scholarly foundations, while Chapter 6 develops an integrated discussion and general conclusion. The studies use distinct datasets, and the integration concerns the relationships among their findings. Because Chapters 3 to 5 retain the form of the articles, each has its own introduction and theoretical framing, and some overlap with Chapters 1 and 2 is expected. I am the sole author of the three articles and this thesis. The research was conducted under academic supervision at the University of Ottawa.

Research ethics and permissions

Studies 2 and 3 were covered by University of Ottawa Research Ethics Board approval obtained before data collection (Ethics File No. S-05-22-8008). Written informed consent was obtained for the interviews in Study 2. Under the approved protocol for Study 3, individual consent was not required for analysis of publicly accessible Facebook material. Reporting uses paraphrased excerpts and omits group names and identifying details. Ethics approval records and applicable amendments are provided in Appendix A.

Study 1 examined publicly available institutional materials and did not involve human participants; research ethics approval was not required for that document analysis.

Abstract

Post-diagnostic autism information can be available while caregivers remain uncertain about its relevance to their child or how to use it in decisions about care. This dissertation examines how institutional resources present information, how caregivers describe receiving and using it, and how care-related uncertainty and coping are expressed in online peer spaces.

Three independent qualitative studies addressed these questions. Study 1 used document analysis to examine 234 resource items from 11 healthcare and community organizations serving Ottawa and the National Capital Region. Study 2 examined 20 semi-structured interviews with ten caregivers, each interviewed twice approximately three months apart. Study 3 analyzed 118 selected textual contributions, including originating posts and comments, from two public Facebook groups during March-April 2024. Communication Accommodation Theory informed interpretation in Studies 1 and 2, while transactional stress and coping theory informed Study 3.

Public resources combined autism education, service navigation, audience tailoring, and opportunities for caregiver participation and peer support. Interview accounts showed that information could be helpful while leaving questions about meaning, relevance, and next steps. Additional searching served different purposes, including obtaining practical guidance and examining proposed options. Peer contributions expressed uncertainty about services and recommendations, the significance of everyday experiences, provisional practical knowledge, and self-questioning about caregiving responsibilities.

The integrated findings distinguish information availability from the support needed to interpret and apply it, locating informed decision-making in the interpretive work caregivers

carry out. Professional and experiential knowledge addressed overlapping concerns, while caregiver agency coexisted with the effort and responsibility of navigation. The dissertation contributes a communication-centred account of post-diagnostic information use across institutional, experiential, and peer settings. It identifies priorities for connecting resources with discussion, revisiting questions, recognizing caregiver knowledge, and sharing responsibility for navigation within services.

Keywords: autism diagnosis; parental decision-making; caregiver communication; post-diagnostic information; communication accommodation theory; coping

Résumé

L'information sur l'autisme peut être disponible après le diagnostic sans que les parents sachent comment l'appliquer à la situation de leur enfant ni s'en servir pour prendre des décisions de soins. Cette thèse examine la présentation des ressources institutionnelles, les expériences de réception et d'utilisation de l'information, ainsi que l'expression de l'incertitude et de l'adaptation dans les espaces d'entraide en ligne.

Trois études qualitatives indépendantes ont été réalisées. L'étude 1 repose sur une analyse documentaire de 234 ressources provenant de 11 organismes de santé et communautaires desservant Ottawa et la région de la capitale nationale. L'étude 2 analyse 20 entretiens semi-dirigés avec dix parents, rencontrés deux fois à environ trois mois d'intervalle. L'étude 3 examine 118 contributions textuelles, comprenant des publications initiales et des commentaires, sélectionnées dans deux groupes Facebook publics en mars-avril 2024. La théorie de

l’accommodation communicationnelle éclaire l’interprétation des études 1 et 2; le modèle transactionnel du stress et de l’adaptation guide celle de l’étude 3.

Les ressources combinaient information sur l’autisme, orientation vers les services, adaptation aux publics et possibilités de participation et d’entraide. Dans les entretiens, une information jugée utile pouvait laisser des questions sur sa signification, sa pertinence ou les prochaines démarches. Les recherches complémentaires visaient notamment des conseils pratiques ou l’examen d’options. Les contributions en ligne exprimaient l’incertitude concernant les services, la signification d’expériences quotidiennes, des connaissances pratiques provisoires et des interrogations sur les responsabilités parentales.

L’intégration distingue la disponibilité de l’information du soutien nécessaire à son interprétation et à son utilisation, et situe la prise de décision éclairée dans le travail d’interprétation que les parents assument. Elle rapproche connaissances professionnelles et expérientielles, tout en soulignant le travail associé à la participation aux décisions. Cette thèse éclaire le rôle de la communication dans l’utilisation de l’information après le diagnostic. Elle propose de relier ressources et dialogue, de revenir sur les questions, de reconnaître les connaissances parentales et de partager la responsabilité de l’orientation vers les services.

Mots-clés : diagnostic d’autisme; prise de décision parentale; communication avec les aidants; information postdiagnostique; théorie de l’accommodation communicationnelle; adaptation (coping)

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List of abbreviations

ABA	Applied behaviour analysis
ADHD	Attention-deficit/hyperactivity disorder
ASD	Autism spectrum disorder
CAT	Communication Accommodation Theory
CHEO	Children's Hospital of Eastern Ontario
COREQ	Consolidated Criteria for Reporting Qualitative Research
REB	Research Ethics Board
RTARG	Reflexive Thematic Analysis Reporting Guidelines
SRQR	Standards for Reporting Qualitative Research
T1	First interview
T2	Second interview

CHAPTER 1

General Introduction

1.1 Background and context

Receiving an autism diagnosis for a child introduces questions about the meaning of assessment findings, possible supports, and decisions concerning care and education. These questions arise within families with different histories, resources, and relationships to services. Makino et al.'s (2021) scoping review identifies information and support alongside assessment, disclosure, and parental emotions as important dimensions of the diagnostic experience. The subject of this dissertation is the communication through which families encounter autism-related information and seek support after diagnosis.

Canadian Paediatric Society guidance recommends sensitive discussion of assessment findings, understandable verbal and written information, referrals, and a follow-up plan (Brian et al., 2019). Continuing care involves medical, therapeutic, educational, and community services (Ip et al., 2019). The communication relevant to families therefore includes professional encounters and resources produced or recommended by organizations, as well as information obtained through personal contacts and online communities. Questions about care may concern a proposed intervention, the interpretation of a report, or the process of accessing a service.

Post-diagnostic communication is used here to refer to information and exchanges relevant to understanding and responding to a child's diagnosis and subsequent care needs. It does not designate a uniform period shared by all families. The early months following diagnosis are the resource-selection focus of Study 1, while the caregiver interviews and online material concern

questions arising across different circumstances. Care-related decision-making likewise includes considering options and seeking clarification; it is not restricted to a discrete treatment choice or assumed to follow immediately from receiving information.

This dissertation is situated in communication research. Its concern is how information is presented, understood, and discussed in relation to caregiving and care. It does not evaluate the effectiveness of autism interventions. The terms parents and caregivers follow the populations and material examined in each study. Identity-first language is used in the dissertation's own discussion of autistic people, while published titles and source terminology are retained where necessary. Attention to caregiver communication is accompanied by recognition that caregivers' accounts are perspectives on a child's care and do not substitute for autistic people's own experiences and priorities.

Informed decision-making is used here in a broad sense. It refers to the process through which caregivers come to understand what options exist for their child, relate those options to the child's needs, the family's circumstances and their own values, and decide, defer or decline. It includes decisions that are not discrete treatment choices, such as which service to contact, how to read an assessment report, or whether to seek a particular school or home support. None of the three studies measured decision quality or outcomes. Decision-making is the stake that gives the communication its importance, and the studies examine the communication through which it unfolds.

1.2 Research problem and rationale

Caregivers of autistic children are expected to make informed decisions about care, and clinical guidance emphasizes understandable information and follow-up to support them (Brian et al., 2019; Ip et al., 2019). Existing research shows that this is not straightforward. Studies of diagnostic communication show that explanation, sensitivity and continuing support matter (Abbott et al., 2013; Makino et al., 2021). Studies of intervention choices show that information is only one influence among several (Edwards et al., 2018; Grant et al., 2016). Studies of online communities show that caregivers turn to peers for practical knowledge and recognition (Mohd Roffeei et al., 2015; Reinke & Solheim, 2015). The problem this dissertation addresses is what remains between available information and an informed decision about a particular child.

The problem is approached as one of communication, at three levels. Public resources present guidance, anticipate caregivers' needs and describe routes to support, but how they do so in the Ottawa region has not been examined. Caregivers describe what they received and why they kept searching, but their accounts are seldom read in relation to the decisions they face. In peer spaces, uncertainty and coping are voiced without researcher prompting, but, to my knowledge, they have not been read alongside institutional guidance or caregivers' accounts of using it. Studying the three together does not assume that the same families move through them. It asks what each setting shows about the work of turning information into an informed decision, and what is left over when they are read side by side.

1.3 Overall aim and objectives

The purpose of this dissertation is to examine post-diagnostic autism information and communication through publicly available institutional resources, caregivers' accounts, and online peer discourse. It asks how information and support are presented and experienced in relation to understanding a child's needs and considering care.

The three study objectives are:

1. To examine how publicly available resources from healthcare and community organizations serving Ottawa and the National Capital Region structure post-diagnostic information, address anticipated caregiver communication needs, and position caregivers in navigating services and participating in care.

2. To examine caregivers' accounts of the informational materials they received, the resources they consulted, and their perceived usefulness in understanding their child's needs and considering care options.

3. To examine expressions of care-related uncertainty, caregiving experiences, and coping in selected posts from public Facebook peer-support groups.

1.4 Research questions

The overarching research question is: How do families encounter and engage with autism-related information and support in the context of care-related questions following a child's diagnosis?

The question is framed around information and support because these are what communication research can examine directly. Its stake is informed decision-making: what the communication around diagnosis makes possible, and what it leaves for caregivers to work out, when families consider care for their child.

Three study-specific questions guide the inquiry:

1. How do publicly available resources from healthcare and community organizations serving Ottawa and the National Capital Region structure post-diagnostic information, address anticipated caregiver communication needs, and position caregivers in navigating services and participating in care?

2. What informational materials do caregivers report receiving following their child's autism diagnosis, which resources do they consult, and what do they perceive as useful in understanding their child's needs and considering care options?

3. How do parents and caregivers of autistic children express care-related uncertainty, caregiving experiences, and coping in selected posts from public Facebook peer-support groups?

These questions establish the focus of the three studies. Their relationship is the shared concern with information and communication in the context of care. The designs used to address them are outlined in Section 1.5 and detailed in the corresponding study chapters.

1.5 Overview of the research program

The dissertation comprises three qualitative studies using separate datasets. Studies 1 and 2 focus on Ottawa and Canada's National Capital Region. Study 3 examines public Facebook groups whose membership was not geographically restricted to Canada. The studies do not follow the same families through successive settings, and their findings are brought together in Chapter 6.

Communication Accommodation Theory (CAT) informs interpretation in Studies 1 and 2 (Giles et al., 2023), and Lazarus and Folkman's (1984) transactional account of stress and coping informs Study 3. Chapter 2 develops the literature and theoretical foundations for these perspectives.

Study 1 is a qualitative document analysis of 234 resource items from the websites of 11 healthcare and community organizations, collected in fall 2024 and selected for relevance to families of autistic children aged 3-11 years during the first six months following diagnosis. Study 2 is a two-time-point interview study with ten caregivers in the National Capital Region, each interviewed twice approximately three months apart; participants were at least six months beyond their child's diagnosis, so accounts of the diagnostic period are retrospective. Study 3 is a reflexive thematic analysis of 118 selected textual contributions from two public Facebook groups, published between March 10 and April 10, 2024; individual contributions were the units of analysis, and complete discussion threads were not systematically analyzed.

Qualitative inquiry is suited to these questions because they concern how information is presented and how people describe its meaning and use. Documents show organizational communication, interviews elicit accounts through researcher-participant interaction, and online

contributions show expressions produced for a peer audience. None is treated as an interchangeable measure of one underlying experience.

Thematic analysis in all three studies is informed by Braun and Clarke (2006, 2021b), and the researcher conducted all coding; supervisory discussions supported reflection but did not constitute independent coding or an intercoder agreement procedure. My experience as a parent informed my engagement with the topic, and shared familiarity is not treated as evidence that participants' experiences or the meanings of online posts are already known (Berger, 2015; Corbin Dwyer & Buckle, 2009). Each study chapter reports its analytic process, researcher positioning, ethical approvals and data-handling procedures.

1.6 Significance of the dissertation

The significance of the research lies in examining post-diagnostic autism support as a communication concern across institutional resources, caregiver accounts, and peer discourse. The program brings questions about available guidance into relation with questions about its perceived usefulness and the concerns expressed outside professional encounters. This scope creates an opportunity to consider communication across settings while preserving the distinct purposes and evidence of the three studies.

For communication scholarship, the value of this inquiry is its attention to institutional materials and caregiver perspectives within a common research problem. It examines communication through the organization of public information, participants' explanations of information use, and expressions directed to a peer audience. CAT and coping provide concepts suited to interpreting

these different forms of communication. The integrated discussion develops the resulting contribution in relation to existing scholarship.

The practical relevance concerns resource organization, explanation, follow-up, and engagement with information families obtain from other sources. An inquiry into these matters can inform discussion among healthcare and community organizations about post-diagnostic support. It can also identify questions that require evidence from other perspectives or evaluation of proposed approaches. The specific recommendations, limits, and future directions are developed in Chapter 6.

1.7 Organization of the dissertation

This thesis by articles comprises six chapters. Chapter 1 establishes the background, defines the research problem, and presents the purpose, objectives, research questions, methodological overview, and significance.

Chapter 2 presents the comprehensive literature review and theoretical foundations covering all three studies.

Chapter 3 presents Study 1, the document analysis of public resources from healthcare and community organizations serving Ottawa and the National Capital Region. Chapter 4 presents Study 2, examining caregivers' accounts of receiving, understanding, using, and supplementing information through two interviews. Chapter 5 presents Study 3, analyzing care-related uncertainty and coping in selected contributions from public Facebook groups.

Chapter 6 provides the integrated discussion and general conclusion. It develops the cross-study interpretation, considers the dissertation's contribution and theoretical implications, and presents implications for practice and service organization. It also addresses limitations and future research, including inquiry into professionals' perspectives on post-diagnostic communication.

CHAPTER 2

Comprehensive Literature Review and Theoretical Foundations

2.1 Introduction and organization of the review

The literature relevant to this inquiry spans diagnostic communication, health information use, intervention decisions, service navigation, and online support. These areas differ in their questions and evidence. Reviews of diagnostic experience synthesize parents' accounts; studies of decision-making examine choices and their influences; research on online support considers participation, messages, or reported experiences. The following review considers what these approaches establish and the questions that remain when information and support are examined across settings.

The central concern is the relationship between information and the circumstances in which families need to understand and use it. A diagnosis can prompt questions about a child's development, available services, and everyday support. Those questions are addressed through professional encounters, written and digital resources, personal contacts, and peer communities. Reviewing these forms of communication together provides the foundation for examining institutional guidance, caregivers' accounts of information use, and the concerns expressed in online peer spaces.

The chapter begins with the diagnostic and post-diagnostic context and caregivers' information needs. It then examines institutional resources, caregiver-professional communication, online peer support, and research on uncertainty and coping. The theoretical foundations establish the contribution of Communication Accommodation Theory to Studies 1 and 2 and transactional

coping theory to Study 3. The final section brings these bodies of literature together to identify the questions addressed by the three studies.

2.2 Autism diagnosis and the post-diagnostic information context

Makino et al.'s (2021) scoping review of 122 articles examines caregiver experiences across the diagnostic process. Their synthesis identifies the journey to assessment, assessment processes, disclosure and feedback, and information and support as connected dimensions of diagnostic experience. The review situates information and support within a diagnostic pathway that encompasses different encounters, purposes, and service conditions. Its scope makes clear that receiving an explanation of the diagnosis and finding support afterwards are connected parts of families' experiences.

Canadian clinical guidance places communication and family participation within this pathway. Brian et al. (2019) recommend a sensitive feedback appointment, conducted in the family's primary language with interpretation where needed, and time for questions. Assessment findings should be communicated verbally and in a written report suitable for a lay audience. Recommended report content includes information about resources and a follow-up plan. These recommendations connect the explanation of assessment findings with assistance in identifying what comes next for the child and family.

Post-diagnostic management extends across medical, developmental, educational, and psychosocial concerns. Ip et al. (2019) describe a continuing role for primary care providers in coordinating care, discussing intervention options, connecting families with community supports,

and attending to family and sibling needs. Their follow-up checklist includes educational resources, respite and social assistance, information sharing with schools and other services, and support during transitions. This scope places information provision within continuing care and coordination, rather than locating responsibility solely in a diagnostic feedback appointment.

Family-centred care provides a related account of participation. Kuo et al. (2012) discuss information sharing, partnership, respect for family differences, and attention to family and community circumstances. They also note the distance between widespread endorsement and implementation in practice. This tension is relevant to informational support: partnership requires opportunities for families to understand recommendations, contribute questions, and have their circumstances recognized. It directs inquiry toward the communication through which participation is organized and experienced.

Participation also involves whose priorities count in decisions about a child. Leadbitter et al. (2021) discuss autistic self-advocacy and the implications of neurodiversity for intervention research and practice, including respect for autistic experience and autonomy. This scholarship makes caregiver and professional judgments part of a wider discussion about appropriate goals and support. It is relevant to communication research because disagreements can concern the meaning and desirability of an intervention as well as factual information about it. A caregiver-focused inquiry therefore requires care in distinguishing reported preferences from conclusions about what is best for autistic children.

These perspectives establish a communication problem with informational and relational dimensions. Information can be examined for its content, while participation raises questions about explanation, recognition, and opportunities to contribute. Family-centred principles and

communication pathways situate questions about information use within established scholarship on relationships, participation, and care. They support examining what caregivers need from communication and the opportunities services provide for them to take part.

2.3 Caregivers' information needs after diagnosis

Research on diagnostic communication establishes that the way information is communicated matters to families' experience of assessment. Abbott et al. (2013) use qualitative interviews to examine parents' experiences of receiving an autism diagnosis, bringing attention to the encounter in which diagnostic information is explained. Legg and Tickle's (2019) meta-ethnography of 11 UK studies identifies emotional, informational, and relational needs across the diagnostic process. Their synthesis connects the provision of explanations, relationships with professionals, and attention to parents' emotions. These findings connect what is communicated with how the encounter supports families in making sense of the diagnosis.

Later qualitative work examines what parents experience after diagnosis. Hughes et al. (2024) describe continuing concerns, experiences with professionals, and needs for support. This focus extends the inquiry beyond the disclosure encounter and raises questions about the assistance available as families consider everyday implications. These accounts support attention to families' different emotional responses and to the circumstances in which they seek explanations and support.

Parents' questions concern both the meaning of autism and the practical implications of a diagnosis. They may want to understand an assessment, consider a proposed intervention, locate

services, or identify ways to support their child in everyday settings. Martinović and Stričević (2016) approach these questions through parents' reports of their information needs and information behaviour. Their focus complements clinical accounts by treating parents as active seekers of information with questions, preferences, and prior experiences that shape what they consult.

The quantity and timing of information affect its usefulness. Rabba et al. (2019) documented that many parents experience significant emotional overwhelm immediately following diagnosis, highlighting the difficulty of processing information during this initial period. Their findings emphasize parents' need for support that is sensitive to emotional readiness and paced over time. These findings suggest that even well-intentioned, comprehensive information may be difficult to absorb if delivered without regard for timing and emotional context.

The practical implication of this literature is that the information needed at one point may differ from the information sought at another. An initial explanation can establish the meaning of assessment findings, while subsequent questions may concern a particular service, a new concern, or an educational transition. Ongoing support allows questions to be revisited as families gain experience and as the child's circumstances develop (Ip et al., 2019; Rabba et al., 2019).

What parents find useful in terms of information can change over the course of their child's development. As children grow, new questions and challenges emerge. Parents may seek information about school placements, support in different settings, or emerging developmental needs. In adolescence, topics like preparing for adulthood, vocational training, or mental health supports might come to the forefront. The relevance of a resource therefore depends partly on

the question facing the family and the stage at which it is consulted (Ip et al., 2019; Rabba et al., 2019).

Cultural relevance involves the extent to which information and resources are sensitive to and respectful of families' cultural backgrounds, values, and linguistic needs. Families approach an autism diagnosis with different experiences of disability, different relationships to services, and different opportunities to obtain explanations. These circumstances can shape the meaning of a recommendation and the support needed to act on it (Casale et al., 2023; Papoudi et al., 2021).

Papoudi et al.'s (2021) scoping review examines the perceptions, experiences, and needs of culturally and linguistically diverse families. The review identifies communication barriers involving language and specialist terminology, as well as differences in beliefs, service experiences, and perceived needs. Its findings support a view of cultural responsiveness that includes how explanations are offered, how questions are heard, and whether services recognize family circumstances. A translated resource can improve linguistic access while still requiring discussion of its relevance to a particular family.

In Canada, Casale et al. (2023) reviewed 28 studies of newcomer caregivers' experiences of accessing autism-related services. Their synthesis describes barriers in navigating services, including language and communication difficulties, unfamiliarity with systems, and financial and organizational constraints. It also documents caregivers' active efforts to seek information and advocate for support. These experiences place information needs within the conditions of service access: knowing that a service exists, understanding eligibility, and being able to secure that service involve related but distinct demands.

Attention to cultural responsiveness also requires recognition of racism. Čolić et al. (2022) discuss Black caregivers' perspectives on racism in autism services and the implications for culturally responsive practice. This work indicates that trust in information depends on how caregivers are treated and on their relationships with services, as well as on how information is worded or translated. Alongside the reviews of culturally diverse and newcomer families, it supports examining the social conditions in which information is offered and evaluated.

2.4 Organizational information resources and public communication

Written and digital resources deserve attention as forms of organizational communication. Clinical guidance recommends information and referrals after diagnosis (Brian et al., 2019; Ip et al., 2019), but those recommendations leave empirical questions about how materials are assembled and presented. Headings, topic selection, language availability, and service contacts are features through which an organization addresses an anticipated audience. These features organize an information environment through which families can seek explanations, identify options, and locate support.

Post-diagnostic resources take several forms, including diagnostic reports, printed information packages, brochures and fact sheets, recommended reading, websites, and information about community or peer support. These formats serve different purposes. A short resource sheet may identify a contact or immediate next step, while a report or guide can provide detail for later consultation. Canadian guidance supports combining understandable assessment information with resources and referrals relevant to the child and family (Brian et al., 2019; Ip et al., 2019).

Research on diagnostic reports provides a focused example. Wilson and Gunn (2023) interview parents about what they want in an autism diagnostic report. The 30 parents interviewed wanted reports that combined detail with accessible structure and sensitive, balanced language. They valued practical recommendations tailored to the young person's strengths and difficulties. These preferences make accessibility more specific than brevity: a document can need detail while also requiring clear organization. Diagnostic reports and service directories have different purposes, but the study establishes the relevance of examining a resource in relation to the tasks and expectations of its intended users.

Comprehensiveness refers to how fully resources cover the topics and questions relevant to families after diagnosis. These can include the meaning of assessment findings, care options, service and funding pathways, educational support, and everyday family concerns. Comprehensive information is useful when readers can locate what they need and distinguish immediate questions from information to revisit. The relationship among detail, organization, and relevance is therefore central to a resource's communicative purpose (Ip et al., 2019; Wilson & Gunn, 2023).

Research on support design similarly suggests that families value information connected to their circumstances. Battanta et al. (2024) emphasized differing needs among families. This work supports attention to a resource's content and format, as well as what it enables a caregiver to understand or do.

Digital design research also links information with practical navigation. Burke et al. (2024) describe development of an app incorporating feedback from families and other parties, including family navigators. Feedback concerned usability, action planning, and identifying

services and providers. The study connects resource development with the tasks users need to accomplish and with feedback from people who will use or help deliver the support.

Resources also communicate through their selection of topics, the audiences they address, and the actions they recommend. A guide organized around anticipated questions offers a different route through information from a list of disconnected links. Funding instructions and service contacts address practical navigation, while material directed to siblings or extended family recognizes a wider audience. Viewing documents as purposeful communications makes their organization and context part of their meaning (Bowen, 2009).

This perspective places publicly available resources within the wider literature on family participation. Information can invite readers to ask questions, prepare for a consultation, seek a referral, or connect with other families. It can also leave substantial work of interpretation and coordination to the reader. The literature on reports, navigation support, and information needs consequently supports attention to both the content of resources and the forms of participation they anticipate (Burke et al., 2024; Kuo et al., 2012; Martinović & Stričević, 2016).

2.5 Caregiver-professional communication and the use of information

Broader health communication scholarship offers a basis for examining why communication matters beyond satisfaction with an encounter. Street et al. (2009) describe pathways connecting clinician-patient communication with outcomes through intermediate processes such as understanding, trust, agreement, and participation. Their account directs attention to the mechanisms through which communication may matter. For post-diagnostic autism research, this

suggests asking what an explanation enables a caregiver to understand or consider and how an exchange supports participation in care.

Studies of intervention choices show that information is one consideration within a wider decision context. Grant et al. (2016) examine parents' information preferences and decision-making following a child's diagnosis. Edwards et al. (2018), using constructivist grounded theory, identify values, experience, information, motivation, understanding, needs, and logistics as influences on intervention decisions. These accounts challenge an explanation in which supplying facts is sufficient to explain a choice. They support examination of the relationship between information, the question facing a family, and the options available to it.

Lindly et al. (2022) connect parent health literacy with autism services use through mixed methods. Their findings include consultation of multiple sources, parents' own research, and the influence of family and system characteristics on service use. This work situates understanding within active information seeking. It also cautions against locating every difficulty within an individual caregiver's knowledge: opportunities to use information are related to service conditions as well as the capacities of the person consulting it.

Independent searching can therefore have several possible meanings. It may be undertaken to understand a recommendation, compare options, locate a service, or examine a concern not resolved in an earlier exchange. Examining these possibilities requires attention to the purpose and circumstances of the search. The analytical issue is how caregivers explain their engagement with particular sources. A design that revisits those explanations can preserve the relationship between an information-seeking activity and the purpose attributed to it.

Smith et al. (2020) examine information seeking and decisions concerning complementary medicine for autistic children. Their specific focus illustrates why the subject of a decision matters when considering sources and credibility. Across these studies, a useful direction is to examine caregivers' reasons for consulting information and the conditions under which they consider it relevant. This leaves room for uncertainty and deliberation without treating them as failures to act.

The communication question extends beyond whether a resource was supplied or described as helpful. A parent may appreciate an explanation while remaining unsure which option is relevant to their child. A website may answer a general question but leave a practical problem unresolved. Additional searching can therefore occur alongside positive evaluations of professional information. Examining these relationships can help clarify what caregivers mean when they describe information as useful and why they continue to seek explanations elsewhere.

The distinction between communication and its consequences is especially relevant when interpreting reports of helpfulness. A favourable appraisal may concern the clarity of an explanation, the manner of a professional, or the usefulness of a resource for one task. Examining the purposes attached to information use and the explanations caregivers give for their appraisals helps make the meaning of usefulness more specific.

Information seeking across sources is part of this continuing process. Professional explanations, written resources, independent searching, and conversations with other parents can address different aspects of the same concern. Examining those purposes allows the relationship among sources to remain an empirical question. It directs attention to caregivers' reasons for consulting

information, the authority they attribute to it, and the practical choices open to them (Grant et al., 2016; Lindly et al., 2022; Smith et al., 2020).

2.6 Online information seeking and peer communication

Borkman's (1976) account of experiential knowledge distinguishes knowledge grounded in direct experience from professional knowledge within self-help groups. This distinction offers a useful starting point for considering why another caregiver's account might be sought alongside professional guidance. Such an account may make an everyday situation recognizable or describe what using a service involved for one family. Its experiential relevance does not establish the accuracy of every claim or its applicability to another child.

As parents seek both practical advice and emotional validation, online peer communities provide a supplement to formal care systems. These digital spaces offer caregivers opportunities to share experiences, crowdsource knowledge, vent frustrations, and find solidarity amid ongoing caregiving demands (Abel et al., 2019; Mohd Roffeei et al., 2015; Reinke & Solheim, 2015).

Lee et al. (2024) place autism-specific parent-to-parent support within a broader literature. Their review includes 25 studies, encompassing support groups as well as individual matching and mentoring arrangements. Parents sought and provided emotional support, advocacy, knowledge about autism, and practical advice. The range of models is relevant to understanding peer support as a field with different purposes and forms of participation, including structured mentoring and more open opportunities to share experiences.

Autism-focused research documents both informational and emotional dimensions of online support. Mohd Roffeei et al. (2015) examine support messages in Facebook groups, while Reinke and Solheim (2015) interview 14 mothers about seeking online support. The latter study identifies continuing searching and the desire for connection and understanding. Together, the message analysis and interview accounts show the relevance of examining both what caregivers communicate to peers and what they value in seeking support.

Abel et al. (2019) examine the stated purposes of autism-focused Facebook groups, including support, social connection, and advocacy. Group purposes matter because they shape the audience to which an experience or question is directed. A request for practical advice may appear among expressions of frustration, accounts of milestones, or discussion of the responsibilities associated with parenting. The literature therefore supports attention to the relationship between a group's orientation and the concerns made visible within it.

Broader caregiver research places these studies within a diverse field of online groups. Daynes-Kearney and Gallagher's (2023) scoping review examines online support groups for family caregivers. The diversity of populations, group formats, and research approaches makes it important to specify the setting being studied. A public Facebook group, a membership-restricted forum, and a professionally facilitated intervention provide different conditions for participation. Group format, access arrangements, and purpose are consequently important parts of the context in which support is sought and offered.

Research on belonging provides a further perspective on these exchanges. Daynes-Kearney and Gallagher (2024) interviewed members of an established online group for family caregivers about shared group identity. Their analysis links identification with similar others to recognition,

meaningful membership, and social support. This broader caregiver research helps specify what belonging can involve: an experience can be understood by an audience with related responsibilities, and a person can recognize a place for themselves within the group. It offers context for examining caregiver identity and recognition in relation to the practical content of online communication.

Kelly et al. (2022) examine participation in a Facebook-based group for caregivers of children and young people with complex care needs. Participants described peer connection, informational support, and a valued space for sharing caregiving concerns. Although the population extends beyond autism, the study illustrates how practical guidance and a sense of community can form part of the same account of participation. It complements autism-focused work by examining the meanings caregivers attach to an online support setting.

The distinction between professional and peer support is also not a simple separation between two independent sources. Hermaszewska and Sin (2021) examine parents' perspectives on developing an online intervention and identify interest in peer support alongside credible information and access to professionals. Their work concerns preferences for a proposed resource. It nevertheless illustrates why the relationship among sources is a relevant question: families can value different forms of assistance within the same support environment.

The social-media literature also situates these activities within parents' wider searches for child-health information. Frey et al. (2022) review parents' use of social media as a health information source. This wider field helps locate autism-related peer communication within practices of seeking experiences, recommendations, and support through digital networks. Its relevance lies

in understanding why a familiar and accessible platform can become part of a parent's information environment, alongside professional and organizational sources.

Information quality remains an important dimension. Treadgold et al.'s (2025) scoping review documents variable quality and misinformation in online health peer-support groups, as well as responses that challenge or correct questionable claims. The review concerns health conditions broadly. It makes information quality and the evaluation of advice important considerations alongside the social value of supportive exchanges.

The visibility of online communication also has ethical significance. Internet research guidance treats the context of disclosure, people's expectations, and possible harms as central considerations when examining digital material (franzke et al., 2020). Ayers et al. (2018) demonstrate how verbatim social-media quotations can be traced to the people who posted them. For caregiver communication about children and family life, these concerns connect the study of peer support with questions about privacy, audience, and the circulation of sensitive experiences beyond their original setting.

2.7 Uncertainty, coping and the work of navigating support

Service navigation adds an organizational dimension. Smith-Young et al. (2020) examine Canadian parents' experiences of accessing diagnostic and treatment services and describe the changing strategies through which families manage waiting. This work situates information seeking within the practical conditions of service access. Knowing which service exists is different from being able to obtain it. For research on post-diagnostic information, this makes it

useful to distinguish explanations of service pathways from the availability and timeliness of the services themselves.

Uncertainty in this context can concern what an assessment means, which support is suitable, how to obtain it, and whether a source can be trusted. These questions involve practical action and emotional experience. Research on intervention decisions identifies information alongside values, family needs, experience, and logistics (Edwards et al., 2018), while research on post-diagnostic experience draws attention to continuing communication and support needs (Hughes et al., 2024). Together, these accounts situate uncertainty within families' responsibilities and the options available to them.

Vernhet et al.'s (2019) systematic review brings an autism-specific evidence base to coping. The review includes 11 studies using self-report measures and examines relationships among coping strategies, perceived stress, and quality of life. It reports more favourable associations for problem-focused coping and less favourable associations for emotion-focused coping within the classifications and measures used. The variation in questionnaires and the relationship between strategies and circumstances make the meaning of a coping category important when interpreting these findings.

Higgins et al. (2023) examine adaptation through an online survey of 136 parents of autistic children. Positive perceptions, adaptive coping, self-efficacy, and social support were each associated with one or more adaptation outcomes in their regression analyses. The study places coping within a wider set of personal and social resources. Considered together with the systematic review, it supports attention to the combination of resources surrounding a caregiver's response, without assuming that a single strategy is sufficient to explain adaptation.

Recent intervention research also addresses continuing post-diagnostic support. In the UK REACH-ASD trial, Leadbitter et al. (2025) evaluated an online program combining autism psychoeducation with acceptance and commitment therapy. Caregiver mental-health benefits were sustained at 52 weeks compared with the usual local psychoeducation offer plus usual care. The program's combined informational and psychotherapeutic content provides evidence for a structured approach to post-diagnostic family support. Its relevance here is the attention to caregivers' understanding and well-being within continuing support.

The work involved in seeking support includes locating contacts, understanding eligibility, comparing recommendations, and connecting information with a child's needs. Service-navigation research and parents' accounts of information use show why these activities can continue after the diagnosis itself has been explained (Casale et al., 2023; Lindly et al., 2022; Smith-Young et al., 2020). This work is also relational: caregivers may consult professionals, relatives, friends, and other parents for different kinds of help. Practical information and recognition of experience can therefore be relevant to the same concern.

The online support and coping literatures consequently overlap without answering the same questions. Support research identifies forms of assistance and experiences of participation. Coping research addresses how demands are appraised and responded to. Reading them together supports an inquiry into the practical and emotional meanings expressed in caregiver posts.

2.8 Theoretical foundations

2.8.1 Communication Accommodation Theory

Communication Accommodation Theory (CAT) concerns adjustments in communication in relation to others and the social meanings and evaluations attached to those adjustments (Giles et al., 2023). It places language and interaction within interpersonal and intergroup contexts. Communication can signal recognition, distance, expertise, or assumptions about another person's capacities. This makes the theory relevant to encounters involving different forms of knowledge and different responsibilities, including the relationship between professionals and caregivers.

The theory's relevance cannot be reduced to whether language becomes simpler. A communication adjustment may be intended to help while being experienced as insufficient, inappropriate, or condescending. Conversely, detailed information may be welcomed when a person wants an explanation in depth. Attention to perceived accommodation therefore raises questions about the recipient's needs and the purposes of the exchange. These questions are particularly pertinent when caregivers differ in prior knowledge and in the concerns they bring to a discussion.

Healthcare applications of CAT examine how communication addresses differences in knowledge, roles, and expectations between participants. Farzadnia and Giles (2015) review patient-provider interaction through this perspective. Their discussion makes accommodation relevant to the explanation of unfamiliar concepts, the management of participation, and responsiveness to another person's communication needs. Giles's (2016b) account also situates

accommodation within personal relationships and social identities across contexts. The theory therefore offers more than a criterion of simple or complex language.

Applied to written and digital resources, CAT provides an interpretive lens for examining features directed to an anticipated audience (Giles et al., 2023). Explanations of terminology, organization around questions, language options, and audience-specific material can be considered in relation to the needs they appear to address.

In Study 1, CAT informs interpretation after inductive thematic analysis of resources. In Study 2, it supports interpretation of caregivers' descriptions of information delivery, explanation, and relevance. The two uses retain the difference between anticipating a broad audience and responding to a particular person's questions.

2.8.2 Transactional stress and coping

The second theoretical foundation is Lazarus and Folkman's (1984) transactional account of stress and coping. Appraisal concerns how a situation is understood in relation to well-being and the resources available for responding. This orientation places coping within a relationship between the person and the situation. It provides concepts for examining how caregivers describe uncertainty and efforts to respond, without assuming that an event has the same significance for every family.

Problem-focused and emotion-focused coping concern functions of responding. Efforts to clarify a procedure may address a practical demand, while an account of the same situation may express a need for reassurance. The functions can coexist. These functions can be considered together

when people discuss a practical difficulty and the emotions associated with it (Lazarus & Folkman, 1984).

Folkman and Moskowitz (2004) review conceptual and methodological challenges in coping research, including the importance of context and the limits of broad classifications. This literature cautions against using coping categories as fixed labels for people or assuming that a strategy has the same meaning across situations. Skinner et al. (2003) similarly review and critique systems for classifying coping, drawing attention to the conceptual work involved in organizing responses into broad categories. These contributions support attention to the demand described and the function of a response in context.

2.8.3 Meaning and social dimensions of coping

Meaning-focused coping adds attention to positive meaning during continuing difficulty. Folkman (2008) discusses positive emotions, adjustments in goals and priorities, and the significance attributed to ordinary events. This perspective broadens inquiry beyond distress and efforts to remove a problem. It provides a reason to attend to accounts of valued experiences as well as requests for assistance.

Social approaches also distinguish different processes that may occur when experiences are communicated. Lyons et al. (1998) conceptualize communal coping in terms of shared appraisal and efforts to respond together. Rimé's (2009) review considers the social sharing of emotional experience. Communicating a difficulty to others and jointly taking ownership of it are related possibilities, but they are not identical. These perspectives sharpen the questions that can be asked about a peer audience and about the evidence needed to infer a collaborative process.

Helgeson et al. (2018) update communal coping theory in relation to chronic illness and review evidence concerning adjustment. Their account further develops the relationship between shared understandings of a difficulty and collaborative responses. Considered with research on social sharing and online support, communal coping offers a basis for asking when a difficulty is discussed with others, when responsibility is understood as shared, and how help is organized. These are related dimensions of social life with distinct conceptual meanings.

2.8.4 Relationship between the theoretical perspectives

CAT and coping address different analytical questions. CAT directs attention to how communication anticipates or appears responsive to another person's needs. Coping directs attention to how demands and responses are expressed. Their use follows the questions and materials examined in the studies.

The dissertation's coherence rests on its research problem and the relationship among its questions. Each study uses the theoretical perspective relevant to its focus. This allows each study to retain an appropriate analytical focus. The integrated discussion considers how the interpretations can inform a broader account of post-diagnostic communication, and the study chapters explain how the relevant concepts inform interpretation.

2.9 Informed decision-making and decisional support

Two frameworks from health decision research offer a vocabulary for what informed decisions require. An informed decision involves more than access to facts. The Ottawa Decision Support

Framework asserts that support addressing a person's decisional needs improves decision quality. Those needs include adequate knowledge and information, clear values, manageable uncertainty or decisional conflict, and adequate support (Hoefel et al., 2020; Stacey et al., 2020). Information is therefore one decisional need among several and meeting it does not resolve the others. Shared decision-making models make a related point about process. Elwyn et al. (2012) describe three kinds of conversation in the clinical encounter: making clear that a choice exists, describing the options, and supporting the person to explore preferences and decide. They place a relationship in which information is shared and deliberation is supported at the centre.

Applying these frameworks to autism requires caution in three respects. First, both were developed largely for patients deciding about their own care, whereas parents decide for a child whose preferences and autonomy are themselves a matter of debate, as autistic self-advocacy scholarship emphasizes (Leadbitter et al., 2021). Second, autism care rarely involves a single decision at a single time; parents consider interventions, services and accommodations as questions arise (Edwards et al., 2018; Grant et al., 2016). Third, both frameworks centre the clinical encounter, whereas the communication examined here occurs largely around it, in written resources, personal searching and peer spaces.

For these reasons the frameworks serve in this dissertation as sensitizing perspectives. They inform the integrated discussion in Chapter 6, where they help specify what resources, caregiver interpretation and peer support each contribute to, or leave unresolved, in an informed decision. They were not used as analytic templates: the three studies were guided by the perspectives described in Section 2.8, and the frameworks were not used to code or interpret them.

2.10 Synthesis of the literature and research gaps

The literature reviewed in this chapter establishes the importance of communication and information support following an autism diagnosis. Research on diagnostic experiences and post-diagnostic needs emphasizes explanation, emotional responsiveness, and continuing support. Studies of information resources and caregiver decision-making examine how information is presented, evaluated, and used, while research on online peer support and coping identifies additional sources of practical knowledge, recognition, and emotional support. These bodies of scholarship address related aspects of post-diagnostic communication but provide different forms of evidence. Their consideration together supports examining the relationships among publicly available resources, caregivers' accounts of information use, and expressions of uncertainty and coping in peer communication.

Each body of work explains part of why information may or may not support an informed decision. Diagnostic communication research shows what caregivers need to be told and how, decision research shows that information is one decisional need among several, and peer-support research shows where caregivers turn when it is not enough. What has not been examined, to my knowledge, is how institutional resources, caregivers' accounts of use and peer communication look when read side by side as one communication environment: what the resources provide, what caregivers still have to work out, and where they take their questions.

The following three chapters present the studies addressing these questions. Each retains its own research focus and introduction to the relevant literature. The integrated discussion subsequently develops what the findings contribute when considered together, drawing on the scholarly foundations established here.

CHAPTER 3

Study 1 Post-diagnostic information resources

3.1 Introduction

Research on diagnostic disclosure and parents' subsequent experiences establishes the importance of communication surrounding an autism diagnosis (Abbott et al., 2013; Hughes et al., 2024). A related question concerns how organizations construct the written and digital information environment available after diagnosis. These materials communicate through the selection of topics, the ordering of information, the audiences addressed, and the actions recommended. In this study, publicly available institutional resources are the information, resource listings, and links made accessible through the public websites of healthcare and community organizations. Qualitative document analysis permits examination of these materials in relation to their purpose, intended audience, and context (Bowen, 2009; Prior, 2010). It therefore provides a way to interpret how publicly available institutional resources frame post-diagnostic support and the caregiver roles they present.

Communication Accommodation Theory (CAT) examines how communicators adapt their communication in relation to others' perceived needs, characteristics, and social identities (Gallois et al., 2005; Giles, 2016b). Here, it provides an interpretive framework for examining how publicly available institutional resources appear to anticipate caregiver communication needs. Chapter 2 (Section 2.8.1) develops the theoretical foundations for this application. In written and digital materials, relevant features include explanations of specialist terminology, organization around anticipated questions, language availability, and guidance directed to

particular caregiver circumstances. Attention to the intended audience and to linguistic and cultural circumstances is relevant to interpreting these features (Casale et al., 2023; Giles et al., 2023).

Accordingly, this qualitative document analysis examined the publicly available information environment for families of autistic children aged 3-11 years in Ottawa and the National Capital Region, with a focus on resources relevant to the first six months following diagnosis. The study asked: How do publicly available resources from healthcare and community organizations structure post-diagnostic information, address anticipated caregiver communication needs, and position caregivers in navigating services and participating in care? Inductive thematic analysis was used to develop codes and themes from the recorded content and features of the resources. CAT subsequently informed interpretation of the communicative significance of those patterns.

3.2 Methods

3.2.1 Research design

This study used qualitative document analysis to examine publicly available autism-related information from healthcare and community organizations serving Ottawa and the National Capital Region. The analysis focused on resources relevant to families of children aged 3-11 years during the first six months following diagnosis. Documents and webpages were examined as publicly available institutional materials whose content, structure, intended audiences, and recommended actions could be interpreted in context (Bowen, 2009; Prior, 2010).

Inductive thematic analysis was used to develop patterns across the materials (Braun & Clarke, 2006, 2021a). CAT was subsequently used as an interpretive framework to examine how those patterns appeared responsive, or insufficiently responsive, to anticipated caregiver communication needs. The documentary approach attends to both the information contained in a resource and its placement within the organization's wider public resource collection.

3.2.2 Resource sources and material examined

Data consisted of publicly accessible informational resources identified through the official websites of healthcare and community organizations serving Ottawa and the National Capital Region. Materials were selected for their relevance to parents or caregivers of children aged 3-11 years during the early post-diagnostic period.

The dataset included organizational webpages, brochures, guides, resource sheets, frequently asked questions, educational materials, referral and funding information, recommended books, videos, and links to external services and supports. It captured both information provided by organizations and resources they recommended or linked through their public websites. English- and French-language materials were included where available, and equivalent versions in both languages were reviewed. For recommended books and other linked materials, the analysis concerned their presentation within the organizations' public resource collections.

Resources were collected and archived in fall 2024. The dataset therefore represented the publicly available information environment at the time of collection.

3.2.3 Search and selection procedures

Purposive sampling, in which sources are selected for their relevance to the research question, was used to identify organizations providing information relevant to the study objective (Patton, 1990). The initial sampling frame drew on the Service Coordination for People with Developmental Disabilities "Available Resources in the Community" list and the Ontario Autism Program service-provider portal. Targeted Google searches supplemented these sources by combining "Ottawa" or "National Capital Region" with terms including "autism services," "autism diagnosis services," "autism treatment services," "autism intervention services," "ABA services," "autism parent support," and "autism resources." In the search terms listed, ABA denotes applied behaviour analysis.

The supplementary searches widened that initial frame beyond the organizations listed in those directories. Additional organizations identified through this process included ACT Learning Centre, Full Circle Therapy, Gamache Behaviour Consulting, Horizons Behavior Consulting, and The Core Learning Centre.

Organizations were eligible if they provided autism diagnostic, intervention, treatment, or family-support services; made relevant parent- or caregiver-directed information publicly available; served children up to age 11; operated within or served Ottawa and the National Capital Region; and provided material in English or French. Organizations were excluded if they lacked relevant public family-directed autism information, restricted access to that information, or focused exclusively on adolescents or adults. Both publicly funded and private providers were eligible when their public information met these criteria.

Of 26 organizations screened, 11 were included. These represented hospital-based, community and nonprofit, private clinical or therapy, behavioural, and educational services. Their different mandates, funding structures, and relationships to diagnosis formed part of the context for interpreting their resources. The final dataset comprised 234 resource items: 149 online resources, 18 recommended books, and 67 text-based informational excerpts. A resource item was an entry in the collection record; depending on its category, the evidence consisted of the resource itself, its publicly available listing or description, or the recorded excerpt. The organizations and selected resource-identification pathways are described in Appendix D.

Selection was applied at two related levels. Organizations were screened for their service context, geographic reach, and provision of relevant public family information. Within eligible organizations, individual resources were identified through the titles, descriptions, placement, and content that indicated relevance to the study. The screening record for the 26 organizations is retained in Table D3; Table D1 describes the 11 included organizations.

Within each eligible organization, resource identification followed the structure of its website. Sections were examined when their titles, descriptions, location, or visible content indicated relevance to parents or caregivers of autistic children. On the website of the Children's Hospital of Eastern Ontario (CHEO), the recorded navigation path was Home → Resources and Support → A–Z Resources → Autism. This page led to books and guides, websites, local contacts, and videos. It also listed "Our ASD Journeys," a community event for parents and caregivers of autistic children; ASD denotes autism spectrum disorder.

Resource identification documented both the information made available and the routes through which it was presented. The selected pathways in Table D2 illustrate this process within the different website structures.

3.2.4 Analytical approach

The principal researcher conducted an inductive thematic analysis informed by Braun and Clarke (2006, 2021a). The analysis involved familiarization with the material, generating initial codes, developing and reviewing candidate themes, defining and naming themes, and preparing the written findings. These phases were iterative, with movement between the recorded material, codes, and developing themes. Familiarization involved repeated review of the collected resource information and recorded textual content, with initial notes about recurring topics, communicative features, and questions relevant to the study purpose. Resources were first characterized according to observable features, including resource type, intended audience, language, topic, organization, and the information or guidance provided. Relevant textual and structural content was then coded inductively in a coding grid. Coding focused on meaningful portions of recorded content and features of presentation relevant to the research question. The grid brought together the recorded material and descriptive codes, allowing the researcher to revisit the basis of a code and consider its meaning within the resource and organizational context. Descriptive codes captured features such as explanations of information, step-by-step guidance, audience-specific resources, bilingual availability, service contacts, funding information, peer-support content, and access barriers.

Codes and their associated material were compared across the collection to examine similarities, differences, and relationships relevant to the research question. Related codes were brought

together into candidate themes, and the supporting material was examined to identify the broader pattern each grouping represented. Earlier coding was revisited as these interpretations developed; codes were revised or merged when their meanings overlapped or required clarification. For example, question-based organization in frequently asked questions contributed to interpretation of how resources anticipated caregiver concerns, while financial-help information and service links contributed to patterns concerning practical guidance and navigation. Candidate themes were reviewed against the resources, refined, and defined by their central organizing concepts. Review considered the coherence of coded material within each candidate theme and the interpretation in relation to the wider collection. Themes were named to convey their central organizing concepts (the shared meanings connecting the coded material within each theme), and their definitions specified their focus, scope, and relationship to the research question. The written findings were prepared by selecting illustrative examples from the recorded material and explaining how these supported the interpretation of each theme.

CAT was applied after theme development to interpret whether the patterns appeared responsive, or insufficiently responsive, to anticipated caregiver communication needs. Interpretation considered how explanation, organization, audience tailoring, language availability, practical guidance, and emotional or relational framing adapted communication to the anticipated caregiver audience. Judgments about accessibility and accommodation concerned observable features of the materials. No standardized readability, health-literacy, accessibility, or usability assessments were undertaken. Resource counts described the dataset; frequency did not determine the analytical importance of a theme.

3.2.5 Researcher role, trustworthiness and ethics

Trustworthiness was supported through documentation of resource selection, coding decisions, and developing interpretations (Lincoln & Guba, 1985). The principal researcher maintained notes within the coding grid and handwritten analytic notes, revisited earlier coding, and compared interpretations with the textual and structural features recorded in the resources.

The principal researcher conducted all coding. During regular supervision meetings held while the coding grid, codes, and themes were being developed, the researcher shared the emerging analysis with the research supervisor. Discussions addressed the coding structure, wording of codes, development of themes, and feedback on the grid. Coding and final interpretation remained the principal researcher's responsibility; there was no second coder or formal intercoder agreement procedure.

The principal researcher was bilingual in English and French and analyzed materials in their original language. As a parent of an autistic child, the researcher brought experiential familiarity with post-diagnostic questions and navigation difficulties. This experience sensitized attention to terminology, unclear next steps, fragmented information, and features that organized practical guidance.

This positioning involved familiarity with the intended caregiver audience while remaining outside the organizations producing the materials. Corbin Dwyer and Buckle (2009) describe the complexity of occupying a position between insider and outsider, and Berger (2015) explains how personal experience can influence what a researcher notices and interprets.

Because all materials were obtained from publicly accessible organizational websites, no human participants were involved and institutional research ethics approval was not required. Reporting was guided by the Standards for Reporting Qualitative Research (SRQR), a 21-item guideline intended to strengthen transparency in qualitative research reports (O'Brien et al., 2014). Bowen's (2009) methodological guidance informed the explanation of document selection and interpretation, including attention to the purpose, intended audience, and organizational context of the resources. The READ approach (ready the materials, extract data, analyze data, and distil the findings; Dalglish et al., 2020) informed how resource identification, recording, analysis, and presentation are reported here.

3.3 Results

3.3.1 Description of the resource collection

The final collection comprised 234 recorded resource items: 149 online resources, 18 recommended books, and 67 text-based informational excerpts (Table 3.1). The collection included resources presented directly by organizations and items recommended or linked through their public websites.

Table 3.1 Composition of the resource collection

Recorded material category	Resource items
Online resources	149
Recommended books	18
Text-based informational excerpts	67
Total	234

The 11 organizations represented different parts of the local service environment. English- and French-language resource pages were recorded for ACT Learning Centre and CHEO; the other included organizations' resource pages were recorded in English (Table D1). These entries describe the organizational resource pages rather than every external item to which a page linked.

Analysis of 234 resource items from 11 healthcare and community organizations developed six interrelated themes (Table 3.2). The themes are presented within three broader communication domains, which group themes with related communicative functions: Information Architecture, concerning how educational content and practical guidance were assembled; Communicative Accessibility, concerning adaptation to anticipated caregiver audiences; and Caregiver Activation, concerning how resources positioned caregivers in learning, seeking services, and connecting with support.

Table 3.2 Six themes organized within three communication domains

Communication Domain	Theme
Information Architecture	Comprehensive Information Resources
	Service Navigation
Communicative Accessibility	Accessible and Inclusive Communication
	Tailored Information for Diverse Caregiver Needs
Caregiver Activation	Empowerment Through Knowledge
	Community Engagement and Peer Support

3.3.2 Information Architecture

The Information Architecture domain describes how organizations structure and organize information to support families during the early post-diagnostic period. Organizations moved beyond presenting isolated facts by developing integrated resources that connected educational information with practical guidance for accessing services, interventions, funding opportunities,

and community supports. This architecture positioned information as a tool for helping families understand both autism and the systems they would subsequently navigate.

3.3.2.1 Comprehensive Information Resources

All included organizations provided informational materials designed to increase caregivers' understanding of autism and its implications. Resources commonly introduced the characteristics of autism, explained diagnostic terminology, described intervention approaches, and provided recommendations for supporting children across home, school, and community settings.

Many organizations adopted a layered approach in which introductory materials were supplemented by more specialized resources addressing communication, behaviour, sensory processing, education, family well-being, and available intervention programs.

Resources extended beyond the diagnostic appointment to include materials supporting different stages of the child's development, transitions into school, access to specialized services, and ongoing family adaptation. This developmental range acknowledged that learning about autism is an ongoing process rather than a single event immediately following diagnosis.

In addition to autism-specific information, organizations frequently incorporated practical information intended to reduce uncertainty. These materials explained referral processes, outlined available clinical and community services, summarized funding opportunities, and directed caregivers toward credible external organizations.

3.3.2.2 Service Navigation

A second component of the information architecture focused on helping families navigate complex healthcare, educational, and community service systems.

Service navigation resources commonly outlined recommended next steps following diagnosis, including referrals to intervention services, developmental programs, educational supports, financial assistance, and family organizations. Step-by-step guidance, checklists, and next-step guides organized practical actions and service information.

Resources also highlighted collaboration among healthcare professionals, educators, therapists, and community organizations. Materials frequently situated individual services within a broader network of coordinated care, emphasizing connections among professionals and encouraging families to engage with multiple providers throughout their child's development. Information describing multidisciplinary teams reinforced the importance of ongoing communication across sectors to support children's evolving needs.

Many organizations additionally provided directories of local and provincial resources, contact information for relevant agencies, and links to government-funded programs.

Across organizations, navigation information framed caregivers as active participants in coordinating their child's care. Informational materials encouraged parents to maintain records, prepare questions for appointments, communicate with service providers, and become familiar with available programs and eligibility criteria. Structured guidance accompanied educational information, providing caregivers with practical directions for navigating services during the early post-diagnostic period. Portia Learning Centre's financial-help information and Emerging

Minds' links to Ontario services and supports illustrated how educational collections also directed caregivers toward practical assistance (Table 3.3).

3.3.3 Communicative Accessibility

The Communicative Accessibility domain refers here to observable features of language, organization, format, and the audiences addressed that were interpreted as anticipating caregivers' communication needs. Beyond the content itself, informational resources showed attention to the accessibility, inclusivity, and adaptability of communication. The materials varied in language availability, format, and the caregiver audiences addressed.

3.3.3.1 Accessible and Inclusive Communication

Across organizations, informational materials were presented using communication strategies intended to improve accessibility. Plain language was frequently used to explain diagnostic terminology, intervention options, and service pathways while minimizing technical jargon. Information was organized using headings, bullet points, frequently asked questions, and visual formatting to present routes through the material for caregivers processing large amounts of new information.

English- and French-language resources were available within the collection. Several organizations also incorporated visual supports, infographics, videos, downloadable fact sheets, and hyperlinks to additional resources, allowing caregivers to access information using different information formats.

Some materials also addressed the emotional circumstances surrounding diagnosis through supportive and reassuring language. Materials emphasized children's strengths, developmental potential, and available supports alongside clinical characteristics of autism. This balanced communication style framed the medical diagnosis as the beginning of a broader pathway toward understanding and support.

Portia Learning Centre's frequently asked questions and CHEO's written and video resources illustrated question-based organization and varied formats for presenting information (Table 3.3).

3.3.3.2 Tailored Information for Diverse Caregiver Needs

Alongside features intended to improve accessibility, organizations frequently tailored informational resources to address the diverse circumstances of families. Resources identified particular audiences and informational concerns through their titles, descriptions, and organization.

Several organizations organized information according to children's age, developmental stage, or specific service needs, providing age- or service-specific points of entry into the information. Resources addressing school transitions, early intervention, communication development, behavioural supports, and family well-being reflected an understanding that informational needs evolve throughout a child's development. Resources included language options where available and information directed to identified audiences. This range of resources offered information addressing different immediate concerns and needs that could emerge over time.

3.3.4 Caregiver Activation

The Caregiver Activation domain concerns how resources invited caregivers to learn about autism, consider care options, seek services, ask questions, and connect with professional and community support. Informational materials positioned parents not simply as recipients of information but as informed partners in supporting their child's development.

3.3.4.1 Empowerment Through Knowledge

Across organizations, informational resources emphasized the importance of equipping caregivers with the knowledge necessary to make informed decisions regarding interventions, education, and long-term planning. Resources encouraged parents to understand available services, ask questions during clinical encounters, monitor their child's progress, and advocate for appropriate supports. Many organizations provided practical guidance regarding educational rights, funding programs, referral processes, and available intervention options.

Educational materials emphasized skill development, problem-solving, and access to reliable information as ways of preparing caregivers for participation in care. Organizations presented families as active partners in care, encouraging parents to become knowledgeable collaborators capable of navigating complex healthcare and educational systems.

QuickStart's recorded advisory text encouraged readers to examine services and professional qualifications before making a choice, while distinguishing the information provided from an endorsement of a particular treatment or provider. The advice positioned caregivers as people who would ask questions and consider options.

3.3.4.2 Community Engagement and Peer Support

The resources presented connections with broader support networks as part of post-diagnostic support. Informational resources frequently directed caregivers toward parent support groups, autism organizations, educational workshops, community programs, and peer mentoring opportunities. These resources acknowledged that valuable knowledge extends beyond healthcare professionals and may also be acquired through interactions with other families experiencing similar circumstances. Community-based organizations were presented as important sources of emotional support, practical advice, advocacy, and shared experiences.

Peer support was frequently presented as complementing professional services by providing opportunities for families to exchange experiences, discuss challenges, and identify practical strategies for navigating everyday situations. CHEO's listing of Our ASD Journeys, a family-oriented community event, placed community connections alongside educational resources (Table 3.3).

Table 3.3 Documentary examples and interpreted communication functions by theme

Theme	Named documentary example	Recorded feature	Interpreted communication function
Comprehensive Information Resources	CHEO Autism page; Fundamentals Child Behaviour Solutions Links section	CHEO grouped books and guides, websites, local contacts, Our ASD Journeys, and videos. Fundamentals combined educational articles with external resource links.	Brings educational topics and resource formats together for caregiver reference.

Theme	Named documentary example	Recorded feature	Interpreted communication function
Service Navigation	Portia Learning Centre financial-help information; Emerging Minds Resources section	Funding information and links to Ontario services and supports.	Directs caregivers toward funding information and service options.
Accessible and Inclusive Communication	Portia Learning Centre frequently asked questions; CHEO Autism page	Question-based organization and the availability of written resources and videos.	Anticipates caregiver questions and offers different information formats.
Tailored Information for Diverse Caregiver Needs	Portia Learning Centre Parent's Guide to ABA	An explicitly identified parent audience and an intervention-specific focus.	Addresses a defined caregiver audience and informational concern.
Empowerment Through Knowledge	Portia Learning Centre Parent's Guide to ABA; Fundamentals Child Behaviour Solutions educational articles	Explanatory information about intervention, autism, assessment, and related developmental topics.	Positions caregiver learning as preparation for considering care and support options.
Community Engagement and Peer Support	CHEO Our ASD Journeys listing and local contacts	A family-oriented community event listed alongside community contacts.	Presents family and community connections as part of post-diagnostic support.

Examples refer to resources recorded during fall 2024. Descriptions paraphrase recorded resource listings and relevant textual or structural features. Communication functions are analytical interpretations of the materials rather than measured effects on caregivers.

Together, the six themes, presented within three communication domains, describe related dimensions of the publicly available post-diagnostic information environment.

3.4 Discussion

This study examined publicly available post-diagnostic autism resources from healthcare and community organizations serving Ottawa and the National Capital Region. Six themes were presented within three communication domains: Information Architecture, Communicative Accessibility, and Caregiver Activation. Together, these themes indicate that post-diagnostic resources serve functions extending well beyond the provision of clinical information. These findings reinforce the importance of viewing post-diagnostic resources as an integral component of healthcare communication and patient education rather than as supplementary materials provided after the diagnostic encounter.

3.4.1 Resources as continuing post-diagnostic communication

The findings also expand existing literature on post-diagnostic communication. Studies of diagnostic disclosure and parents' subsequent experiences have shown the importance of communication surrounding diagnosis (Abbott et al., 2013; Hughes et al., 2024). Those accounts approach information through caregivers' experiences; examining publicly available institutional materials adds a perspective on how information is assembled and presented for an anticipated audience. The present study extends this literature by showing that written and digital resources can be read as a continuation of healthcare communication. Consequently, informational resources should be understood as active components of post-diagnostic care, with roles in organizing information, communicating expectations, and directing caregivers toward support.

The presence of broad information collections is significant because the questions surrounding care extend across services and over time. Canadian post-diagnostic guidance places ongoing

medical and psychosocial support within a coordinated approach to care (Ip et al., 2019). CHEO's combination of educational material and local contacts, and the funding and service links presented by Portia Learning Centre and Emerging Minds, connected learning about autism with finding routes to support.

Comprehensiveness consequently has an organizational dimension. A collection can contain many items while still requiring the reader to decide where to begin, which material applies, and how different services fit together. The distinction between a repository and navigation guidance is therefore analytically useful. The first assembles information; the second makes possible next steps and connections visible.

Research on autism diagnostic reports provides a related perspective on the relationship between detail and organization. Wilson and Gunn (2023) found that parents valued detailed reports alongside clear structure, sensitive language, and meaningful recommendations. Their work concerns a different form of communication, but it helps explain why breadth and accessibility belong together when considering resources. Useful design can preserve information in depth while offering readers a clear route through it.

3.4.2 Communication accommodation in public resources

CAT examines how communicators adapt their communication in relation to others' perceived needs, characteristics, and social identities, and how these adaptations are evaluated (Gallois et al., 2005; Giles, 2016b). Healthcare applications have used CAT to examine professional–patient interactions (Farzadnia & Giles, 2015). Informational resources were interpreted as anticipating caregiver communication needs by presenting information in accessible language, organizing

content logically, providing practical guidance, and acknowledging the diverse circumstances of families. These characteristics were interpreted as attempts to address potential barriers to understanding and engagement during a period frequently characterized by uncertainty and emotional distress.

The theoretical significance lies in the relationship between resource features and the reader those features anticipate. A frequently asked questions section assumes that a reader may approach a topic through practical questions. An explanation of terminology anticipates unfamiliarity with professional language. A parent-directed guide identifies a role and a set of concerns. These are observable ways in which communication is organized in relation to an audience. CAT gives those features a relational meaning by directing attention to assumptions about knowledge, identity, and participation (Giles, 2016b; Giles et al., 2023).

This interpretation also connects accessibility with tailoring. The use of headings or a clear explanation can make a general resource easier to approach, while audience labels and topic-specific guidance locate the information within a more particular caregiving concern. The age- and service-specific points of entry and Portia Learning Centre's intervention-specific guide illustrate different degrees of that specificity. Considering both features makes accommodation more precise than a general judgment that a resource is clear or supportive. The question becomes what anticipated need a particular feature appears to address (Gallois et al., 2005; Giles, 2016b).

The documentary findings extend CAT's healthcare applications to the public information through which an organization addresses a broad caregiver audience. The contribution is a contextual account of anticipated accommodation in resource design. The relationship between

that design and a particular caregiver's appraisal remains an empirical question for research with resource users.

3.4.3 Caregiver participation and the work of using information

The findings further highlight the importance of communication in supporting caregiver activation. Across organizations, informational materials encouraged parents to understand available services, participate in decision-making, advocate for their children, and engage with community supports. These findings can be considered alongside literature on pathways linking healthcare communication to health-related action and on associations between parent-provider relationships and adherence to paediatric guidance (Fuzzell et al., 2018; Street et al., 2009).

The caregiver role represented in these resources involved several forms of work: learning terminology, identifying services, considering funding, preparing questions, and making contact with professional or community supports. The QuickStart advisory to examine services and qualifications made that role explicit. Information thus communicated expectations about how caregivers would participate while also offering knowledge to support that participation.

Edwards et al. (2018) situated information among several influences on parents' intervention decisions, including values, experience, understanding, needs, and logistics. Their findings help contextualize the roles invited by the resources examined here. Guidance to compare an option or pursue a referral enters a decision context shaped by more than the amount of information available. The communicative task includes making options, responsibilities, and routes to assistance understandable within that wider context.

Community Engagement and Peer Support adds a social dimension to this account. The presence of “Our ASD Journeys” and parent experience within publicly available institutional resource collections presented other families as possible sources of recognition and practical knowledge.

Lee et al. (2024) reviewed parent-to-parent support in autism and identified both support-group approaches and individual matching or mentoring. Their review situated peer support in relation to emotional support, advocacy, knowledge, and practical advice. This literature helps contextualize the inclusion of parent experience and community contacts in the present resource collections.

3.4.4 Organizational context and audience diversity

Despite these strengths, variation was observed across organizations in the scope, accessibility, and comprehensiveness of available resources. CHEO brought together books, guides, videos, and local contacts; Portia Learning Centre combined parent-directed ABA information with frequently asked questions and financial-help information; and Emerging Minds linked to Ontario services and supports. Differences were evident in topic coverage, resource formats, language availability, and reliance on external links. These differences should be interpreted in relation to the organizations’ differing clinical, community, behavioural, and educational mandates (Table D1).

Organizational mandate helps explain why different resource collections emphasized different kinds of guidance. A hospital-based collection addressed a broad range of developmental and family concerns, while a service provider’s parent guide could concentrate on a particular intervention or route to funding. Attention to mandate also supports asking where the

connections among collections provide continuity and where caregivers must assemble that continuity for themselves.

Language availability is one part of that context. The English- and French-language resources in the collection addressed the region's official-language setting, while the recorded differences among organizational pages made variation in that provision visible. Casale et al. (2023) identified additional service-access difficulties for immigrant caregivers in Canada, including language and navigation barriers. Alongside that literature, the present findings support attention to how organizations identify an audience and make routes to information visible across linguistic and family circumstances.

Audience labels also need to be read in relation to the concern they address. A parent-directed intervention guide represents one form of tailoring; resources responsive to a family's language, cultural context, or service circumstances involve further design questions. The value of distinguishing Accessible and Inclusive Communication from Tailored Information for Diverse Caregiver Needs is that it keeps these different forms of adaptation visible.

3.4.5 Implications for organizational information and communication

The findings have several implications for the development and communication of post-diagnostic information resources. First, healthcare and community organizations should make informational resources a core element of continuing patient education after diagnosis. Resources should be developed using communication principles that prioritize clarity, accessibility, and responsiveness to caregivers' evolving informational needs. Second, organizations should provide structured guidance that assists families in navigating healthcare, educational, and

community systems while reducing the burden associated with independently locating reliable information. Finally, greater attention should be given to developing culturally responsive, linguistically accessible, and family-centred resources that reflect the diversity of caregivers accessing autism services.

The three domains provide a practical structure for reviewing resources. An organizational review can use these domains to consider the relationship between the information offered and the work expected of a reader.

The recorded variation supports coordination in resource development and maintenance. Hospitals, clinical providers, and community organizations can make their respective roles clearer through descriptions of services, eligibility, contacts, and links to complementary supports. A shared approach to organizing essential information can preserve local and audience-specific detail. Because public webpages change, responsibility for maintaining links and reviewing service information also forms part of the continuing communication task.

These findings support involving caregivers in resource development. Consultation with caregivers can examine whether the concerns anticipated by designers correspond to the questions readers bring, and whether the organization and wording support the tasks for which a resource is used. Such work would connect the features identified in the document analysis with user perspectives and inform subsequent resource evaluation.

Further research can develop this evaluative direction by examining how families interpret and use resources, and how navigation guidance works within different service contexts. Comparative studies across regions, and evaluations of resource design with caregivers from

different linguistic and family circumstances, can extend understanding of the relationships among information provision, explanation, and access to support.

3.5 Strengths and limitations

A strength of the study is its direct examination of the public information environment through which organizations address families after diagnosis. The collection of 234 resource items from 11 organizations allowed content to be considered together with organization, language, format, intended audience, and service context.

The inclusion of English- and French-language material, analyzed by a bilingual researcher, supported attention to the local linguistic context. Documentation of the screening frame, included organizations, resource characteristics, and selected identification pathways provides a basis for assessing how the collection was assembled.

The analytic sequence also contributes to the study's interpretive clarity. Inductive coding and theme development established the patterns before CAT was used to interpret their communicative significance. The six themes and three domains provide a contextual account of the collection that can inform further inquiry and resource review.

This study has several limitations. The analysis was limited to publicly available informational resources identified through organizations serving Ottawa and the National Capital Region. Consequently, the findings may not reflect communication practices in other jurisdictions or healthcare systems. Website content may change, and public materials may differ from

information available through other organizational channels. Interpretations of accessibility and accommodation concerned observable resource features and were not based on standardized assessments.

The findings characterize the resources organizations made publicly available during the collection period. They do not establish what individual families received during diagnostic feedback or follow-up, what clinicians recommended or explained, or whether caregivers accessed or used particular materials. Caregiver comprehension, usability, and experienced accommodation require evidence from resource users. The themes reflected the principal researcher's interpretation, informed by experience as a parent of an autistic child and by supervisory discussions about codes and theme development.

The themes constitute a contextual interpretation of the selected material. Other researchers or theoretical perspectives could organize aspects of the collection differently. The organizations' differing mandates and service roles also need to remain part of comparisons among their resource collections.

3.6 Conclusion

Post-diagnostic informational resources can play an important role in supporting families following an autism diagnosis. The findings show how resources combine clinical information with communication intended to support understanding, service navigation, caregiver participation, and community connections. Viewed through the lens of Communication Accommodation Theory, post-diagnostic communication extends beyond the accuracy of

information to encompass the ways in which that information is organized, communicated, and adapted to anticipated caregiver needs. Strengthening the quality, accessibility, and consistency of informational resources may support post-diagnostic patient education and provide families with clearer guidance during the early stages following an autism diagnosis.

In answer to the study question, the resources structured information through educational collections and guidance for navigating services; addressed anticipated caregiver audiences through explanations, formats, language options, and targeted material; and positioned caregivers as people who would learn, ask questions, pursue supports, and connect with others.

CHAPTER 4

Study 2 Caregivers' experiences of receiving and using information

4.1 Introduction

Following a child's autism diagnosis, parents may be asked to consider unfamiliar interventions, contact services, and understand recommendations while also responding to the meaning of the diagnosis for their family. Reports, leaflets, websites, and referral information can support these tasks, but their practical value depends on how caregivers understand and use them. Parents' accounts of diagnostic communication have identified a need for clear explanations and sensitive discussion, as well as information about what to do next (Abbott et al., 2013; Legg & Tickle, 2019).

The communication question extends beyond whether a resource was supplied or described as helpful. A parent may appreciate an explanation while remaining unsure which option is relevant to their child. Additional searching can therefore occur even when professional information is evaluated positively. Examining these relationships can help clarify what caregivers mean when they describe information as useful and why they continue to seek explanations elsewhere.

The shared literature and theoretical foundations are developed in Chapter 2. The present study focuses on caregivers' own explanations of what they received, which resources they consulted, and what made information useful in a particular situation. Hughes et al. (2024) identified ongoing communication demands and active information seeking in parents' experiences after diagnosis. Building on that work, this study examines the relationship between a caregiver's

appraisal of information and the reasons given for using it, requesting further explanation, or looking elsewhere.

Communication Accommodation Theory (CAT) concerns adjustments in communication and recipients' evaluations of those adjustments in interpersonal and intergroup contexts (Giles et al., 2023). For this study, CAT directs attention to the relationship between the explanations or resources described and the understanding a caregiver sought.

Accessible wording, sufficient explanation, and opportunities to ask questions can be considered in terms of perceived accommodation, meaning caregivers' appraisals of how well communication responds to their needs. The present analysis uses CAT to interpret these appraisals.

The study asks what informational materials caregivers reported receiving, which resources they consulted, and what they perceived as useful in understanding their child's needs and considering care options. Two interviews provided opportunities to revisit and elaborate these accounts.

4.2 Methods

4.2.1 Research design and interview timing

A two-time-point qualitative interview study was conducted with parents of autistic children living in Canada's National Capital Region. Each participant completed two semi-structured interviews approximately three months apart. Initial interviews (T1) were conducted in February-April 2023, with recorded follow-up (T2) dates in May-July 2023. The interviews elicited

accounts of information received after diagnosis and subsequent experiences of consulting and using resources. Analysis used reflexive thematic analysis (Braun & Clarke, 2006, 2019), with CAT informing interpretation after inductive coding and theme development.

Participants entered the study at least six months after their child's diagnosis. Accounts of the diagnostic encounter and its immediate aftermath were therefore retrospective; for some participants, these recollections concerned events up to approximately three years earlier.

Reading the two interviews together allowed a request for clarification, an account of using a resource, or an explanation of a care choice to be considered within the same participant's wider account.

4.2.2 Recruitment and participants

The principal researcher managed recruitment directly. Parent recruitment contacts were recorded from February to April 2023. English and French materials were circulated through autism organizations and posted on the researcher's Facebook profile; Autism Ontario also posted the advertisement on its website. Interested caregivers contacted the researcher directly, or organizations forwarded their inquiries. The researcher checked eligibility, collected sociodemographic information, obtained signed consent, and arranged interviews. Recruitment used convenience sampling, drawing on eligible volunteers reached through these channels, without demographic quotas or targeted efforts to achieve a particular distribution of characteristics.

Eligibility required participants to be at least 18 years old, be a parent or informal caregiver of an autistic child, live in the study region, and be at least six months beyond the child's diagnosis.

Participation was available in English or French. All completed interviews were conducted in English. The recruitment tracker recorded 31 initial contacts. Ten participants formed the final sample, and all ten completed both interviews and transcript review, yielding 20 interviews. Missed appointments were followed up by email; contacts were closed when no response was received. Reasons for non-participation were not systematically recorded.

The focused purpose and repeated interviews supported detailed engagement with particular caregivers' accounts. Malterud et al.'s (2016) concept of information power proposes that a sample providing more information relevant to the study's purpose may require fewer participants. It provides a basis for considering these features in relation to sample specificity, theoretical perspective, quality of dialogue, and analytic approach when assessing the adequacy of the dataset. Information power is used here to explain the adequacy of the material for this purpose; it does not imply that ten participants covered the range of experiences among families of autistic children.

4.2.3 Interview procedures and transcript review

The principal researcher conducted all interviews through Zoom. The researcher and each participating caregiver were alone at their respective locations. Interviews lasted approximately 45 minutes on average and were recorded in audio and video with consent, then transcribed verbatim. Participants were offered a $40 gift card in recognition of their time.

The interviews were guided by broad, open-ended questions that invited participants to describe and reflect on their experiences in their own terms. The interview guide was available in both English and French, depending on participant preference.

Both interview guides addressed information in relation to care decisions. The first asked about the sources, types, and delivery of information received after diagnosis, participants' experience of its communication, decisions made or being considered, and the influence of information on those decisions. The second asked about use of the original materials, new resources consulted, changes in perceptions, and further decisions since the first interview. Additional prompts concerned helpful or unhelpful resources, desired improvements, independent searching, and how independently obtained information complemented or differed from professional information.

Transcripts were returned to participants for review. Where participants supplied clarifications, the researcher incorporated them and returned the revised transcripts for confirmation. Review was completed once participants confirmed their transcripts. This process concerned the accuracy and clarification of participants' accounts; it did not constitute independent confirmation of the final themes.

The interview guides are included in Appendix C, and the consent materials are included in Appendix B.

4.2.4 Analytical approach

Analysis followed Braun and Clarke's (2006, 2019) six-phase approach to reflexive thematic analysis, in which themes are developed through the researcher's interpretive engagement with the data. The phases involved familiarization, initial coding, developing candidate themes, reviewing themes, defining and naming themes, and producing the thematic account. Work moved between these activities as codes and interpretations were refined. Both interviews for

each participant were considered together, while themes were developed across participants to address the research questions. During familiarization, transcripts were read multiple times in full to gain an overall sense of each participant's account.

Line-by-line coding was applied to all transcripts using a spreadsheet-based coding grid to record and organize codes. Codes were generated inductively from the data rather than from a predefined codebook, following a reflexive thematic analysis approach. This process involved close attention to participants' own language and descriptions of their experiences with informational materials. Explicit evaluations of materials were considered in relation to the meanings participants attached to them, including descriptions of confusion, reassurance, and difficulty deciding how to proceed.

Codes were then examined for patterns of similarity and difference and grouped into candidate themes. For instance, codes describing materials as helpful frequently shared features such as simplicity, clarity, and relevance, which informed the development of a theme focused on what makes information usable. Conversely, codes reflecting excess, confusion, or irrelevance clustered into themes related to overload or misfit between materials and families' needs.

Candidate themes were reviewed against the full dataset to ensure internal coherence and clear distinction between themes. Some themes were split or merged where conceptual overlap was identified. Throughout this process, analytic decisions were documented to support reflexivity and transparency. The five themes were defined by their central concern: emotional responses and support, comprehensibility and content, delivery and discussion, the role of information in decisions, and additional searching.

The principal researcher conducted all coding and discussed developing codes and themes with the research supervisor. These discussions supported analytic refinement; they did not involve independent coding or assessment of agreement. Earlier coding was revisited and code definitions were refined in the coding grid. The five themes were reviewed against extracts and transcripts, and quotations were selected to illustrate the interpretation while retaining participant and interview identifiers.

CAT was used to interpret participants' descriptions of language, explanation, tone, delivery formats, and opportunities for clarification. The interpretation concerns caregivers' perceptions of accommodation and the practical meaning of information for them. Paired accounts were used to clarify reasons for information use, continuity, and differences in emphasis. Explicit descriptions of perceived or recalled change were distinguished from differences that could reflect the interview prompts. Themes represented patterns across accounts; participants' interviews were not presented as complete individual narratives.

Returning to the wider account helped distinguish what information had been received from what it enabled the participant to understand. This distinction informed the interpretation of accounts in which information was valued while practical questions remained. The analysis used participant context to situate these accounts and did not seek to establish demographic group differences.

4.2.5 Researcher reflexivity, ethics and data availability

The principal researcher approached the study as a doctoral researcher in communication and a parent of an autistic child, bringing experiential knowledge of caregiving to the interviews. An

insider position can support familiarity while requiring attention to differences among participants' circumstances and interpretations (Corbin Dwyer & Buckle, 2009). The researcher had no prior relationships with participants, who responded to recruitment advertisements. The researcher's personal background was not presented to or discussed with participants.

Experiential knowledge made the responsibilities of seeking explanations and considering services familiar to the researcher. That familiarity also required attention to assumptions about what a caregiver might find overwhelming, useful, or sufficient. In this study, parenthood was one aspect of the researcher's position; it did not make the participating parents' circumstances or interpretations interchangeable with the researcher's own.

Reflexive attention therefore involved examining the basis for an interpretation in the account being analyzed. The coding grid, informal analytic notes, return to earlier coding, and supervisory discussions supported this work. Differences among accounts were particularly relevant: a preference for more discussion could coexist with another parent's request for a detailed document, and a positive appraisal of information could accompany a need for further explanation. The Consolidated Criteria for Reporting Qualitative Research (COREQ) is a 32-item reporting checklist for interview and focus-group studies (Tong et al., 2007). Relevant items informed the reporting of recruitment, researcher positioning, interview procedures, and analysis.

Ethical approval was obtained from the University of Ottawa Research Ethics Board before recruitment and data collection (Ethics File No. S-05-22-8008). Participants received written and verbal information about the study. Written informed consent was obtained before participation. Participants could decline a question, pause an interview, or withdraw. Identifying details were removed from transcripts and reporting, and participants are referred to by codes P1–P10. Digital

files were stored on password-protected, encrypted drives and physical documents in locked storage. Support information was available where discussing the diagnosis generated emotional discomfort.

The interview transcripts are not publicly available because they contain potentially identifying information about caregivers and their children. Selected de-identified interview excerpts are presented in this chapter to substantiate the findings.

4.3 Results

4.3.1 Participant context

The sample comprised ten parents, six mothers and four fathers, aged 27–37 years. Their children were aged 3–8 years. Nine parents were married and one was single or not partnered. Reported education comprised college/CEGEP (general and vocational college) qualifications or bachelor's degrees. Participants self-described their ethnicity as African American (n = 5), Black (n = 3), Haitian American (n = 1), or African (n = 1). Participant and child characteristics are summarized in Table 4.1.

Table 4.1 Participant and child characteristics

Code	Parent	Child gender	Child age in years	Age at diagnosis in years
P1	Mother	Female	6	3
P2	Mother	Male	6	4
P3	Mother	Male	4	4
P4	Father	Male	6	5
P5	Mother	Female	3	2
P6	Father	Female	7	5

Code	Parent	Child gender	Child age in years	Age at diagnosis in years
P7	Mother	Male	5	3
P8	Father	Female	8	6
P9	Mother	Female	7	5
P10	Father	Male	4	3

Ages and gender are those reported for the participating families. Ages recorded in whole years do not establish exact time elapsed since diagnosis.

Reported service connections included different kinds of support. Seven participants named autism-related organizations or programs, whereas two listed only a paediatrician and one listed no service connection. These descriptions help situate individual accounts of receiving information and seeking further help. For example, P3's report of a paediatrician as the only source of support provides context for the account of feeling overwhelmed below. The participant information provides context for understanding the accounts without treating all parents as equally connected to services.

4.3.2 Overview of the themes

The five themes concerned emotional overwhelm and support; clarity, comprehensibility, and content; communication and delivery; information in decisions; and additional information seeking. Interview labels T1 and T2 identify where an extract was generated.

Table 4.2 Themes and their analytic focus

Theme	Analytic focus
Emotional overwhelm and the need for support	Emotional responses to receiving and processing information, and the support caregivers wanted while responding to it.
Clarity and content in relation to a particular child	The comprehensibility, detail, and practical relevance of information in relation to caregivers' questions about their child.

Theme	Analytic focus
Delivery formats and opportunities for discussion	What verbal, written, and digital communication allowed caregivers to do, including asking questions and reviewing information independently.
Information and the reasons for care decisions	The role caregivers attributed to information when explaining a care choice, alongside the child-related concern motivating it.
Further searching to fill gaps and examine options	The purposes of consulting additional sources, including practical advice, examining options, and obtaining experiential perspectives.

4.3.3 Emotional overwhelm and the need for support

For P3, recalling the information received after diagnosis brought together its volume, the tasks it appeared to require, and sadness about the diagnosis. The difficulty concerned what the parent was being asked to understand and undertake within that emotional situation:

> The information was a lot to comprehend. There was a lot of things that I will have to do. First of all, I was overwhelmed with this information […] I was also very sad because my child has the diagnosis. (P3, T1)

The account connects information with anticipated responsibilities. Receiving material introduced matters requiring attention without necessarily providing an immediate sense of how to proceed. The account locates the information within a family situation in which the next steps and the support available for taking them were consequential concerns.

A need for reassurance was also articulated at the second interview:

> "Sometimes, dealing with a diagnosis can be overwhelming, and additional support can be reassuring." (P10, T2)

These accounts locate emotional support alongside informational support. Across these examples, the relevant issue is the relationship between the information a caregiver encounters and the support available to engage with it.

4.3.4 Clarity and content in relation to a particular child

Participants evaluated information in terms of both comprehensibility and practical relevance. P4 valued the explanation of terminology and acronyms, and P6 described the value of plain English. P9 described feeling overwhelmed by the information and unsure what needed to be done:

> "I was feeling the information was a lot to take in. The information was to me very overwhelming. I didn't know the various things that I needed to do." (P9, T1)

P8's assessment combined an acknowledgement of usefulness with difficulty interpreting the options presented:

> "The information was a bit helpful but very confusing as well for a first-time user. The way they laid out therapy information it would be better if they found a way to include a bit of every therapy that exist, so all information is provided." (P8, T2)

Helpful and confusing were compatible appraisals in this account. P8 wanted a basis for understanding the range of proposed options. P5 explained the need for further explanation:

> "Yes, I would want more information. Not more papers, more explanation. It was all new, some of the things did not make any sense to me at all." (P5, T2)

The requested response concerned explanatory support rather than an increase in the amount of material. Together, these accounts show why a favourable appraisal of some content did not necessarily mean that a caregiver had enough explanation for the question they were trying to address.

4.3.5 Delivery formats and opportunities for discussion

Participants described verbal discussions, printed materials, emails, website links, and an e-book. Their preferences concerned what these formats allowed them to do. P1 wanted greater opportunity for direct discussion:

> "All information was given through websites. I would prefer talking to the doctor more." (P1, T1)

P1 continued to express a preference for more discussion with the doctor at T2. Access to online information did not fully address this caregiver's wish for interaction.

P9 valued the possibility of reviewing information independently as well as obtaining explanation:

> "I would have preferred a book of the various options or a very detailed document so I could go home and take time to review." (P9, T2)

In the context of P9's earlier uncertainty about what needed to be done, this request indicates a desire for explanation and information that could be reviewed at home. The accounts suggest that discussion and written resources serve different functions, with preferences differing among parents.

Participants also raised accessibility needs beyond their own preferred formats. P4 proposed information in other languages, and P6 called for information accessible to people with disabilities. These suggestions concerned the range of families resources might need to reach. They indicate that caregivers considered the ability to access and revisit information when discussing its usefulness.

4.3.6 Information and the reasons for care decisions

Participants differed in whether they described information as supporting an immediate choice. At the first interview, P6 indicated that the family was continuing to observe:

> "Not yet, we are still observing. It is tough." (P6, T1)

At T1, P5 described the information positively and reported having made intervention decisions. At T2, P5 distinguished the information's helpfulness from the reason for choosing speech therapy:

> "Yeah, it was helpful. But it did not help me decide to do speech therapy. The decision was mainly because my child had communication problem." (P5, T2)

P10, by comparison, attributed a clear decision-related value to professional information:

> "The information we received from healthcare professionals was very helpful in our decision-making process. It allowed us to understand the various options available and the potential benefits of each treatment." (P10, T2)

The account describes information as helping the family understand options and their perceived benefits. P5's explanation emphasized a concern about the child that motivated the choice. These different accounts show that information could contribute to a decision while its role depended on the question facing the family. Describing a resource as helpful did not, by itself, identify how much influence it had on the eventual choice.

4.3.7 Further searching to fill gaps and examine options

Information provision was uneven across the accounts. P7 recalled receiving no materials and feeling insufficiently informed:

> "I did not receive anything […] I can say I am very uninformed." (P7, T1)

Other participants described information as useful while reporting continuing needs. P2 evaluated an e-book positively and reported applying its advice at T1. At T2, the same caregiver described seeking practical tips online and from friends because professional information did not answer all the questions.

P8 described searching to understand and examine a proposed option:

> "After I received information, I went and did some background research through google. I consulted different websites just to know what I was getting my kid into." (P8, T2)

P8 also forwarded the organization's information to a friend who was a doctor, reporting that "he was fine with it."

P10 described consulting several kinds of source:

> "We looked for resources from reputable websites, books written by experts, and personal stories of other parents who had been through similar experiences. The information we gathered complemented what we received from doctors and provided us with additional insights and perspectives." (P10, T2)

Across these examples, the reasons for further searching included obtaining practical advice, understanding a proposed option, and drawing on experience. Those purposes explain more about the activity than its occurrence at the second interview alone.

4.3.8 Relationships within paired interview accounts

Table 4.3 brings together four of the paired accounts. P1's continuing preference for discussion provides a further example of continuity across interviews.

Table 4.3 Examples from paired interview accounts

Code	First interview	Second interview	Relationship within the account
P2	Valued an e-book and reported applying its advice.	Sought practical tips online and from friends because professional information did not answer all their questions.	A resource could be useful while leaving practical questions that prompted further searching.
P5	Described information positively and reported having made intervention decisions.	Connected the therapy decision to the child's communication difficulties and requested further explanation.	Information was considered in relation to a specific concern about the child.
P8	Described treatment information as insufficiently detailed.	Researched care options online and forwarded the organization's information to a doctor friend.	Further searching served to examine and understand options.

Code	First interview	Second interview	Relationship within the account
P9	Described overwhelm and uncertainty about what needed to be done.	Valued personalized explanations, questions, further discussion, and written information to review.	Explanatory support and resources for independent review served related purposes.

The comparisons relate participants' descriptions at the two interviews; differences in emphasis were interpreted in light of the interview prompts.

The paired examples clarify the relation between an appraisal and the purpose attached to information. They give substance to the themes by showing how a caregiver could value information while continuing to seek something that the original resource or conversation had not resolved.

4.4 Discussion

4.4.1 Usefulness in relation to the question being addressed

This study examines the relationship between receiving information, finding it useful, and having sufficient explanation to use it for a particular purpose. The contribution lies in specifying what caregivers were trying to accomplish when they evaluated or supplemented information.

Existing research has documented communication demands after diagnosis (Hughes et al., 2024), parents' own research as part of understanding autism information (Lindly et al., 2022), and expectations of diagnostic reports (Wilson & Gunn, 2023). A positive appraisal of a resource could refer to one aspect of its content while a later search addressed a question it did not answer.

Continued searching therefore needs to be interpreted alongside what caregivers considered useful and what remained unresolved.

This distinction also helps explain the relationship between clarity and practical meaning. P9's account highlights the difficulty of identifying what to do next when information feels overwhelming. Readability and the availability of material remain important, but these accounts direct attention to opportunities for caregivers to discuss the implications of what they have received. A resource's usefulness cannot be fully understood without the purpose for which the caregiver was consulting it.

General information may explain an intervention without answering why it is relevant to a particular child or what the caregiver should consider next. Wilson and Gunn (2023) found that parents wanted diagnostic reports to combine detail with accessible presentation, sensitive language, and meaningful recommendations. That combination is relevant here because requests for explanation and requests for detailed reference material can be compatible. The issue is how information is organized around a caregiver's question, including the opportunity to discuss its implications.

A global assessment of helpfulness consequently leaves important questions open. It does not specify which part of a resource was useful, what the parent did with it, or which question remained unanswered. The study's contribution is to show how favourable appraisals and unresolved needs can coexist within the same account, and to identify the purposes of continuing engagement.

4.4.2 Emotional and relational conditions of information use

The connection between information and emotional support is consistent with research on parents' diagnostic experiences. Legg and Tickle's (2019) synthesis identified emotional, informational, and relational needs, making the relationship with professionals part of the support context. Rabba et al. (2019) also described support needs following an early autism diagnosis. In the present study, P3 connected information with sadness and the responsibilities that lay ahead, while P10 described the reassurance that additional support could provide.

Hughes et al. (2024) similarly situated ongoing communication demands and active information seeking within parents' wider experiences after diagnosis. A caregiver may need help identifying the first question to address, relating advice to a child, or deciding which material deserves attention. Emotional support and explanatory support can therefore be considered together: the communication encounter offers a setting in which uncertainty can be expressed and the information discussed in manageable terms.

This does not require assuming that all caregivers need less detail when discussing a diagnosis. P9's request for a detailed document points to the importance of having material available for later review. Abbott et al. (2013) and Wilson and Gunn (2023) place clarity and sensitivity within parents' expectations of diagnostic communication. The present findings support attention to pacing, explanation, and opportunities to return to questions while retaining access to substantive information.

4.4.3 Perceived communication accommodation

CAT provides a way to interpret caregivers' appraisals of whether communication met their needs. Its healthcare application concerns both linguistic and social aspects of an exchange (Farzadnia & Giles, 2015; Giles et al., 2023). In these accounts, accommodation was relevant to how much explanation was available, whether questions could be asked, and whether a resource could be related to the child.

The language dimension of accommodation is visible in what parents found helpful and what they requested. Explaining terminology addressed unfamiliarity with professional vocabulary. P5's request for explanation concerned how that information made sense in the family's circumstances. Through CAT, these are related communication tasks: making language interpretable and responding to the understanding the recipient is seeking.

The differences between P1 and P9 also clarify why accommodation cannot be reduced to choosing one format. P1 wanted more discussion despite access to websites. P9 wanted detailed information to review as well as explanation. Dialogue could address questions arising from a resource, while a written or digital reference could support later review.

Opportunities to ask questions also give caregivers a role in directing the exchange. P1's preference for discussion can be understood as a request for interaction with the doctor in addition to access to a source. A conversation allows the caregiver to identify which explanation is needed; a document allows earlier information to be revisited. CAT's attention to recipients' appraisals helps explain why the same delivery format need not be experienced as equally accommodating by different people.

The relational dimension concerns whether there is room to express confusion, uncertainty, or a need for reassurance. P10's account of reassurance and P3's description of overwhelm place those concerns alongside the informational task. In this interpretation, accommodation involves attending to the emotional circumstances in which explanations are sought.

4.4.4 Information within decisions and the use of multiple sources

Edwards et al. (2018) situate information among the considerations influencing intervention choices. The present findings similarly show the importance of asking what role information played in a decision. P10 described professional information as clarifying options and benefits, while P5 connected a choice to the child's communication difficulties. These explanations preserve the distinction between considering information and attributing a choice to it.

The reasons for additional searching also varied. P2 sought practical advice, P8 examined a proposed option, and P10 sought complementary perspectives.

The distinction between a care concern and the information consulted to address it is especially useful. P5's explanation gave the child's communication difficulty a central place in the choice. Professional information could be helpful without being the reason the parent assigned to that decision. This suggests that communication support should explore what the caregiver wants an option to address and how the available information helps examine that purpose.

When caregivers sought explanation elsewhere, their activity could address a gap in the original exchange, but it also served purposes beyond correcting a failure. P10 valued personal stories as additional perspectives alongside doctors' information. These accounts describe an information

environment in which people and materials could be consulted in combination, with the value of each linked to the kind of understanding sought.

Lindly et al. (2022) described parents' research, appraisal of information, and understanding of services as interconnected parts of autism services use. That perspective helps explain why consulting another source can be part of making professional information usable. The relevant analytic question is what the additional source contributed to the caregiver's understanding.

Smith et al. (2020), studying complementary medicine decisions, found that parents encountered complex and sometimes conflicting information and wanted a reliable source to help navigate it. Alencar et al. (2025) also documented continuing information needs in parent communities. In the present interviews, the reasons for searching were identifiable: obtaining practical guidance, understanding an option, or gaining experiential perspectives. Attending to those purposes offers a more precise basis for discussion with caregivers than assuming that further searching always signals dissatisfaction.

4.4.5 Implications for communication and information support

The findings support asking caregivers which questions remain after resources are supplied and what further explanation would help them use the information. P5's request suggests that adding material may leave an explanatory need unresolved. Discussions can connect options to the child's circumstances, clarify the purpose of a recommendation, and help the caregiver identify the next question or action.

Written and digital information should be available for review alongside opportunities for discussion. P1 and P9's accounts support a flexible approach to these functions. Follow-up

opportunities may enable questions that arise when a caregiver consults information independently. This implication is consistent with Canadian guidance on continuing care and support after diagnosis (Ip et al., 2019) and research emphasizing differences among family needs (Battanta et al., 2024).

A practical response is to ask what the caregiver needs to understand at that point in the conversation. Questions about which option is unclear, what the parent wants to review at home, and which next step remains uncertain can help connect a resource to its use. P5's request for explanation and P9's preference for a detailed document support different responses to different needs. Providing substantive material together with an opportunity to discuss it allows those functions to be addressed within the same support process.

Caregivers can also be invited to discuss information obtained from other sources. Asking what they found useful, what remains confusing, and how it relates to an option under consideration may support a more informed exchange with professionals. P4 and P6's suggestions also support attention to language and alternative formats, while further work is needed with families who encounter those access barriers directly.

Burke et al. (2024) illustrate how family feedback can inform the communication functions and practical content of digital service-navigation support. Their work supports involving caregivers in identifying what a resource should help them do. In light of the present accounts, resource development and review could examine whether caregivers can find an explanation, relate it to a concern, and identify where to seek clarification. These questions connect the design of information with its use, while recognizing that preferred formats and explanatory needs differ among families (Battanta et al., 2024; Wilson & Gunn, 2023).

Future research could follow comparable questions across repeated interviews and examine caregivers' accounts in conjunction with the resources or consultations they discuss. Studies involving a wider range of family circumstances could clarify how access to explanations and support differs across contexts. Evaluation of communication approaches should examine whether caregivers can understand and apply information to their questions, in addition to satisfaction with the materials received.

4.5 Strengths and limitations

Two interviews with each participant provided opportunities for elaboration and contextual interpretation. Considering the interviews together helped retain individual concerns within the thematic account, including continuity in P1's preference for discussion and the coexistence of useful information and additional searching in P2's account.

All ten participants completed both interviews, giving the analysis paired material for every caregiver in the final sample. Transcript review provided an opportunity for participants to clarify their accounts before those accounts were confirmed.

The detailed participant description also contributes to contextual interpretation. It identifies the reported range of service connections and makes it possible to situate an example such as P3's overwhelm in the context of the support named in the demographic information.

The study also has limitations. Accounts of diagnosis were retrospective, sometimes extending several years before participation. Recollections may have been shaped by subsequent

experiences, and the interviews were not observations of the diagnostic encounter. The regional convenience sample was small and recruited through organizations and online networks. It may underrepresent families less connected to those settings. Although English and French participation was offered, the final sample contributed English-language accounts only. Findings cannot establish experiences across linguistic, cultural, socioeconomic, or geographic circumstances not represented or examined in sufficient detail.

The two guides differed in emphasis. The follow-up interview asked more directly about independent searching and subsequent decisions, as well as inviting reflection on changes in perceptions of the original materials. Greater attention to a topic at T2 may therefore reflect the questions asked. Paired accounts support interpretation of continuity, elaboration, and explicitly reported change; differences between interviews alone do not demonstrate a general progression in caregivers' engagement with information.

The participant description provides context for interpreting the accounts, but demographic characteristics were not systematically used to establish differences between groups. Transcript review supported clarification of participants' accounts, rather than confirmation of every interpretation. Consistent with reflexive thematic analysis, interpretation was situated in the researcher's engagement with the data (Braun & Clarke, 2019).

The analysis concerns caregivers' reported experiences and interpretations. The study did not observe diagnostic consultations, assess the materials themselves against standardized criteria, or measure decision quality and subsequent outcomes. Professional intentions and the effects of a communication practice cannot be established from these accounts.

4.6 Conclusion

Caregivers' accounts show that professional information could be valued while leaving questions about its meaning, relevance to a child, or implications for a care option. Further searching served different purposes, including obtaining practical advice and checking proposed options. These relationships help explain why receiving information and finding it helpful did not necessarily resolve the need for explanation. Post-diagnostic communication can respond by connecting resources with discussion, recognizing caregivers' use of other sources, and providing opportunities to revisit questions.

In relation to the research questions, participants described receiving information through discussion, print, email, websites, and an e-book, although provision varied across accounts. They used supplied resources and consulted additional sources for practical advice, clarification, and perspectives on care options. Perceived usefulness was connected to understandable language, relevance to the child, opportunities for discussion, and information that could be reviewed independently.

CHAPTER 5

Study 3 Caregiver communication and coping in online peer spaces

5.1 Introduction

Parents and caregivers of autistic children often assume substantial informational, emotional, and decision-making responsibilities following diagnosis. They may need to evaluate intervention options, coordinate services, interpret professional recommendations, advocate within educational and health systems, and respond to their child's changing needs. Canadian research has documented parents' experiences of waiting for diagnostic and treatment services, including the practical and financial adjustments families make while seeking support (Smith-Young et al., 2020).

Formal health and social care systems do not always provide the sustained communication caregivers need during this period. Diagnostic consultations may offer clinical findings and initial recommendations, but caregivers frequently report insufficient guidance about how to translate that information into everyday decisions (Crane et al., 2016; Hughes et al., 2024). This gap can leave caregivers uncertain about available services, intervention choices, and the credibility or relevance of competing recommendations (Edwards et al., 2018; Grant et al., 2016).

Research on intervention decision-making describes emotional and practical demands developing together as parents seek information and consider options following an autism diagnosis (Grant et al., 2016). These findings support examining care-related questions alongside the emotions and responsibilities caregivers express when discussing them.

Many caregivers use online communities to supplement information and support obtained through formal systems. These communities may be particularly relevant when professional guidance is unavailable, difficult to access, or insufficiently responsive to the practical details of family life (Abel et al., 2019; Frey et al., 2022).

Facebook groups have become prominent sites of autism-related peer communication. Previous research indicates that parents use autism-focused Facebook groups to obtain information, share experiences, socialize, and advocate for their children (Abel et al., 2019; Mohd Roffeei et al., 2015). The literature reviewed in Chapter 2 situates these exchanges within research on online peer support, experiential knowledge, and the social dimensions of coping.

The transactional model of stress and coping developed by Lazarus and Folkman (1984) provides a useful framework for examining caregiver communication. In this model, coping is a dynamic process shaped by appraisal, the assessment of what a situation means for the individual and what resources they perceive as available to respond.

The distinction between problem-focused coping (efforts to manage or alter the conditions contributing to stress) and emotion-focused coping (efforts to regulate emotional responses) does not imply that these functions occur separately. Existing scholarship has examined their overlap and questioned their adequacy as overarching categories for organizing coping responses (Folkman & Moskowitz, 2004; Skinner et al., 2003). In this study, these concepts support interpretation of the functions expressed in caregiver posts without requiring each segment to fit a single category.

Later developments in transactional coping theory also address meaning-focused coping and the contribution of positive emotions during sustained stress (Folkman, 2008). This perspective is relevant to interpreting caregivers' accounts of meaningful milestones and valued experiences during periods of difficulty.

Autism-focused research has addressed social support, information exchange, advocacy, and group purposes (Abel et al., 2019; Mohd Roffeei et al., 2015; Reinke & Solheim, 2015). The present study builds on this work by examining how care-related uncertainty, practical knowledge, emotional experience, and perceived caregiving responsibilities are expressed together in selected Facebook posts.

The objective was to interpret patterns of meaning across caregiver-generated posts from two publicly accessible Facebook groups focused on parenting autistic children. Lazarus and Folkman's transactional model informed interpretation of the themes developed through reflexive thematic analysis. The intended contribution is a contextual account of caregiver discourse, with attention to the responsibilities and self-questioning expressed alongside practical care concerns. The study addressed the following research question:

How do parents and caregivers of autistic children express care-related uncertainty, caregiving experiences, and coping in selected posts from public Facebook peer-support groups?

5.2 Methods

5.2.1 Research design and online setting

This qualitative study used reflexive thematic analysis to examine naturally occurring caregiver discourse in two publicly accessible Facebook peer-support groups. The analysis focused on how parents and caregivers of autistic children expressed care-related uncertainty, shared practical knowledge, and described emotional and caregiving demands outside formal health and social care settings.

Reflexive thematic analysis was selected because it supports the interpretation of both explicit meanings and underlying patterns across qualitative data. The analysis followed Braun and Clarke's six-phase approach: familiarization, initial coding, generation of candidate themes, review and refinement of themes, definition and naming of themes, and production of the analytic account (Braun & Clarke, 2006, 2021b). Lazarus and Folkman's transactional model of stress and coping was used as a sensitizing framework, offering concepts that guided interpretation of the themes. It informed attention to problem-focused and emotion-focused coping without predetermining the initial codes or treating the two forms of coping as mutually exclusive.

5.2.2 Group selection and context

Data were obtained from two active publicly accessible Facebook groups focused on parenting autistic children. The researcher purposively selected the groups following a preliminary review conducted between January and March 2024. The review considered public

accessibility, observed posting activity, relevance to autism caregiving, and the availability of caregiver discussion relevant to the research question.

Posts were accessible without joining the groups or requesting administrator approval. Group administrators were not informed of or consulted about the study. The groups were not geographically restricted to Ontario or Canada. Contributors' locations could not be independently verified, so the dataset was not treated as an Ontario or Canadian sample.

The groups are identified as Group 1 and Group 2 throughout this chapter. Group names are withheld to reduce the possibility that contributors or posts could be located through online searches. The archived material collected during March 10-April 10, 2024, displayed approximately 260,500 members for Group 1 and 2,200 members for Group 2. Membership figures describe the groups' displayed size, not the number of active contributors or individuals represented in the analysis.

5.2.3 Data collection and selection of contributions

The analytic dataset was restricted to material published from March 10 to April 10, 2024. The same one-month sampling window was used for both groups to establish a common timeframe and keep the material manageable for repeated reading and detailed manual analysis. The study was designed to examine discourse within this bounded period rather than changes over time.

No automated scraping tools or bots were used. Publicly visible posts were manually reviewed and transcribed into a structured dataset. No researcher-initiated interaction occurred, and contributors were not contacted or recruited.

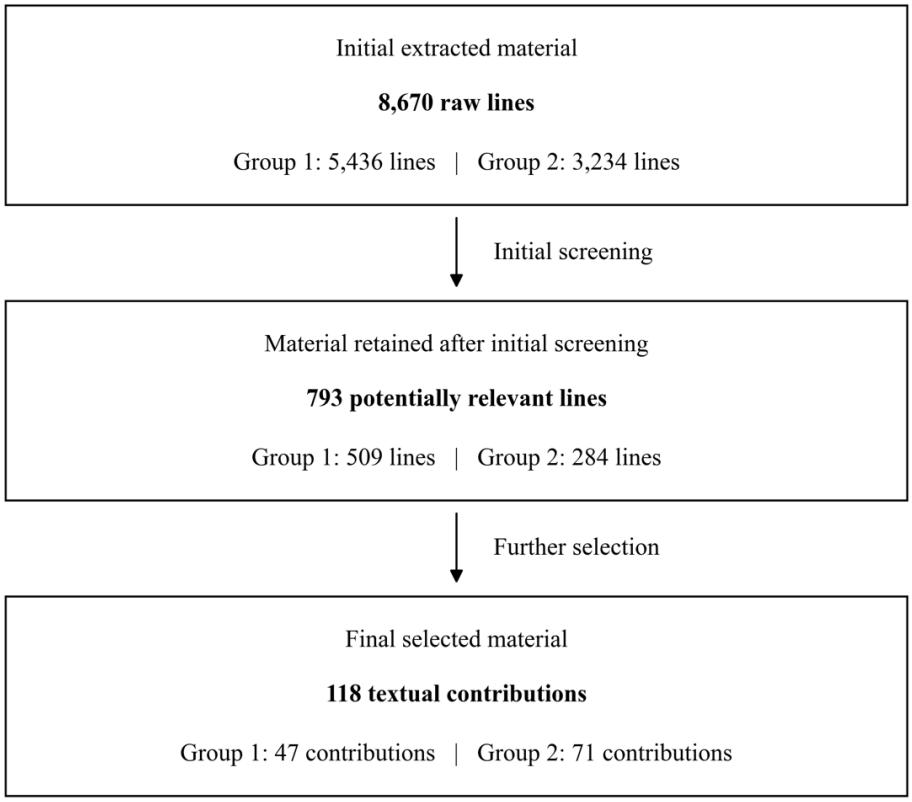
The researcher manually extracted 5,436 raw lines of text from Group 1 and 3,234 from Group 2, totaling 8,670 lines. A line represented a row of transcribed text and described the volume of material rather than a distinct post, comment, or contributor. Initial screening removed duplicates, moderator announcements, memes, and material judged unrelated to caregiving or care navigation, leaving 509 potentially relevant lines from Group 1 and 284 from Group 2, totaling 793 lines.

Further selection produced a final inventory of 118 textual contributions: 47 from Group 1 and 71 from Group 2. The inventory includes both originating posts and comments retained as individual entries. Throughout this chapter, "selected posts" refers collectively to these retained contributions, not to 118 complete discussion threads or 118 distinct contributors. Figure 5.1 summarizes the selection stages, distinguishing text-volume counts from the number of selected contributions.

Selection focused on content addressing at least one of the following: care-related uncertainty or service navigation; treatment or intervention-related decisions; everyday caregiving strategies; emotional responses to caregiving demands; requests for or provision of peer support; and reflections on coping with autism-related caregiving responsibilities.

The retained material varied in length and detail. It included brief affirmations and acknowledgments, as well as some contributions promoting products or resources. Brief responses were interpreted only for the meanings expressed in the retained text, without assuming their effects on other contributors.

Figure 5.1 Selection of material for analysis



Lines measure text volume; contributions are selected posts or comments. The stages use different units. Counts do not represent complete threads or unique contributors. Exclusions by reason were not separately logged.

5.2.4 Data preparation

Source-group identifiers were retained during data preparation so that each item could be traced to its original dataset. Usernames, profile photographs, links to personal accounts, geographic details, names, and other potentially identifying information were removed during transcription. Emojis were removed unless their communicative meaning was directly relevant to the surrounding text, in which case their general emotional function was recorded in an analytic memo rather than reproduced verbatim.

Each post was assigned a study identifier indicating its source group and location in the dataset. Line numbers supported retrieval during coding and documentation of code and theme development. The researcher manually organized the cleaned material in a structured coding matrix.

Because demographic information was not systematically available, the study did not infer contributors' race, ethnicity, socioeconomic status, immigration status, or geographic location. The contextual inventory distinguishes relationships stated in the text from unverified role labels in the coding record. Appendix E1 summarizes the relationships stated in the selected material.

5.2.5 Reflexive thematic analysis

The author conducted all coding and analysis, beginning with repeated reading of the 118 selected posts to develop familiarity with their content and language. Initial coding was primarily inductive and focused on meaning-bearing segments expressing uncertainty, information seeking, advice giving, care-related decisions, emotional disclosure, validation, adaptation, and perceived caregiving responsibility.

Coding included both semantic and latent interpretation. Semantic codes captured what contributors explicitly discussed, while latent coding examined the assumptions, relational dynamics, and meanings underlying those discussions. Posts could receive multiple codes when they contained overlapping informational, emotional, and relational functions.

Manual coding involved active interpretation of the material and reflection on how the researcher's perspective shaped that interpretation. Initial coding began with open review of

contributions from Group 1, followed by Group 2. Analytical memos were written at each stage to document evolving interpretations and intersections with the theoretical framework.

Codes were compared within and across the two groups and consolidated into candidate thematic patterns. Candidate themes were reviewed against the complete dataset to assess internal coherence, distinctiveness, and relevance to the research question. Themes were then refined, defined, and named through repeated examination of coded extracts and analytic memos. Appendix E2 provides paraphrased summaries of the selected entries, their source-group identifiers, and their theme and subtheme assignments.

After developing the themes, the researcher used Lazarus and Folkman's transactional model to interpret expressions of appraisal, problem-focused coping, and emotion-focused coping within the selected posts. The framework did not serve as a fixed coding template. The eligibility criteria had directed selection toward coping, support, and care-related experiences, while coding and theme development attended to the meanings expressed within that material.

Table 5.1 Application of the six phases of reflexive thematic analysis

Phase	Description (as applied in this study)
1. Familiarization	Repeated reading of all included posts; analytic memos documented early impressions
2. Initial Coding	Inductive coding of meaningful phrases related to coping or decision-making
3. Searching for Themes	Grouping of codes into candidate themes and subthemes
4. Reviewing Themes	Cross-checking theme coherence and adjusting overlaps or inconsistencies
5. Defining and Naming Themes	Clarifying the scope of each theme and selecting final theme names
6. Writing Up	Integrating analysis with paraphrased excerpts and theory in a coherent narrative

5.2.6 Researcher positionality, reflexivity and ethics

The author is a communication researcher and the parent of an autistic child. This personal and academic familiarity with autism caregiving formed part of the interpretive position from which the material was read. Reflexive journaling and analytic memoing throughout data collection and analysis documented methodological decisions, evolving interpretations, emotional responses, and reflection on how this familiarity shaped attention to particular accounts and meanings (Ortlipp, 2008).

Personal experience of autism caregiving sensitized the author to uncertainty, service-navigation demands, and the distinction between receiving information and being able to use it. This familiarity also created a risk of assuming that contributors' experiences resembled her own (Corbin Dwyer & Buckle, 2009). Early coding emphasized vulnerability; subsequent review gave greater attention to resilience and adaptive capacity. Repeated engagement with the material and discussions with the research supervisor supported examination of these interpretations.

The author discussed the study with the research supervisor at each stage while retaining responsibility for all coding and analysis. The research supervisor did not act as an independent coder, and no intercoder agreement procedure was undertaken. This approach is consistent with reflexive thematic analysis, in which themes are developed through the researcher's interpretive engagement with the material and coding agreement is not treated as a criterion of analytic quality (Braun & Clarke, 2021a, 2023). Quality was addressed through sustained engagement with the posts, reflexive examination of interpretations, and documentation of the development and evidentiary basis of the themes. Appendix E3 cross-references the chapter's reporting against the Reflexive Thematic Analysis Reporting Guidelines (Braun & Clarke, 2024), which support

clear explanation of the analytic process, the researcher's interpretive role, and the relationship between the chosen method and the account presented.

The study analyzed posts from publicly accessible Facebook groups and involved no direct interaction, recruitment, or intervention with contributors. Under the approved research protocol, individual consent was not required for the analysis of publicly available material.

Public accessibility does not necessarily mean that contributors expect their posts to be reproduced in research outside the group. Internet research ethics guidance emphasizes the context of disclosure, potential vulnerability, and possible harms from dissemination (Eysenbach & Till, 2001; franzke et al., 2020). These considerations are particularly relevant when caregivers disclose information about children's diagnoses, behaviour, and family circumstances.

The material was treated as potentially sensitive. Group names are withheld and identifying details are omitted from reported excerpts. Illustrative excerpts are paraphrased to reduce the risk of reverse identification, in which searches for quoted wording can lead back to the original post and its contributor (Ayers et al., 2018). The author checked the paraphrases against the original material to preserve their analytic meaning and conducted online searches of revised excerpts to assess traceability. These measures reduce identification risks but cannot guarantee anonymity.

The data were stored in a secure research archive accessible only to the research team. Findings are reported at the thematic level, and no attempt was made to identify contributors, verify their personal characteristics, or access information outside the publicly visible group discussions.

The qualitative dataset is not publicly available because the Facebook posts contain sensitive caregiver narratives and may remain identifiable despite the removal of usernames and other direct identifiers.

5.3 Results

5.3.1 Material analyzed and thematic overview

The final analytic inventory comprised 118 selected textual contributions, including originating posts and comments: 47 from Group 1 and 71 from Group 2. The material was published in English between March 10 and April 10, 2024. Entries varied from short acknowledgments to fuller accounts of practical problems, emotional experiences, and caregiving dilemmas.

The reflexive thematic analysis of the selected material produced four themes: navigating uncertainty in fragmented systems, making meaning through peer connection, practical wisdom in everyday parenting, and moral labor and invisible strain.

Findings are presented across the combined dataset. Group identifiers indicate the source of illustrative material. The themes do not imply equal representation in both groups, and the analysis does not establish differences in the prevalence of particular experiences between their memberships.

Table 5.2 summarizes the four themes, their subthemes, and an illustrative paraphrase for each subtheme. Source-group identifiers provide context without attributing demographic characteristics to contributors.

Table 5.2 Themes and subthemes in caregiver communication

Theme	Subtheme	What caregivers described	Illustrative paraphrased excerpt
Navigating uncertainty in fragmented systems	Delayed access	Waiting for assessments, interventions, benefits or school accommodations; questions about timelines and retroactive support; strain that continued while support was unavailable.	My 5-year-old is suspected of having ADHD and autism, but he masks at school, so I receive almost no help from them. They provided a letter of support for the referral. (Group 1)
	Systemic opacity	Difficulty interpreting rules, assessments, school letters and procedures; peers asked to explain them and to say whether a requirement was standard or open to challenge.	They could not calculate her full-scale score because the individual scores were too different. Does anyone know why that happens? (Group 1)
	Perceived limitations of professional guidance	Professional encounters experienced as unhelpful, unsettling or inconsistent, leaving interpretive and emotional questions open.	Our paediatrician has not been helpful. Another doctor was extremely negative and increased our anxiety, but we have decided to continue with genetic testing. (Group 2)
Making meaning through peer connection	Emotional disclosure and validation	Gratitude, shared experience and disclosures of difficulty that also asked for usable understanding.	I am in the same situation and have no help. I wish I understood how to respond to his moods and understand him better. (Group 2)

Theme	Subtheme	What caregivers described	Illustrative paraphrased excerpt
	Milestone sharing	Changes presented as meaningful because of the child's history, inviting recognition.	She did not have her usual meltdown. She went upstairs and fell asleep without the comfort item. (Group 1) He came over, sat beside me, and leaned his head against me. It was the first time he had approached me in that way to show affection. (Group 2)
	Collective witnessing	Discussions placing caregiving in wider questions about autism, intervention, disability and social expectations, including the controversy over applied behaviour analysis.	We celebrate the small things that other people may take for granted. Today felt like a fortunate day. (Group 2)
Practical wisdom in everyday parenting	Adaptive parenting strategies	Adjustments described as evolving, trial-and-error responses rather than solutions, such as staged changes in the caregiver's involvement around bathing.	I remove his hands and firmly say no. I cannot say that it works, but it is the response I can manage at the moment. (Group 1)
	Tactical crowdsourcing	Requests for specific resources, products or methods; some recommendations, such as cannabidiol products and an alternative-health documentary, rested on personal testimony.	How can I break this concept into smaller steps for my son? He can pronounce and read the words, but he does not appear to understand the underlying idea. (Group 1)
	Iterative learning	Awareness that strategies must change as children grow and needs shift, framed hopefully.	There is hope for our children. Find what interests them and develop it. They may excel in a few areas rather than perform equally across all of them. (Group 1)

Theme	Subtheme	What caregivers described	Illustrative paraphrased excerpt
Moral labor and invisible strain	Internalized stress and guilt	Seeking guidance while questioning one's adequacy, and reassurance about decisions that might seem restrictive, such as using a mobility buggy.	A caregiver asked whether it would be wrong to use a mobility buggy for a 5-year-old because of frequent meltdowns. (Group 2)
	Tensions between caregiving needs and institutional expectations	Competing responsibilities when meeting one need depended on another institution's requirements; questioning a school's characterization of a child.	A caregiver sought toilet-training advice because childcare providers would not accept the child until toilet trained, while the caregiver needed childcare to continue working. (Group 2)

5.3.2 Navigating uncertainty in fragmented systems

This theme concerns the interpretive work caregivers described when formal systems left them without a clear course of action. Questions about schools, assessments, financial support, and therapies expressed uncertainty about what institutional information meant and what could be done with it. Having a letter, assessment result, or professional recommendation did not necessarily provide direction. Caregivers brought these unresolved questions into peer spaces, seeking experiential knowledge that might make their next steps clearer.

Across these posts, caregivers positioned peers as informal interpreters of institutional processes. They asked others to explain letters, assessment results, eligibility rules, and procedural expectations.

In the excerpt on perceived limitations of professional guidance (Table 5.2), the analytic importance lies in the coexistence of a practical next step, continuing genetic testing, and unsettled feelings about the guidance received. The group offered an audience to whom that reaction could be expressed.

5.3.3 Making meaning through peer connection

This theme concerns caregivers' efforts to make their experiences recognizable to others who might understand their significance. Disclosures of difficulty and accounts of meaningful milestones invited acknowledgment of what caregiving felt like and why a particular event mattered. Requests for advice could carry a wish to be understood, while celebrations expressed meanings grounded in a child's and family's circumstances. The posts were interpreted as bids for recognition addressed to a peer audience.

The emotional disclosure in Table 5.2 was also a request for usable understanding. Wanting to understand the child's moods connected the contributor's sense of being unsupported with a concrete question about responding to the child. In this way, an expression of shared experience carried both a relational meaning and a practical concern.

The milestone posts in Table 5.2 framed success according to the child's individual history and the caregiver's understanding of its significance. By presenting these events to a peer audience, caregivers invited recognition of their significance within the child's and family's circumstances.

In Group 1, contributors discussed controversy surrounding applied behaviour analysis, an approach that applies principles of learning to understand and influence behaviour. One caregiver asked why the intervention generated strong opposition. Responses referred to disability rights concerns and efforts in some jurisdictions to restrict particular practices. The exchange showed that treatment decisions were not discussed solely in terms of effectiveness. They were also situated within ethical and political debates.

Posts grouped as collective witnessing (Table 5.2) articulated why an event mattered and invited others to recognize it. The selected material included invitations to reflect on social expectations and intervention ethics as well as accounts of individual family life.

5.3.4 Practical wisdom in everyday parenting

This theme concerns caregiving knowledge presented as provisional and grounded in attempts to respond to a particular child. Accounts of communication, sensory needs, bathing, sleep, literacy, safety, and transitions described what caregivers had tried, what remained difficult, and how they adjusted their approach. A strategy could be offered as useful experience even when the contributor remained uncertain about its effectiveness. Practical wisdom here refers to this situated, experience-based reasoning.

The product and approach recommendations in Table 5.2 are examined as caregiver communication, and the study makes no claim that any product or strategy is safe or effective.

These accounts presented practical knowledge as contextual and revisable. Sharing an approach did not necessarily imply certainty about its effectiveness or applicability to another family.

5.3.5 Moral labor and invisible strain

This theme concerns the work of judging what responsible caregiving requires when a clear or acceptable course of action is difficult to identify. The term moral labor describes the self-questioning and evaluation of obligations expressed in accounts of guilt, inadequacy, and

conflict. The supporting material came from Group 2 and contributed a distinct dimension to the interpretation of the combined dataset.

In the example of internalized stress and guilt in Table 5.2, uncertainty concerned not only what would work but what a responsible caregiver should do.

The exchanges about institutional expectations in Table 5.2 positioned caregiver knowledge and professional guidance as potentially conflicting sources of authority. Contributors used the group to articulate why a recommendation felt inappropriate and to ask whether others interpreted the situation similarly. The accounts expressed strain when recommendations appeared inconsistent with caregivers' observations or values.

Across these accounts, uncertainty concerned both the available options and the caregiver's responsibility for choosing among them.

5.4 Discussion

The four themes show how care-related uncertainty was expressed alongside practical reasoning, emotional experience, and judgments about responsibility. A question about a school letter concerned the meaning of institutional information; a request for a strategy could also express exhaustion or self-doubt. In this study, the findings locate coping in the ways caregivers described the demands of care and addressed those demands to a peer audience.

5.4.1 Uncertainty and the work of interpretation

The theme of navigating uncertainty aligns with evidence that parents of autistic children face service delays, fragmented pathways, and difficulty interpreting intervention options (Gentles et al., 2022; Grant et al., 2016; Smith-Young et al., 2020). The findings add that informational uncertainty may persist even after information has been provided. Caregivers asked peers to help interpret assessment scores, school correspondence, benefit procedures, and professional recommendations. This suggests that access to information and the ability to use that information should not be treated as equivalent outcomes. In several cases, caregivers turned to peer groups not just for emotional support but for translation, asking others to help decode the meaning of a letter, a test result, or an administrative process.

This distinction helps specify what caregivers were asking peers to do. Waiting, assessment results, and school conflicts are related forms of uncertainty, but they place different demands on communication. Supplying another document may respond to a request for information while leaving a question about meaning or applicability unanswered.

Research on post-diagnostic experiences and intervention decisions describes communication needs that continue beyond the diagnostic encounter (Crane et al., 2016; Edwards et al., 2018; Grant et al., 2016; Hughes et al., 2024). The selected posts give those needs a concrete communicative form: caregivers articulated what remained unclear and identified the point at which guidance ceased to be usable for them. The contribution of the systemic opacity subtheme is to distinguish the availability of institutional information from the interpretive work required to act on it. A letter or recommendation could be present while the caregiver's practical question remained open.

5.4.2 Recognition and belonging in peer communication

The findings are consistent with previous research showing that caregivers use online peer groups to seek informational, emotional, appraisal, and practical support (Daynes-Kearney & Gallagher, 2023, 2025). Autism-focused Facebook groups have been described as spaces for support, social connection, advocacy, and information exchange (Abel et al., 2019; Mohd Roffeei et al., 2015).

Lee et al.'s (2024) review of parent-to-parent support among parents of autistic children identifies emotional support, advocacy, knowledge, and practical advice across group and individual support arrangements. This broader literature helps explain why the selected Facebook material cannot be understood solely as an exchange of facts. In one post, a practical question about responding to a child's moods was expressed in terms of a caregiving experience that the writer hoped another person would recognize.

Reinke and Solheim (2015) found that mothers of autistic children described seeking online support as an ongoing activity, with both obtaining information and feeling connected and understood described as important. The present theme of making meaning through peer connection similarly brings attention to the audience for a disclosure. The communicative act included making the significance of an event available to people imagined as familiar with comparable experiences.

Belonging offers a further interpretive perspective. In interviews with family caregivers, Daynes-Kearney and Gallagher (2024) examined shared identity, feeling understood, and experiences of invisibility in relation to online support groups. Their study concerns family

caregiving more broadly. It draws attention here to how writers addressed others as people who might appreciate what outsiders overlooked. The selected posts document that invitation to recognition; questions about how belonging develops over time require attention to the continuing relationships among members.

Previous research involving caregivers of children with complex care needs found that Facebook-based peer support could facilitate discussion of services, treatments, programs, and caregiving experiences (Kelly et al., 2022). The present findings similarly show caregivers using peer discourse to interpret service systems and present practical knowledge.

5.4.3 Coping functions within caregiving accounts

The selected material included practical questions accompanied by expressions of fear, exhaustion, or self-doubt, as well as emotional accounts containing requests for concrete guidance. This overlap is consistent with established coping scholarship (Folkman & Moskowitz, 2004; Skinner et al., 2003). The contribution lies in showing how these functions were expressed in the specific circumstances caregivers described, including interpreting assessment results, seeking school support, and adapting everyday routines.

The transactional model directs attention to both the demand being appraised and the resources a caregiver perceives as available (Lazarus & Folkman, 1984). In the selected material, institutional letters, waiting periods, and a child's distress appeared as situations requiring a response. Peers were addressed as possible sources of explanations, practical ideas, or understanding. The same contribution could therefore express efforts to change a situation and efforts to make its emotional weight intelligible. Maintaining that overlap preserves the meaning

of an account more adequately than assigning it exclusively to problem-focused or emotion-focused coping (Folkman & Moskowitz, 2004; Skinner et al., 2003).

Accounts of milestones can be interpreted in relation to meaning-focused coping, including the attribution of positive significance to everyday events during ongoing difficulty (Folkman, 2008). Caregivers described events whose importance depended on a child's history and family circumstances, such as managing a routine differently or initiating an unfamiliar expression of affection. These events did not remove service difficulties or other demands described in the dataset. They expressed positive meaning within everyday caregiving, which is consistent with Folkman's (2008) account of positive emotions and meaning during sustained stress.

Research on parental coping and adaptation provides an important context for this interpretation. Vernhet et al. (2019) reviewed studies relating coping strategies to stress and quality of life, while also identifying heterogeneity in how coping was assessed. Higgins et al. (2023) examined positive perceptions, coping, **s**elf-efficacy (confidence in one's capacity to manage demands), and social support in relation to parental adaptation. The present analysis contributes an account of how coping-related concerns were communicated in situated posts, complementing this literature on assessed coping and adaptation.

Communal coping involves viewing a stressor as shared and responding to it together. This concept and research on the social sharing of emotion illuminate the relevance of addressing an experience to others (Helgeson et al., 2018; Lyons et al., 1998; Rimé, 2009). They raise questions about whether a difficulty becomes understood as shared, how practical help is organized, and what emotional disclosure invites from an audience. In this study, expressions of

shared experience and requests for acknowledgment make the peer audience analytically important. Establishing shared appraisal, coordinated action, or changes in understanding would require following complete exchanges.

5.4.4 Experiential knowledge and the interpretation of advice

The findings concerning practical wisdom also support research showing that caregivers develop expertise through repeated decision-making and close observation of their children (Edwards et al., 2018). In the analyzed groups, contributors did not simply request expert recommendations. They described adaptations, acknowledged uncertainty about strategies, and proposed modifications based on context. Such exchanges positioned caregiver knowledge as provisional and specific to a family's circumstances.

The bathing account illustrates the reasoning underlying this practical knowledge. The contributor described changes in their own involvement in response to the child's comfort, making the adaptation intelligible through a sequence of reported observations. The learning example similarly located a proposed approach in the child's interests and strengths. Such accounts are useful for understanding what caregivers regard as relevant knowledge: the conditions under which an approach was attempted, the child's response, and the possibility that it may need further adjustment.

Research on online peer groups has documented both misinformation and efforts by contributors to question claims or direct others toward additional resources (Treadgold et al., 2025). In the present study, references to health-related products and alternative approaches were incidental observations within the selected material. Because complete response sequences were

not systematically analyzed, the study cannot characterize how the groups handled those recommendations. Their inclusion illustrates the presence of advice based on personal testimony without establishing its accuracy, acceptance, or consequences.

The practical wisdom theme therefore includes an important distinction between explaining an individual experience and establishing a recommendation's evidentiary basis. The selected examples motivate further attention to how experiential credibility is expressed and assessed, particularly where a product or intervention is presented as beneficial.

The material concerning applied behaviour analysis also requires consideration of neurodiversity and autistic self-advocacy. This literature raises questions about intervention goals, respect for autistic identity, autonomy, and whose priorities guide support (Kapp et al., 2013; Leadbitter et al., 2021). It provides a context for interpreting caregiver questions about interventions and conflict with professional guidance without assuming that caregiver or professional perspectives alone establish what is appropriate for a child.

5.4.5 Responsibility and moral labor

Finally, the theme of moral labor and invisible strain focused attention on how caregivers evaluated their responsibilities and their own adequacy when discussing difficult decisions. Some contributors questioned whether they were sufficiently capable, whether a contemplated decision was morally acceptable, or whether following professional advice would conflict with their knowledge of their child. This recursive work of judging one's own decisions and responsibilities constituted a distinct form of strain within the analyzed discourse.

Moral labor is used here as an interpretive label for the work of evaluating what responsible caregiving requires under uncertain conditions. It connects with scholarship on invisible work, which draws attention to activities that receive limited recognition, including unpaid work associated with women's domestic responsibilities (Daniels, 1987). In the selected posts, this interpretation concerns the self-questioning accompanying practical decisions: whether an accommodation is acceptable, whether a caregiver is doing enough, or how to respond when professional instructions conflict with personal observations. The label keeps attention on how responsibility is expressed within an account in relation to its practical and emotional content.

The mobility buggy question makes this distinction especially clear. The caregiver asked about the acceptability of an accommodation, so a response limited to equipment features would address only part of the expressed concern. In the childcare account, the need to remain employed depended on access to care, which was described as conditional on toilet training. Treating such questions only as gaps in parenting knowledge would overlook how writers evaluated the obligations attached to the available options.

Blum's (2007) research on mothers of children with invisible disabilities offers a related account of expectations to advocate, explain difficulties, and assume extensive responsibility. This literature helps situate self-questioning within social expectations of caregiving. Contributors' gender composition was not established in the present study; the comparison therefore concerns social expectations of caregiving and does not imply gender differences in these groups. The moral labor theme draws attention to how a request for advice can also be a request for perspective on what one ought reasonably to be able to do.

5.4.6 Implications and directions for further research

The posts seeking explanations of assessment scores, school correspondence, and service procedures suggest a need for follow-up communication about information caregivers have already received. Professionals could review the specific document or recommendation with the caregiver, explain its practical implications, and identify a contact for unresolved questions.

Accounts of adapting routines and questioning professional instructions suggest that consultations should make room for caregivers to describe what they have observed and tried. Discussing the reasoning behind a recommendation, its limits, and possible adaptations could help clarify disagreements. Such discussions should also attend to the child's communication, preferences, and autonomy (Leadbitter et al., 2021).

The presence of health-related recommendations based on personal testimony suggests a role for inviting caregivers to bring online claims into consultations for review. Professionals could help distinguish an individual account from evidence relevant to the proposed use. A discussion of the claim's evidentiary basis and relevance to the child would address a different question from whether another caregiver found it persuasive.

Finally, posts expressing guilt, uncertainty about acceptable accommodations, and perceived inadequacy suggest that caregiver communication should address the responsibilities families feel they carry. Asking what makes a decision difficult could reveal concerns that a list of services or strategies would leave unanswered.

The findings also support acknowledging the different purposes for which caregivers may seek peers. Practical advice, an explanation of a procedure, recognition of an experience, and

room to discuss responsibility represent distinct needs. Professionals and support organizations can ask which of these a caregiver is seeking when discussing peer support, recognizing that information alone may leave other concerns unanswered.

Research following complete sequences of posts and replies could examine how advice is received, clarified, questioned, or endorsed and how contributors express changes in understanding. Repeated sampling across longer periods could explore the continuity and variation of topics as children's needs, school circumstances, and service conditions change. Interviews or participant diaries could then examine how caregivers describe the relation between online discussion and later decisions, including what they choose not to act on.

Further research should also include caregivers who read without posting and people using private, culturally specific, or non-English-language communities. Participatory work with autistic people and caregivers could examine intervention priorities, disagreements, and forms of support while attending to whose experiences are represented. These approaches would extend the questions raised here about recognition, experiential knowledge, and responsibility across a wider range of communicative settings.

5.5 Strengths and limitations

Naturally occurring public posts offered access to communication generated without researcher prompting. The variety of posts supported an interpretation attentive to how caregivers presented concerns to a peer audience, including aspects of responsibility that might be obscured by treating the posts only as requests for factual information.

Using the same sampling window for both groups established a common timeframe, while the bounded inventory allowed repeated reading and close engagement with each selected contribution. Paraphrased examples and the accompanying inventories make the basis of the interpretation visible while reducing the risks associated with reproducing searchable social-media text.

The study also has limitations. The dataset comprised selected material from two publicly accessible Facebook groups during a bounded sampling period. Facebook's ranking and display functions, together with group moderation, may have influenced which material was visible for collection and which contributions remained available. The study did not assess these influences. Caregivers participating in private groups, culturally specific communities, or other platforms may communicate differently, and people who read without posting were not represented. Group creation dates and overall posting rates were not systematically established, and individual members' contribution rates were not tracked. Frequent contributors and views accepted within each group may therefore be more visible in the selected material.

Demographic and geographic information could not be independently verified. Self-described caregiver roles provided limited context but did not establish the demographic composition of either group. The findings cannot be attributed specifically to Ontario or Canadian caregivers, and the study does not support comparisons by gender, race, socioeconomic position, immigration status, or location.

Children's experiences were represented through caregiver accounts. Some contributors may themselves have been autistic, but this was not established. The dataset therefore supports

interpretation of the selected caregiving discourse rather than a systematic account of autistic people's own perspectives.

The sampling period, March 10 to April 10, 2024, included World Autism Awareness Day and the beginning of Autism Acceptance Month. This timing may have increased the visibility of advocacy, milestone sharing, and discussion of autism-related values or interventions. The study did not compare this period with other months, so the extent of any influence cannot be determined.

Eligibility criteria explicitly selected material concerning coping, support, emotional experience, and care-related questions. This shaped the patterns available for interpretation. The findings describe how these matters were expressed within the selected material; they do not establish their prominence across all group activity. No separate screening log was maintained to document exclusions by reason.

The analysis did not systematically examine complete reply sequences. It cannot establish how appraisals developed across an exchange, how advice was received, challenged, or corrected throughout a thread, or whether contributors reached agreement. The text also provides no direct evidence of subsequent actions or outcomes. Paraphrasing may have reduced linguistic detail, further limiting fine-grained interpretation of how contributors expressed particular meanings.

The analysis was interpretive and shaped by the researcher's theoretical orientation and positionality. Reflexive journaling, memoing, and discussions with the research supervisor supported examination and documentation of the researcher's interpretive role in developing the themes.

5.6 Conclusion

This study examined care-related uncertainty and coping in 118 selected caregiver contributions, including originating posts and comments from two public Facebook groups. Four themes brought together difficulties interpreting formal guidance, efforts to make caregiving experiences recognizable, the sharing of provisional practical knowledge, and self-questioning about caregiving responsibilities. The findings illustrate established coping concepts within a specific communication setting and draw attention to the perceived obligations accompanying practical care questions.

The posts suggest areas for more responsive professional communication, including explaining how institutional information applies to a family's circumstances, discussing caregivers' observations and online recommendations, and acknowledging what makes a decision feel difficult or morally consequential.

CHAPTER 6

Integrated Discussion and General Conclusion

6.1 Introduction

The three studies bring into view the continuing work involved in interpreting information for decisions about care. Across the findings, knowing that a service or approach exists sits alongside questions about its relevance to a child, how to access it, and whether a recommendation fits everyday life. Caregiver accounts connect clarity and opportunities for explanation with emotional support, while peer discourse reveals practical judgment and the pressures of deciding under uncertainty. These relationships make communication central to understanding how post-diagnostic information is used.

This chapter integrates findings from the analysis of public resources, caregiver interviews, and online peer posts. Different sources of support address overlapping needs, and the findings show where interpretation remains demanding for caregivers. The discussion develops this contribution in relation to existing literature, considers its theoretical implications, and identifies priorities for post-diagnostic support.

The overarching question asked how families encounter and engage with autism-related information and support when they consider care after a child's diagnosis. Each study answers part of it. Study 1 found that public resources from 11 organizations offered substantial information alongside navigation guidance, audience tailoring, and invitations to participate and connect with other parents. Study 2 found that caregivers valued professional information yet often remained unsure what it meant for their child, and searched further for practical guidance

and to examine options. Study 3 found that peer contributions voiced uncertainty about services and recommendations, provisional practical knowledge, a wish for recognition, and self-questioning about responsibility.

The studies show families encountering an environment that offers substantial information, though not to every family or at every point, and in which the work of turning information into an informed decision falls largely on caregivers. They engage with it through continuing interpretation: comparing sources, asking what applies to their child, seeking explanation and recognition, and carrying responsibility for finding a workable course of action. Informed decision-making is therefore best understood here as an interpretive and relational achievement, not an automatic result of receiving information. The rest of the chapter develops this argument and states where the evidence supports it and where it does not.

6.2 Integrated interpretation of the findings

Table 6.1 sets the findings of the three studies side by side, strand by strand. A strand is a recurring concern, not a theme from any single study. For each strand, the table records whether the studies agree, qualify one another, rest on a single dataset, or leave the strand unexamined. The sections that follow develop the strands that carry the argument.

Table 6.1 Cross-study matrix: findings by strand and reading across the studies

Strand	Study 1: public resources	Study 2: interviews	Study 3: peer posts	Reading across
Information provision [knowledge]	Substantial and layered at all 11 organizations, in several formats.	Uneven: P7 received nothing, P1 received websites only, P4 and P6 valued plain explanation.	Not the focus; documents were in hand but unclear (systemic opacity).	Qualified: abundant in public collections, uneven for individual families.
Relevance to a particular child [knowledge; uncertainty]	Age- and audience-specific entry points; relevance to an individual child cannot be assessed.	Helpful yet unclear for the child (P5, P8, P9).	Peers asked to interpret assessments, school letters and rules.	Agree: direct evidence in Studies 2 and 3, contrast supplied by Study 1.
Emotional conditions of use [support]	Some reassuring, strengths-based language.	Overwhelm and sadness (P3, P9); reassurance (P10).	Emotional disclosure intertwined with practical requests.	Partly agree; Study 1 cannot show effects on readiness.
Needs over time	Collections extend beyond diagnosis to school and development.	P1's preference for discussion persisted across interviews; P2 and P8 searched further after using information.	One-month window; strategies described as provisional.	Supports persistence of needs; no study can show change.
Professional and experiential knowledge [support]	Peer support presented as complementing professional services.	Parents' stories, friends and a doctor friend complemented professional information (P10, P2, P8).	Peers interpret institutional documents; some accounts of friction with professionals.	Agree on complementarity; Study 3 adds friction.
Credibility of claims	One advisory to examine services and qualifications.	Checking options (P8); reputable websites and experts (P10).	Product recommendations resting on testimony; debate about ABA.	Thin; strongest in Study 3.

Strand	Study 1: public resources	Study 2: interviews	Study 3: peer posts	Reading across
Values and ethics [values]	Did not arise in the analysis.	P5 attributed the decision to the child's communication difficulty.	Debate about ABA; whether a mobility buggy would be wrong.	Rests on one dataset.
Agency, responsibility and strain [support]	Caregivers expected to learn, ask questions, keep records and advocate.	Unfamiliar tasks and uncertainty about what to do (P3, P9).	Guilt and self-questioning (second group only); contesting schools.	Expectation from Study 1, strain mainly from Study 3.
Service conditions and access [support]	Funding information and directories; English and French availability varied.	Requests for other languages (P4) and disability access (P6).	Waiting, benefit timing, childcare eligibility; jurisdictions unknown.	Rests mainly on Study 3, location unknown.
Role of information in decisions	Knowledge presented as the route to informed decisions.	Helpful but not decisive (P5); helped with options (P10); still observing (P6).	A decision to proceed amid unsettled feelings; treatment debated on ethical grounds.	Information necessary but not sufficient; the link is weaker than the resources imply.

Entries summarize the results chapters (Sections 3.3, 4.3 and 5.3). Participant codes follow Chapter 4. Labels in square brackets show where a strand bears on informed decision-making. Study 3 contributions come from two groups that were not restricted to Canada, so Study 3 entries describe the selected posts and not services in the Ottawa region.

The labels in square brackets name what caregivers need in order to make informed decisions about a child's care: knowledge, clarity about values, manageable uncertainty, and support (Ottawa Decision Support Framework; Hoefel et al., 2020; Stacey et al., 2020). The studies document knowledge most fully. Public resources supply substantial information, and caregivers' accounts show the work of relating it to their child. Uncertainty and support are voiced most

directly in the interviews and peer posts, where information helped caregivers understand options but did not settle the choice. Values appear mainly in Study 3, in questions about what a responsible caregiver should do. Read this way, the studies speak to informed decision-making unevenly: they show how information is provided and how its use is described, and show less about how families weigh what matters to them.

6.2.1 Information availability and practical relevance

A central distinction across the findings is between having information available and being able to use it to inform decisions about care. The public resources offered substantial guidance, including descriptions of services, advocacy tools, materials for different audiences, and links to community support. In the interviews, participants described uncertainty about what information meant for their own child and where to begin. Peer posts made similar practical questions visible in requests for help understanding assessment results, school communications, and routes to services. These findings locate an important part of post-diagnostic support in the gap between general guidance and a particular family's situation.

The resource findings complicate an explanation based entirely on missing information. That holds for organizations' public collections; for individual families, receipt was uneven, and one participant (P7) reported receiving nothing. Portia Learning Centre's parent-directed applied behaviour analysis (ABA) guidance and financial-help information, for example, addressed questions about intervention and access to support. The Children's Hospital of Eastern Ontario's (CHEO) resource categories and links offered ways to locate information relevant to different audiences. These features represent useful starting points for navigation. Yet the interview accounts show why a starting point can still require explanation. A parent considering several

therapies needs to understand how the options relate to the child's needs, which questions to raise, and what is feasible for the family. The meaning of a resource therefore depends partly on the task for which it is being consulted.

This relationship helps explain the coexistence of information abundance and uncertainty. Some interview participants described being overwhelmed by the amount provided; others reported receiving little information or insufficient guidance. Both experiences could leave a caregiver unsure of the next step. The common concern was difficulty establishing a usable basis for action. The synthesis thus distinguishes several demands that can otherwise be collapsed into an undifferentiated need for more information: locating relevant material, understanding it, and relating it to an immediate decision.

The interview findings further distinguish the usefulness of information from its sufficiency and its influence on a choice. P2 described using advice from an e-book while continuing to seek practical guidance elsewhere. P5 evaluated information positively but attributed the decision to pursue speech therapy to the child's communication difficulties. P10, by comparison, described professional information as helping the family understand the available options and their potential benefits. These accounts complicate any direct progression from receiving information to making an informed decision. Alongside the educational and navigational functions of public resources and the unresolved questions in peer posts, they suggest that information can contribute to care without settling every question or determining the eventual choice. Communication therefore has to be judged against what caregivers are trying to establish. A favourable evaluation of a resource can coexist with uncertainty because usefulness concerns a

particular purpose, while subsequent questions may require another explanation or form of support.

Makino et al. (2021) situate information and support within a diagnostic experience that also includes disclosure, parental emotions, and relationships with services. More recent work by Pye et al. (2026) similarly shows caregivers valuing practical, adaptable support while managing uncertainty and the mental load of accessing services. The present findings contribute to this literature by comparing resource provision with reported use and questions expressed in peer spaces. This comparison makes the need for guided interpretation visible even where resources contain substantive information and supportive features.

An implication follows for how communication is assessed. The range of topics covered and the number of resources offered describe provision, while caregivers' questions reveal the work still involved in making that provision relevant. Both perspectives matter. A resource can offer a useful overview, and a family can still need a conversation about its application. Attention therefore belongs on how materials are introduced, prioritized, and revisited within ongoing support.

6.2.2 Emotional readiness and continuing interpretation

The usefulness of information is also connected to the circumstances in which caregivers encounter it. In the interviews, accounts of difficulty absorbing information were accompanied by descriptions of sadness, uncertainty, and feeling overwhelmed. Requests for clearer explanations and opportunities to ask questions concerned both understanding and reassurance.

Peer posts likewise placed practical questions within expressions of fatigue, worry, or doubt. Emotional support and informational support can address different aspects of the same concern.

A caregiver may need an explanation of a service while also needing reassurance that uncertainty is understandable and that help remains available. Treating those needs separately can miss their relationship. A technically detailed explanation may leave the person uncertain about how to proceed; reassurance alone may leave the practical question unanswered. The combined findings make a case for communication that attends to the question and the conditions under which the caregiver is trying to consider an answer.

The accounts of continuing to use and supplement information add a temporal dimension to this interpretation, within the limits of two interviews three months apart. Participants described applying information, looking further when it did not answer a practical question, and checking a proposed option before committing to it. Their preferences highlighted complementary forms of support: clear explanations and discussion, together with detailed information that could be reviewed at home. These preferences suggest that usefulness depends on the purpose and occasion of information use. A single format or level of detail is unlikely to meet every question that arises during care.

The temporal contribution concerns the occasions on which information becomes relevant. P1's continuing preference for discussion across both interviews shows that an explanatory need can persist, while P9's wish for detailed material to review at home identifies a purpose for information beyond the encounter in which it is supplied. Considered with the varied formats in public resources and the specific questions brought into peer spaces, these accounts suggest that information needs cannot be addressed solely by deciding how much to provide at diagnosis.

The interviews were spaced three months apart and the prompts differed between them, so the accounts cannot show how caregivers' concerns changed over time. They show that some needs persisted and that caregivers looked further once they tried to apply information, which is the basis here for emphasizing continuing support. Continuing support therefore involves opportunities to reconnect information with the circumstances of its use. Emotional readiness matters within this process, as do emerging or persistent practical questions.

This interpretation is consistent with the diversity of support needs identified by Battanta et al. (2024). Their Swiss study found a wish for closer follow-up and substantial differences in families' everyday circumstances and available support. Within the present research, the relationship between public resources and caregiver accounts points toward a similar need for flexibility. Materials organized for broad audiences provide an important foundation, while opportunities for discussion allow families to identify what is relevant to them at a particular point.

The peer findings broaden this account of continuing support. In addition to seeking advice, caregivers shared moments of pride, described everyday accomplishments, and sought recognition from others who might understand their significance. These expressions give emotional support a place beyond the diagnostic encounter. They also show that caregivers use peer spaces to seek recognition and connection while practical demands continue. The significance attached to these ordinary events is consistent with meaning-focused coping, which attends to positive meaning during continuing difficulty (Folkman, 2008). Research with family caregivers in an established online support group also situates recognition within experiences of shared identity and belonging (Daynes-Kearney & Gallagher, 2024). This supports repeated

opportunities for explanation and recognition, extending communication beyond the encounter in which information is first provided.

6.2.3 Professional and experiential knowledge

Caregivers' use of multiple sources reflects the different questions those sources can address. Interview participants valued professional information for its perceived authority and described other parents' experiences as useful for understanding everyday care. In the peer posts, questions about services appeared together with accounts of adapting routines, responding to sensory needs, and finding practical supports. These findings suggest that evaluating an option involves both understanding general recommendations and considering how care might work in the family's circumstances.

The distinction between professional and experiential knowledge is useful here. Borkman (1976) describes experiential knowledge as grounded in direct experience and considers its relationship to professional knowledge in self-help groups. In this dissertation, that relationship is visible when caregivers combine explanations of available approaches with accounts of what those approaches involve in practice. A professional source may explain the purpose of a service; another caregiver's account may show the questions that arise while arranging or using it. Each can inform the judgments families make about relevance and feasibility.

Formal and peer support were also connected within the public resources themselves. Parent stories, community events, and links to support networks recognized a role for shared experience alongside professional guidance. This finding matters to the integration because it places peer support within a broader account of post-diagnostic communication. The relationship involves

existing points of connection as well as efforts by caregivers to supplement information. It is therefore useful to examine how those connections could support families in bringing questions between settings.

These connections complicate an account in which caregivers leave professional information behind when they turn to peers. In Study 2, P10 described parents' stories as complementing doctors' information, while P8 combined online searching with consultation of a friend who was a doctor. Professional knowledge could therefore enter a personal network, and experiential accounts could be consulted together with formal guidance. The public resources' links to community support further show that connections between sources were already represented within organizational communication. The setting in which information is obtained does not fully determine its role. Caregivers may consult different sources to explain an option, examine its practical implications, or consider another perspective. The communication environment is connected through these purposes, even though each source retains a different basis of authority and relevance.

The practical and emotional functions of peer support have been documented in autism research. Mohd Roffeei et al. (2015) identified informational and emotional support in Facebook autism groups, while Reinke and Solheim (2015) described mothers' continuing search for information and their need for connection and understanding. The present findings build on that work by relating the purposes expressed in peer posts to the guidance available in public resources and the priorities described in interviews. The added perspective is the relationship among these forms of support: formal information can orient a caregiver toward an option, while discussion with others offers ways to consider its everyday meaning.

Peer knowledge also raises questions of judgment and credibility. Posts included advice based on individual experience, including recommendations about products and therapies. Within an environment valued for recognition and practical insight, caregivers also face the task of assessing how an account applies to their child and what evidence supports a recommendation. Treadgold et al.'s (2025) review of online health peer-support groups documents concerns about information quality as well as instances of members correcting misinformation. That broader literature supports distinguishing the relational value of a peer account from the evidential basis of a treatment claim.

The peer findings show why the distinction matters: experiential accounts did not all make the same kind of claim. A caregiver describing a provisional response to a difficult routine showed what could be managed in that situation, including uncertainty about whether it worked. A recommendation for a health-related product based on personal testimony raised a different question about the evidence supporting its proposed use. Both were expressed through experience, but their relevance and grounds for evaluation differed. When considered with interview accounts of examining options and the explanatory purposes of public resources, this suggests that evaluating information involves asking what kind of claim is being made as well as who is making it. Recognition of experiential knowledge can acknowledge practical insight while maintaining scrutiny of claims about treatment benefits. These are related responsibilities within post-diagnostic communication.

The resulting implication is to support dialogue across sources. Caregivers should be able to bring information from peers into a professional conversation without having their experience dismissed. Equally, professional guidance can help clarify the evidence and suitability of options

discussed online. Hermaszewska and Sin (2021) found that parents involved in designing an online intervention wanted peer support together with credible information and access to professionals. Alongside this dissertation's findings, those preferences support an approach that recognizes the different contributions of professional expertise and lived experience while helping families evaluate the information they encounter.

6.2.4 Caregiver agency and the work of navigation

Across the research program, informed decision-making involves considerable effort by caregivers. Resources addressing advocacy, intervention, and service access encourage families to ask questions and consider available options. Interview accounts describe the work of comparing recommendations, returning to materials, and seeking additional perspectives. Peer posts reveal practical problem-solving alongside requests for help interpreting institutional processes. These findings bring agency and responsibility into the same discussion. Caregivers participate actively in decisions, while also carrying much of the work needed to make those decisions possible.

Edwards et al. (2018) show that parents' intervention decisions draw on values, experience, information, understanding, and practical circumstances. The present synthesis develops the communicative dimension of that account. Learning about an option involves translating general descriptions into questions about a child, a family, and a service system. The public resources address aspects of this work through explanations of interventions, funding information, service contacts, and guidance on caregiver advocacy. Caregiver accounts then reveal why explanation, comparison, and further discussion remain important in using such guidance.

The relationship between empowerment and responsibility becomes particularly visible when decisions remain uncertain. In the peer findings, expressions of guilt and conflict over recommendations showed how choosing a course of action could also involve questioning whether one was doing enough or responding appropriately to a child. These concerns add a moral dimension to the practical demands of navigation. This theme was drawn from the second group only (Section 5.3.5), so it describes a pattern in that material and not a feature of both groups. Recognizing caregivers as knowledgeable partners should therefore include recognizing the pressure involved in making consequential choices with incomplete or conflicting guidance.

Considering caregiver activation together with the peer findings reveals a tension in what informed participation can require. Public resources encourage caregivers to learn, ask questions, and advocate. The peer material shows that practical choices can also become occasions for evaluating one's adequacy as a caregiver. The question about whether using a mobility buggy would be wrong, for example, concerned the acceptability of an accommodation as well as its practical usefulness. These findings suggest that supporting agency involves more than increasing knowledge or confidence. Caregivers may also need space to examine the expectations against which they judge a decision. The integration suggests a distinction between being enabled to participate and feeling personally responsible for finding an acceptable answer to every difficulty. Both belong within an account of the communication surrounding care decisions.

Pye et al. (2026) describe time pressure and mental load even among families accessing publicly funded support. Their findings help situate the effort expressed in the present interviews and peer posts within the wider organization of care. Information gathering is one part of that effort.

Families may also need to coordinate contacts, understand administrative requirements, and fit recommendations around everyday responsibilities. These practical demands sit alongside the expectation, evident in advocacy resources, that families will become informed and active participants.

Service conditions also shape the choices available. In the peer posts, accounts of waiting, financial pressure, and unclear procedures locate some difficulties in how support is organized. Because the groups were not restricted to Canada, these posts show the kinds of structural difficulty caregivers describe without establishing how services in the Ottawa region operate. This distinction matters for interpreting caregiver agency. Knowing what to request is different from having timely access to it, and confidence in asking questions operates within the options that services make available. The findings support communication that explains those options honestly and identifies who can assist with the next step. They also make organizational responsibility part of the discussion of informed decision-making.

The peer account linking toilet training, childcare eligibility, and employment illustrates why this distinction matters. The caregiver's question arose from responsibilities that depended on one another: obtaining childcare required meeting a condition, while childcare was needed to continue working. Information could clarify the requirement or identify possible contacts, but understanding the requirement would not itself resolve the competing demands. Comparing this example with the navigation guidance in public resources and interview requests for explanation shows why communication should be considered within the conditions governing available choices. Difficulty proceeding can reflect a constrained situation as well as an unresolved informational question. Family-centred partnership therefore involves recognizing when a

caregiver needs explanation, when assistance with coordination is needed, and when the difficulty requires an organizational response.

Variation in language availability on organizational resource pages, together with interview requests for additional languages and accessible formats, makes equitable access part of the interpretation. Casale et al. (2023) situate information and navigation needs within language barriers, unfamiliar service systems, and other constraints experienced by newcomer caregivers in Canada. Sharing navigation responsibilities therefore also involves identifying what makes information accessible and usable for a particular family and providing assistance that responds to those circumstances.

Family-centred care provides an established basis for that responsibility. Kuo et al. (2012) emphasize information sharing, partnership, respect for differences, and attention to family and community circumstances. The contribution here is to specify some of the communication work through which these principles become relevant after diagnosis. Supporting participation includes helping a family interpret guidance and navigate its application. The studies suggest why an invitation to make informed choices should be accompanied by accessible opportunities to work through those choices with others.

6.3 Contribution to knowledge and theoretical implications

The dissertation makes three contributions, ordered from the best to the least supported by the evidence. The first is an account of what stands between information and an informed decision. Public resources supply substantial guidance, yet caregivers' accounts and peer posts show

families still working out what applies to their child, what a recommendation requires, and whether it fits everyday life. Table 6.1 sets out where the three settings agree, where they qualify one another and where they leave questions open. The contribution is to locate the difficulty in interpretation and in the support available for it, not only in access to information. The second applies accommodation theory to a new object. Communication Accommodation Theory already separates objective accommodation from accommodation as perceived by interactants, and gives priority to perceptions (Gallois et al., 2005). It has since been applied to written texts, including medical records (Hewett et al., 2009) and institutional webpages (Zhang et al., 2020), and Gallois et al. (2005) noted that institutionally driven contexts were among those where the theory had not yet been developed. The present studies apply it to post-diagnostic resources and to caregivers' accounts of using them, and indicate that accommodation anticipated in a resource, as inferred from its features and not from its authors' intentions, and accommodation perceived by a particular caregiver can come apart. The third is a proposed distinction. Resources invite caregivers to learn, ask questions and advocate, an expectation Blum (2007) also describes for mothers of children with invisible disabilities, while peer posts from one group suggest that taking up that invitation can carry doubt about whether one is deciding responsibly. Being enabled to participate and feeling personally responsible for every answer may be different conditions, and support would need to address them separately. Together these contributions place the work of interpretation at the centre of informed decision-making after diagnosis.

These contributions rest on three relationships in the findings, each stated here with its evidence and its limits. First, substantial provision coexisted with uncertainty about application, but this holds more securely for organizations' collections than for individual families, because receipt was uneven. Second, professional and experiential knowledge were used together, although

Study 3 also shows friction with professionals that Studies 1 and 2 do not. Third, the expectation that caregivers act as informed participants comes from Study 1 and the strain of meeting it mainly from one group in Study 3, so the claim about agency and strain is the least secure of the three. A single emphasis on information access, resource quality, or individual confidence would leave these relationships unexplained. Together they point toward support that helps caregivers relate information to their circumstances and keeps discussion open.

The methodological value of the program lies in bringing complementary forms of qualitative evidence to the same communication problem. Document analysis examines how organizations present information and position caregivers; repeated interviews retain caregivers' accounts of receiving, using, and supplementing information; and naturally occurring peer posts show concerns expressed without researcher prompting. This combination allows organizational provision, reported information use, and communication to a peer audience to be examined side by side while keeping the perspective of each study distinct.

Communication Accommodation Theory (CAT) helps interpret responsiveness across the resource and interview findings. CAT addresses how communication is adjusted in relation to others and how those adjustments are perceived (Giles, 2016a). The public resources adjust in advance: plain language, audience-specific organization and language options anticipate a range of needs. The interviews show what that anticipation can and cannot do. Plain language and varied formats gave caregivers a foundation for understanding, but whether an explanation fit a particular child, or answered the question at hand, was something caregivers established by asking, searching further or talking with someone. A resource can be designed for an audience while its relevance to one family is worked out in discussion, which is consistent with CAT's

attention to context and its application to mediated communication (Giles et al., 2023). In post-diagnostic care, where unfamiliar information, emotional demands and decisions about services meet, this points to the value of opportunities for communication to be adjusted as a family's purposes become explicit. The studies therefore separate accommodation designed into a resource from accommodation perceived by a caregiver, and show that support is needed for the second. No study observed an exchange between a professional and a family, so the argument concerns how accommodation is anticipated in resources and perceived in caregivers' accounts, not how it is enacted in encounters.

CAT's own vocabulary of accommodative strategies (Gallois et al., 2005) offers a way to name what the studies describe. It is used here as an interpretive reading, not a coding scheme, because none of the studies analyzed the data with these categories, and because the strategies were theorized for interaction, so their application to written resources is analogical. Interpretability strategies attend to the partner's capacity to decode and include simpler language and checking understanding; plain language, explained terminology and question-based organization in the public resources (Study 1), and P4's and P6's appreciation of plain explanation (Study 2), can be read in these terms. Emotional expression, which includes reassurance and warmth, can be read in the supportive, strengths-based language of some resources (Study 1) and in P10's account of reassurance (Study 2). Discourse management, which involves sharing the direction of a conversation, can be read in P1's wish for more discussion with the doctor than websites allowed (Study 2). CAT also names over-accommodation, in which well-meant adjustment is received as patronizing; none of the accounts in Chapters 4 and 5 described this, so it remains a possibility the data cannot confirm. The reading suggests that the strategies resources can anticipate in design, interpretability and emotional expression, are also the ones for which caregivers voice

needs for further explanation and reassurance, while discourse management depends on a responsive partner, which is what P1's request points to.

The coping perspective, used in the peer study, adds what CAT does not: an account of what is at stake for the caregiver. Lazarus and Folkman's (1984) distinction between problem-focused and emotion-focused coping helps explain why practical questions and requests for reassurance appear together in the peer posts. Within the peer material, uncertainty could concern an institutional process, the feasibility of a strategy, or what responsible caregiving required, so a question about a service could seek an actionable answer and, at the same time, manage the distress of uncertainty. Read alongside caregivers' requests for explanation and the participatory roles that public resources encourage, these expressions place informational demands within the situations caregivers are appraising. CAT directs attention to whether communication responds to an expressed need, and coping to the demands and resources surrounding it. An unresolved question therefore means more than missing information: it is both what remains unclear and what is at stake for the caregiver in resolving it. This supports pairing practical explanation with emotional recognition.

These perspectives locate post-diagnostic communication within a wider environment of formal resources, professional guidance and peer support. The contribution is to show what each offers and what none supplies on its own. Resources provide information designed in advance, peers supply practical knowledge and recognition, and discussion can respond to a particular family's question, yet the work of relating all of it to one child's care falls to the caregiver. This is the basis for the recommendations in Section 6.4, which concern the interpretation and use of information as well as its provision.

6.4 Implications for practice and service organization

The findings support a practical priority: caregivers need a clear route to help with interpreting and applying information after diagnosis. This priority builds on Canadian Paediatric Society guidance recommending sensitive diagnostic communication, understandable verbal and written information, a follow-up plan, and continuing family support (Brian et al., 2019; Ip et al., 2019). The recommendations below identify how these principles can address the concerns brought into focus across the studies.

6.4.1 Pair resources with guided discussion and follow-up

Diagnostic and post-diagnostic teams should explain how the resources they recommend relate to a family's immediate questions. The combination of substantial public guidance and interview accounts of uncertainty suggests that selecting relevant material and agreeing on initial priorities are valuable parts of the encounter. A clinician or designated team member should identify the family's questions, explain unfamiliar terms, and record the next steps discussed with the caregiver. Written or digital material can then serve as a reference for that conversation and for later review.

Before the encounter ends, families should know whom to contact when further questions arise. A planned opportunity to revisit information responds to caregivers' requests for clarification and for material they could review independently. It is also consistent with Brian et al.'s (2019) recommendations for feedback and follow-up planning. The timing and format should reflect the family's preferences and the responsibilities of the services involved. For an organization seeking

an initial communication priority, assigning responsibility for this follow-up would directly address a concern expressed in the interviews.

6.4.2 Organize information around the decisions families face

Resource developers should build on the strengths identified in existing materials, including audience-specific sections, multilingual guidance, practical tools, and community links. An accessible overview can help a family identify the purpose of a resource and where to begin, while more detailed sections can support later questions. This approach responds to the interview participants' preferences for both clear explanations and information they could review more fully at home.

Materials about services should make the intended audience, purpose, access route, and relevant contact clear. Clinicians and community organizations can help families select among these resources in relation to the decisions they currently face. Involving caregivers with different language and access needs in resource development and review would help organizations examine whether that arrangement of information works in practice. Battanta et al.'s (2024) findings on varied family circumstances reinforce the importance of tailoring support to the needs identified by each family.

6.4.3 Recognize peer knowledge and support its evaluation

Professionals should invite caregivers to discuss information obtained from other families, books, websites, and peer groups. The interview findings show the value attached to combining sources, while the peer findings reveal the practical and emotional concerns such sources address. Asking what a caregiver found helpful or confusing provides a starting point for

recognizing their experience and discussing the evidence and relevance of a recommendation. Ip et al. (2019) similarly recommend non-judgmental discussion of complementary approaches and their evidential basis.

These discussions should also attend to the child's communication, preferences, and autonomy. The peer material's questions about intervention ethics and acceptable accommodations make the goals and values guiding care relevant to the interpretation. Autistic self-advocacy scholarship provides a basis for considering whose priorities are represented when caregivers and professionals evaluate possible supports (Leadbitter et al., 2021).

Organizations can also provide clear information about peer-support options and their purposes. The links and parent stories identified in public resources offer examples of this connection already in practice. Any collaboration between professional services and peer groups should be developed with the people who use and organize those groups. Discussion should address the scope of peer support, routes to professional advice, and the needs members want a partnership to meet. Hermaszewska and Sin (2021) provide a relevant example of involving parents in identifying how peer and professional support could be combined.

6.4.4 Share responsibility for service navigation

Services should identify who can help a family understand a referral, clarify an access requirement, or resolve uncertainty about the next contact. Navigation resources, interview requests for guidance, and peer questions about institutional processes all support making that responsibility explicit. Where care involves several services, a family should be able to distinguish the roles of those services and know which contact can address a particular question.

For service planners, the findings also support examining the practical demands attached to recommendations. Language, cost, appointment access, and administrative procedures affect what families can pursue. The evidence on cost and delay comes mainly from peer posts whose locations are unknown, so local review is needed to establish what applies in the Ottawa region. Reviewing communication should therefore include asking whether the next step is understandable and workable and identifying barriers that require a service-level response. This gives concrete expression to family-centred partnership by sharing the work of navigation and recognizing the circumstances within which caregivers make decisions.

6.5 Limitations

The integration brings together findings from distinct qualitative designs and selected contexts. It supports interpretation across settings, while the relationships described concern patterns of information provision, reported experience, and peer discourse. The regional resource and interview samples limit how readily the findings can be applied to other service systems and caregiver populations. Public materials provide a view of available information, and the interview findings reflect caregivers' perceptions and recollections. Two interview rounds offer repeated accounts, with differences in interview emphasis and retrospective recall limiting conclusions about change over time.

The online findings reflect selected posts from two public Facebook groups. Members' locations, diagnostic circumstances, and subsequent use of advice were not independently verified. The analysis gives access to concerns expressed in posts, with limited insight into readers who do not

post or the negotiation of advice across complete exchanges. The themes describe the selected material and do not establish differences in the prevalence of experiences between the groups' memberships.

Healthcare professionals and other autism service providers were not interviewed. Although the public resources offered insight into organizational communication, they did not establish how professionals selected, explained, or supplemented those materials in encounters with families. Caregiver accounts illuminated how communication was experienced, but could not explain how professionals assessed family readiness, prioritized information, or understood their responsibilities for follow-up and navigation. The integration therefore provides limited insight into the professional judgments and organizational conditions shaping the communication described. It identifies needs for more responsive support while leaving questions about how professionals understand and negotiate those needs within their roles and service settings.

Across the studies, demographic information was insufficiently comparable to examine differences systematically by language, income, racialization, immigration history, or geography. All ten interviewees described themselves as Black, African, African American or Haitian American, and the studies do not address whether ethnicity or access to services shaped what families received. Interviews were conducted in English, although eligibility allowed English or French. Autistic people were not included as a distinct participant group. My position as a parent and researcher informed the interpretation and requires continued attention to the assumptions associated with shared experience (Berger, 2015). Finally, the program did not evaluate the implementation or effects of the proposed recommendations; those questions remain for subsequent research.

6.6 Future research

The integrated findings suggest examining how caregivers relate information from different sources to specific care decisions. A prospective design could follow families from diagnosis through selected decisions, combining repeated interviews with discussion of the actual resources they consult. This would allow attention to when questions arise, how explanations are evaluated, and what forms of support families find useful as their circumstances change.

An important extension of this research is to examine post-diagnostic communication from the perspectives of healthcare professionals and other autism service providers. The findings raise questions about how professionals identify caregivers' informational and emotional needs, decide what information to provide and when, and adapt explanations as questions emerge. Research should also examine how professional roles, organizational expectations, time, resources, and service arrangements shape responsibility for explanation, follow-up, and navigation. Professionals' awareness of the peer, community, and online sources families consult warrants particular attention, including how information from these sources is discussed within professional encounters. Comparing these perspectives with the present findings would deepen understanding of the relationship between caregivers' needs and the judgments and conditions shaping professional communication.

Developing and evaluating the recommendations with caregivers and professionals would help establish their accessibility, acceptability, feasibility, and resource requirements. Evaluation should consider whether caregivers can obtain clarification, understand available options, and

identify the next step, as well as the effort involved in navigating care. It should also examine the organizational arrangements needed to sustain these forms of support.

Further work should deliberately include multilingual, rural, newcomer, and other underserved communities. Autistic people should also participate in identifying priorities and interpreting proposed supports, consistent with Dwyer's (2022) emphasis on learning from neurodivergent people. In peer settings, combining analysis of complete discussions with accounts from people who post and those who read would deepen understanding of how practical advice, emotional support, and judgments about credibility relate to care decisions.

6.7 General conclusion

In answer to the overarching question, the integrated findings show that families meet post-diagnostic information as something to interpret, not simply to receive, and that its use involves continuing interpretation within the practical and emotional circumstances of care. Public resources offer guidance and tools, caregivers evaluate information in relation to their child, and peer spaces provide opportunities to raise questions and share experience. These findings suggest why the usefulness of information depends on the support available for understanding and applying it.

The dissertation contributes a cross-setting account of post-diagnostic information and informed decisions, an application of accommodation theory to written resources that separates anticipated from perceived responsiveness, and a proposed distinction between being enabled to participate and feeling responsible for every answer. It brings caregiver agency into the same account as the

effort and responsibility attached to navigating services. The practical implication is sustained attention to guided discussion, opportunities for clarification, and an explicit sharing of navigation responsibilities. These priorities place the communicative work of informed decision-making within the organization of post-diagnostic care.

Bibliography

Abbott, M., Bernard, P., & Forge, J. (2013). Communicating a diagnosis of autism spectrum disorder: A qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry*, *18*(3), 370–382. https://doi.org/10.1177/1359104512455813

Abel, S., Machin, T., & Brownlow, C. (2019). Support, socialise and advocate: An exploration of the stated purposes of Facebook autism groups. *Research in Autism Spectrum Disorders*, *61*, 10–21. https://doi.org/10.1016/j.rasd.2019.01.009

Alencar, D. C., Sousa Neto, A. R., Ibiapina, A. R. S., & de Oliveira, J. D. (2025). Information needs for parents of children with autism spectrum disorder: A qualitative study. *Cogitare Enfermagem, 30*, Article e97345en. https://doi.org/10.1590/ce.v30i0.97345en

Ayers, J. W., Caputi, T. L., Nebeker, C., & Dredze, M. (2018). Don't quote me: Reverse identification of research participants in social media studies. *npj Digital Medicine*, *1*, Article 30. https://doi.org/10.1038/s41746-018-0036-2

Battanta, N. K., Jenni, O. G., Schaefer, C., & von Rhein, M. (2024). Autism spectrum: Parents' perspectives reflecting the different needs of different families. *BMC Pediatrics*, *24*, Article 439. https://doi.org/10.1186/s12887-024-04912-x

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Blum, L. M. (2007). Mother-blame in the Prozac nation: Raising kids with invisible disabilities. *Gender & Society, 21*(2), 202–226. https://doi.org/10.1177/0891243206298178

Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. *Social Service Review*, *50*(3), 445–456. https://doi.org/10.1086/643401

Bowen, G. A. (2009). Document analysis as a qualitative research method. *Qualitative Research Journal*, *9*(2), 27–40. https://doi.org/10.3316/QRJ0902027

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

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2021a). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology, 18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Braun, V., & Clarke, V. (2021b). *Thematic analysis: A practical guide*. SAGE Publications.

Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. *International Journal of Transgender Health, 24*(1), 1–6. https://doi.org/10.1080/26895269.2022.2129597

Braun, V., & Clarke, V. (2024). Supporting best practice in reflexive thematic analysis reporting in Palliative Medicine: A review of published research and introduction to the Reflexive Thematic Analysis Reporting Guidelines (RTARG). *Palliative Medicine, 38*(6), 608–616. https://doi.org/10.1177/02692163241234800

Brian, J. A., Zwaigenbaum, L., & Ip, A. (2019). Standards of diagnostic assessment for autism spectrum disorder. *Paediatrics & Child Health*, *24*(7), 444–451. https://doi.org/10.1093/pch/pxz117

Burke, M., Li, C., Cheung, W. C., Terol, A. K., Johnston, A., & Schueller, S. M. (2024). Leveraging feedback from families of children with autism to create digital support for service navigation: Descriptive study. *JMIR Formative Research*, *8*, Article e56043. https://doi.org/10.2196/56043

Casale, L. M., Gentles, S. J., McLaughlin, J., & Schneider, M. (2023). Service access experiences of immigrant and refugee caregivers of autistic children in Canada: A scoping review. *PLOS ONE*, *18*(11), Article e0293656. https://doi.org/10.1371/journal.pone.0293656

Čolić, M., Araiba, S., Lovelace, T. S., & Dababnah, S. (2022). Black caregivers' perspectives on racism in ASD services: Toward culturally responsive ABA practice. *Behavior Analysis in Practice*, *15*(4), 1032–1041. https://doi.org/10.1007/s40617-021-00577-5

Corbin Dwyer, S., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods, 8*(1), 54–63. https://doi.org/10.1177/160940690900800105

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. L. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153–162. https://doi.org/10.1177/1362361315573636

Dalglish, S. L., Khalid, H., & McMahon, S. A. (2020). Document analysis in health policy research: The READ approach. *Health Policy and Planning, 35*(10), 1424–1431. https://doi.org/10.1093/heapol/czaa064

Daniels, A. K. (1987). Invisible work. *Social Problems, 34*(5), 403–415. https://doi.org/10.2307/800538

Daynes-Kearney, R., & Gallagher, S. (2023). Online support groups for family caregivers: Scoping review. *Journal of Medical Internet Research*, *25*, Article e46858. https://doi.org/10.2196/46858

Daynes-Kearney, R., & Gallagher, S. (2024). Social identity and online support groups: A qualitative study with family caregivers. *International Journal of Behavioral Medicine*, *31*(3), 479–490. https://doi.org/10.1007/s12529-023-10203-z

Daynes-Kearney, R., & Gallagher, S. (2025). Online support groups for family caregivers: A qualitative exploration of social support and engagement. *British Journal of Health Psychology, 30*(1), Article e12764. https://doi.org/10.1111/bjhp.12764

Dwyer, P. (2022). The neurodiversity approach(es): What are they and what do they mean for researchers? *Human Development, 66*(2), 73–92. https://doi.org/10.1159/000523723

Edwards, A. G., Brebner, C. M., McCormack, P. F., & MacDougall, C. J. (2018). From “parent” to “expert”: How parents of children with autism spectrum disorder make decisions about which intervention approaches to access. *Journal of Autism and Developmental Disorders*, *48*(6), 2122–2138. https://doi.org/10.1007/s10803-018-3473-5

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine*, *27*(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6

Eysenbach, G., & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *BMJ, 323*(7321), 1103–1105. https://doi.org/10.1136/bmj.323.7321.1103

Farzadnia, S., & Giles, H. (2015). Patient-provider health interactions: A communication accommodation theory perspective. *International Journal of Society, Culture & Language, 3*(2), 17–34. https://www.ijscl.com/article_12768.html

Folkman, S. (2008). The case for positive emotions in the stress process. *Anxiety, Stress, & Coping*, *21*(1), 3–14. https://doi.org/10.1080/10615800701740457

Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, *55*, 745–774. https://doi.org/10.1146/annurev.psych.55.090902.141456

franzke, A. S., Bechmann, A., Zimmer, M., & Ess, C. (2020). *Internet research: Ethical guidelines 3.0*. Association of Internet Researchers. https://aoir.org/reports/ethics3.pdf

Frey, E., Bonfiglioli, C., Brunner, M., & Frawley, J. (2022). Parents' use of social media as a health information source for their children: A scoping review. *Academic Pediatrics*, *22*(4), 526–539. https://doi.org/10.1016/j.acap.2021.12.006

Fuzzell, L. N., LaJoie, A. S., Smith, K. T., Philpott, S. E., Jones, K. M., & Politi, M. C. (2018). Parents' adherence to pediatric health and safety guidelines: Importance of patient-provider relationships. *Patient Education and Counseling, 101*(9), 1570–1576. https://doi.org/10.1016/j.pec.2018.05.003

Gallois, C., Ogay, T., & Giles, H. (2005). Communication accommodation theory: A look back and a look ahead. In W. B. Gudykunst (Ed.), *Theorizing about intercultural communication* (pp. 121–148). SAGE Publications.

Gentles, S. J., McLaughlin, J., Schneider, M., Stubbs, A., Lerner, P., Tristani, L., Spoelstra, M., Weiss, J., Lee, V., Georgiades, S., & LeClair, J. (2022). *Families in flux: Findings from the 2021 Ontario Autism Caregiver Survey on education, service access and well-being in the context of COVID-19*. Laurier Autism Research Consortium and Autism Ontario. https://www.wlu.ca/academics/faculties/faculty-of-human-and-social-sciences/faculty-profiles/janet-mclaughlin/larc/assets/documents/families-in-flux-2022-larc.pdf

Giles, H. (2016a). Communication accommodation theory. In K. B. Jensen, E. W. Rothenbuhler, J. D. Pooley, & R. T. Craig (Eds.), *The international encyclopedia of communication theory and philosophy* (pp. 1–7). Wiley. https://doi.org/10.1002/9781118766804.wbiect056

Giles, H. (Ed.). (2016b). *Communication accommodation theory: Negotiating personal relationships and social identities across contexts*. Cambridge University Press. https://doi.org/10.1017/CBO9781316226537

Giles, H., Edwards, A. L., & Walther, J. B. (2023). Communication accommodation theory: Past accomplishments, current trends, and future prospects. *Language Sciences*, *99*, Article 101571. https://doi.org/10.1016/j.langsci.2023.101571

Grant, N., Rodger, S., & Hoffmann, T. (2016). Intervention decision-making processes and information preferences of parents of children with autism spectrum disorders. *Child: Care, Health and Development*, *42*(1), 125–134. https://doi.org/10.1111/cch.12296

Helgeson, V. S., Jakubiak, B., Van Vleet, M., & Zajdel, M. (2018). Communal coping and adjustment to chronic illness: Theory update and evidence. *Personality and Social Psychology Review*, *22*(2), 170–195. https://doi.org/10.1177/1088868317735767

Hermaszewska, S., & Sin, J. (2021). End-user perspectives on the development of an online intervention for parents of children on the autism spectrum. *Autism*, *25*(5), 1234–1245. https://doi.org/10.1177/1362361320984895

Hewett, D. G., Watson, B. M., Gallois, C., Ward, M., & Leggett, B. A. (2009). Communication in medical records: Intergroup language and patient care. *Journal of Language and Social Psychology*, *28*(2), 119–138. https://doi.org/10.1177/0261927X08330612

Higgins, L., Mannion, A., Chen, J. L., & Leader, G. (2023). Adaptation of parents raising a child with ASD: The role of positive perceptions, coping, self-efficacy, and social support. *Journal of Autism and Developmental Disorders*, *53*(3), 1224–1242. https://doi.org/10.1007/s10803-022-05537-8

Hoefel, L., O'Connor, A. M., Lewis, K. B., Boland, L., Sikora, L., Hu, J., & Stacey, D. (2020). 20th anniversary update of the Ottawa Decision Support Framework Part 1: A systematic review of the decisional needs of people making health or social decisions. *Medical Decision Making*, *40*(5), 555–581. https://doi.org/10.1177/0272989X20936209

Hughes, R., Curley, K., & Kotera, Y. (2024). Parents' experiences after their child's autism diagnosis: A reflexive thematic analysis. *Psychiatry International*, *5*(3), 370–394. https://doi.org/10.3390/psychiatryint5030026

Ip, A., Zwaigenbaum, L., & Brian, J. A. (2019). Post-diagnostic management and follow-up care for autism spectrum disorder. *Paediatrics & Child Health*, *24*(7), 461–468. https://doi.org/10.1093/pch/pxz121

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology, 49*(1), 59–71. https://doi.org/10.1037/a0028353

Kelly, K. J., Doucet, S., Luke, A., Azar, R., & Montelpare, W. (2022). Experiences, motivations, and perceived impact of participation in a Facebook-based support group for caregivers of children and youth with complex care needs: Qualitative descriptive study. *JMIR Pediatrics and Parenting*, *5*(3), Article e33172. https://doi.org/10.2196/33172

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal*, *16*(2), 297–305. https://doi.org/10.1007/s10995-011-0751-7

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.

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

Leadbitter, K., Langhorne, S., Smallman, R., Chu, P., Ellis, C., Harrison, L., Hutton, T., Butter, C., Goldie, C., James, K., Hackett, L., Dunkerley, A., Bee, P., Shields, G., Davies, L., Emsley, R., Green, J., & REACH-ASD Team. (2025). Clinical effectiveness of an online psychoeducational and psychotherapeutic programme for caregivers of children newly diagnosed as autistic: A parallel, assessor-masked, randomised controlled trial in the UK (REACH-ASD). *The Lancet Psychiatry*, *12*(4), 289–302. https://doi.org/10.1016/S2215-0366(25)00036-7

Lee, J. D., Terol, A. K., Yoon, C. D., & Meadan, H. (2024). Parent-to-parent support among parents of children with autism: A review of the literature. *Autism*, *28*(2), 263–275. https://doi.org/10.1177/13623613221146444

Legg, H., & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*, *23*(8), 1897–1910. https://doi.org/10.1177/1362361319841488

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE Publications.

Lindly, O. J., Cabral, J., Mohammed, R., Garber, I., Mistry, K. B., & Kuhlthau, K. A. (2022). "I don't do much without researching things myself": A mixed methods study exploring the role of parent health literacy in autism services use for young children. *Journal of Autism and Developmental Disorders*, *52*(8), 3598–3611. https://doi.org/10.1007/s10803-021-05240-0

Lyons, R. F., Mickelson, K. D., Sullivan, M. J. L., & Coyne, J. C. (1998). Coping as a communal process. *Journal of Social and Personal Relationships*, *15*(5), 579–605. https://doi.org/10.1177/0265407598155001

Makino, A., Hartman, L., King, G., Wong, P. Y., & Penner, M. (2021). Parent experiences of autism spectrum disorder diagnosis: A scoping review. *Review Journal of Autism and Developmental Disorders*, *8*(3), 267–284. https://doi.org/10.1007/s40489-021-00237-y

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Martinović, I., & Stričević, I. (2016). Information needs and behaviour of parents of children with autism spectrum disorders: Parents' reports on their experiences and perceptions. *Information Research*, *21*(4), Paper isic1609. https://informationr.net/ir/21-4/isic/isic1609.html

Mohd Roffeei, S. H., Abdullah, N., & Basar, S. K. R. (2015). Seeking social support on Facebook for children with autism spectrum disorders (ASDs). *International Journal of Medical Informatics*, *84*(5), 375–385. https://doi.org/10.1016/j.ijmedinf.2015.01.015

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine, 89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report, 13*(4), 695–705. https://doi.org/10.46743/2160-3715/2008.1579

Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2021). Perceptions, experiences, and needs of parents of culturally and linguistically diverse children with autism: A scoping review. *Review Journal of Autism and Developmental Disorders*, *8*(2), 195–212. https://doi.org/10.1007/s40489-020-00210-1

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). SAGE Publications.

Prior, L. (2010). Researching documents: Emergent methods. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods* (pp. 111–126). Guilford Press.

Pye, K., Gold, L., Le, H. N. D., & Iacono, T. (2026). “What my son needs is me. What I need is... guidance”: Caregiver perspectives about early autism supports amid changing attitudes and policies. *Journal of Autism and Developmental Disorders, 56*(10), 4121–4134. https://doi.org/10.1007/s10803-025-06850-8

Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents’ experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, *66*, Article 101415. https://doi.org/10.1016/j.rasd.2019.101415

Reinke, J. S., & Solheim, C. A. (2015). Online social support experiences of mothers of children with autism spectrum disorder. *Journal of Child and Family Studies*, *24*(8), 2364–2373. https://doi.org/10.1007/s10826-014-0039-9

Rimé, B. (2009). Emotion elicits the social sharing of emotion: Theory and empirical review. *Emotion Review*, *1*(1), 60–85. https://doi.org/10.1177/1754073908097189

Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, *129*(2), 216–269. https://doi.org/10.1037/0033-2909.129.2.216

Smith, C. A., Parton, C., King, M., & Gallego, G. (2020). Parents’ experiences of information-seeking and decision-making regarding complementary medicine for children with autism spectrum disorder: A qualitative study. *BMC Complementary Medicine and Therapies*, *20*, Article 4. https://doi.org/10.1186/s12906-019-2805-0

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

Stacey, D., Légaré, F., Boland, L., Lewis, K. B., Loiselle, M.-C., Hoefel, L., Garvelink, M., & O’Connor, A. (2020). 20th anniversary Ottawa Decision Support Framework: Part 3 Overview of systematic reviews and updated framework. *Medical Decision Making*, *40*(3), 379–398. https://doi.org/10.1177/0272989X20911870

Street, R. L., Jr., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling*, *74*(3), 295–301. https://doi.org/10.1016/j.pec.2008.11.015

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Treadgold, B. M., Coulson, N. S., Campbell, J. L., Lambert, J., & Pitchforth, E. (2025). Quality and misinformation about health conditions in online peer support groups: Scoping review. *Journal of Medical Internet Research*, *27*, Article e71140. https://doi.org/10.2196/71140

Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gélie, F., Miot, S., Roeyers, H., & Baghdadli, A. (2019). Coping strategies of parents of children with autism spectrum disorder: A systematic review. *European Child & Adolescent Psychiatry*, *28*(6), 747–758. https://doi.org/10.1007/s00787-018-1183-3

Wilson, A. C., & Gunn, S. (2023). What parents want in an autism diagnostic report: An interview-based study of parents accessing a neurodevelopmental assessment service. *Clinical Child Psychology and Psychiatry*, *28*(3), 937–951. https://doi.org/10.1177/13591045221138703

Zhang, Z., Tan, S., Wignell, P., & O'Halloran, K. (2020). Addressing international students on Australian and Chinese university webpages: A comparative study. *Discourse, Context & Media*, *36*, Article 100403. https://doi.org/10.1016/j.dcm.2020.100403

Appendices

The appendices bring together the approvals, research instruments, resource records, and supplementary analytical materials supporting the completed studies. They complement the methodological descriptions and findings presented in the dissertation.

Appendix A - Ethics approval letters and relevant amendments or other ethics documentation

19/05/2023

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE I CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	S-05-22-8008
Titre du projet / Project Title	Exploring Communication and Information Processes for Parental Informed Decision-Making in the Context of Autism Diagnosis
Type de projet / Project Type	Thèse de doctorat / Doctoral thesis
Statut du projet / Project Status	Renouvelé / Renewed
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	09/06/2022
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	08/06/2024

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Marie Dominique ANTOINE	Département de communication / Department of Communication	Chercheur Principal / Principal Investigator
Martine LAGACÉ	Département de communication / Department of Communication	Superviseur / Supervisor

Conditions spéciales ou commentaires / Special conditions or comments

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www.recherche.uottawa.ca/deontologie I www.recherche.uottawa.ca/ethics

Appendix B - Recruitment materials, participant information and consent forms

Université d'Ottawa | University of Ottawa

Département de communication · Faculté des arts
Desmarais, 11e étage · 55 Laurier Avenue Est · Ottawa ON K1N 6N5 · arts.uOttawa.ca

Email Recruitment Parental Decision Making in Autism

Title of the study: Exploring communication and information processes for parental informed decision-making in the context of autism diagnosis.

Principal Investigator: Marie Dominique Antoine, PhD Candidate,
Department of Communication, Faculty of Arts,
Desmarais Hall, 55 Laurier Avenue Est, Ottawa,
Ontario K1N 6N5.

Supervisor: Martine Lagacé, Full Professor,
Department of Communication, Faculty of Arts,
Desmarais Hall, 55 Laurier Avenue Est, Ottawa,
Ontario K1N 6N5.

Dear Sir/Madam,

We are a team of researchers at the University of Ottawa who are currently conducting a study to explore the information available to parents in conventional health care settings following a child's diagnosis of autism and parental perceptions of this information in relation to its use in treatment decisions. Specifically, our goal is to assess the extent to which there is a gap between the information available and the information used in decision making and how parents cope with this gap.

We invite parents or informal caregivers living in Canada's National Capital Region whose child received an autism diagnosis at least six months earlier to participate in two semi-structured interviews. The second interview will take place approximately three months after the first. Your input is essential and will help to improve information and communication processes in the context of an autism diagnosis.

Format: Confidential interviews according to the University of Ottawa's Research Ethics and Integrity Board approval standards. Interviews will be conducted online through Zoom.

Duration: approximately 45 minutes per interview.

Each participant will receive one $40 Tim Hortons gift card as a thank you for participation in the two interviews.

To participate, please contact the principal investigator Marie Dominique Antoine.

We thank you in advance for your collaboration. Please do not hesitate to contact us if you have any questions.

Marie Dominique Antoine, PhD(c)
Department of Communication
University of Ottawa

uOttawa

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Département de communication · Faculté des arts
Desmarais, 11e étage · 55 Laurier Avenue Est · Ottawa ON K1N 6N5 · arts.uOttawa.ca

Recrutement par courriel Prise de décision parentale dans l'autisme

Titre du projet : Exploration des processus de communication et d'information pour la prise de décision éclairée des parents dans le contexte de diagnostic d'autisme.

Nom de la chercheuse principale : Marie Dominique Antoine, doctorante,
Département de communication, Faculté des arts,
Pavillon Desmarais, 55, avenue Laurier Est,
Ottawa (Ontario) K1N 6N5.

Superviseure : Martine Lagacé, professeure titulaire,
Département de communication, Faculté des arts,
Pavillon Desmarais, 55, avenue Laurier Est,
Ottawa (Ontario) K1N 6N5.

Chère Madame, Cher Monsieur,

Nous sommes une équipe de chercheures de l'Université d'Ottawa et effectuons présentement une étude qui vise à explorer les informations disponibles fournies aux parents dans les établissements de soins de santé conventionnels après le diagnostic d'autisme d'un enfant et les perceptions parentales quant à ces informations par rapport à leur utilisation dans la prise de décision en lien aux traitements. Plus précisément, notre objectif est d'évaluer dans quelle mesure il existe un écart entre les informations disponibles et les informations utilisées dans la prise de décision et comment les parents font face à cet écart.

Nous invitons les parents ou les personnes proches aidantes qui résident dans la région de la capitale nationale du Canada et dont l'enfant a reçu un diagnostic d'autisme depuis au moins six mois à participer à deux entrevues semi-dirigées. La deuxième entrevue aura lieu environ trois mois après la première. Votre point de vue est essentiel et contribuera à améliorer les processus d'information et de communication dans un contexte de diagnostic d'autisme.

Format : Entrevues confidentielles selon les normes d'approbation du Comité d'éthique et d'intégrité de la recherche à l'Université d'Ottawa. Les entrevues se dérouleront en ligne sur Zoom.

Durée : environ 45 minutes par entrevue.

Chaque participant recevra une carte-cadeau Tim Hortons de 40 $ en guise de remerciement pour sa participation aux deux entrevues.

Pour participer, veuillez contacter la chercheuse principale Marie Dominique Antoine.

Nous vous remercions d'avance pour votre collaboration. N'hésitez pas à nous contacter si vous avez des questions.

Marie Dominique Antoine, PhD(c)
Département de communication
Université d'Ottawa

uOttawa

Université d'Ottawa | University of Ottawa

Département de communication · Faculté des arts
Desmarais, 11e étage · 55 Laurier Avenue Est · Ottawa ON K1N 6N5 · arts.uOttawa.ca

Consent Form

Title of the study: Exploring communication and information processes for informed parental decision-making in the context of autism diagnosis.

Principal researcher: Marie Dominique Antoine, Ph.D. Candidate, Department of communication, Faculty of arts, Desmarais Hall, 55 Laurier Avenue Est, K1N 6N5, Ottawa, Ontario.

Supervisor: Martine Lagacé, Full professor, Department of communication, Faculty of arts, Desmarais Hall, 55 Laurier Avenue Est, K1N 6N5, Ottawa, Ontario.

1. Introduction

Before you agree to participate in this research project, please take the time to read and understand the following information. This document explains the purpose of this research project, its procedures, benefits, and risks.

2. Invitation to participate

You are invited to voluntarily participate in two semi-structured interviews conducted online through Zoom, approximately three months apart and lasting approximately 45 minutes each. The discussions will relate to the information shared with you in conventional healthcare settings in Ottawa and your decision-making regarding treatment options for your autistic child. Your participation will consist of signing this consent form, completing a short sociodemographic questionnaire, and participating in two interviews, approximately three months apart, lasting approximately 45 minutes each.

3. Purpose of the study

This study aims to explore available information provided to parents in conventional healthcare settings after children's autism diagnosis and parental perceptions of the information in relation to usage in treatment decision-making. Precisely, the goal is to assess the extent to which there is a gap in available information and the information used in decision-making and how parents cope with this gap.

4. Inclusion criteria

Participants must be at least 18 years old, be a parent or informal caregiver of an autistic child, live in Canada's National Capital Region, and be at least six months beyond their child's diagnosis. Participants must be able to understand and speak English or French.

5. Participation

Your voluntary participation will consist of completing the consent form and a short sociodemographic questionnaire, followed by two semi-structured interviews conducted online through Zoom, approximately three months apart and lasting approximately 45 minutes each. It should be noted that the interviews will be recorded to ensure accurate transcription and to allow for subsequent analysis of the results. Further, for accuracy purposes, once the interview data is transcribed, you will receive a secure PDF of the transcription by email. You will be invited to submit your comments in the same manner.

6. Benefits

This study provides a voice to parents/caregivers to increase knowledge regarding the information provided in conventional healthcare settings after children's autism diagnosis and the perceptions of the information in relation to usage in treatment decision-making. The results of this project will inform, or at least guide, healthcare system leaders in the context of autism diagnosis and treatment, particularly in reducing the chances of individuals making misinterpretations that may lead to confusion or lead to making wrong decisions.

7. Risks

Although unlikely, there is a minor risk of psychological discomfort associated with participating in the study. You may feel uncomfortable if some questions remind you of unpleasant experiences. Please note that you are free to refuse to answer any question or stop participating in the study. Should you feel any distress, I invite you to contact the Ottawa 24/7 crisis line at 613-722-6914 or 1-866-996-0991. The list of available resources is on the last page of this document.

8. Conservation of data

Data and research documents will be retained for five years, as required by the University of Ottawa's ethics protocol. For analysis purposes, the data may be downloaded on a computer belonging to the Principal researcher. All downloaded data is, at all times, protected via technical safeguards (e.g., password, antivirus) and administrative safeguards (e.g., authorized users only).

9. Confidentiality and Anonymity

The information that you will share will remain strictly confidential. The content will be used solely for the purposes of this research. The only people who will have access to the research data are the researchers mentioned above and authorized members of their team. To minimize the risk of security breaches and to help ensure your confidentiality, we recommend using standard safety measures such as signing out of your account and closing your browser when you have completed the sociodemographic questionnaire and the consent form. All results will be published in a pooled (aggregate) format without individual information. You will be asked a series of sociodemographic questions; however, to guarantee your anonymity, you will not be asked for any key identifying information (e.g., name, date of birth, address). If a particular sociodemographic question might provide identifying information about you, you are under no obligation to provide an answer.

10. Voluntary participation and compensation

Your participation in the research is voluntary. You are free to withdraw at any time or to refuse to answer specific questions without suffering any negative consequences. If you choose to withdraw from the study, the data collected up to that point will be destroyed. Thus, it will not be used in the analysis or subsequent steps.

Each participant will receive a $40 Tim Hortons gift certificate to thank them for participating.

11. Consent

By signing this consent form, you agree to the above conditions and to participate in the study conducted by Marie Dominique Antoine, Ph.D. Candidate supervised by Martine Lagacé, Professor at the Department of communication of the University of Ottawa. If you have any questions or require further information about the study, contact the researcher or supervisor at the numbers provided herein (see contact information on the first page).

For questions regarding the ethical conduct of this study, contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562-5387 or ethics@uottawa.ca.

Thank you for your time and consideration.

Marie Dominique Antoine, PhD(c)

Principal researcher

Université d'Ottawa | University of Ottawa

Consent Form

☐ I agree to participate in this study.

☐ I confirm that I am at least 18 years old and am a parent or informal caregiver of an autistic child whose diagnosis was received at least six months ago.

☐ I confirm that I live in Canada's National Capital Region.

Signature: _____ Date: _____

Resources list

Ottawa 24/7 crisis line

Distress: 613-238-3311 | Crisis: 613-722-6914 or 1-866-996-0991 | Text: 313-306-5550 Chat and Text 10 am to 11 pm

Caring for Caregivers Resources 2.0

https://www.theroyal.ca/sites/default/files/2021-03/Caring%20for%20Caregivers%20Resources%20March25%2C2021.pdf

Ottawa Autism – Ontario Chapter

ottawa@autismontario.com

1-800-742-7789 ext. 318

Autism Parent Resource Kit

https://www.ontario.ca/page/autism-ontario

Coalition of Community Health and Resource Centres of Ottawa

http://www.coalitionottawa.ca/en/find-your-chrc.aspx

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Formulaire de consentement

Titre du projet: Exploration des processus de communication et d'information pour la prise de décision éclairée des parents dans le contexte de diagnostic d'autisme.

Nom de la chercheuse principale: Marie Dominique Antoine, Candidate au Doctorat, Département de communication, Faculté des arts, Pavillon Desmarais, 55 rue Laurier, Est, K1N 6N5, Ottawa, Ontario.

Superviseure: Martine Lagacé, professeure titulaire au Département de communication, Faculté des arts, Pavillon Desmarais, 55 rue Laurier, Est, K1N 6N5, Ottawa, Ontario.

1. Introduction

Avant d'accepter de participer à ce projet de recherche, veuillez prendre le temps de lire et de comprendre les informations suivantes. Ce document explique l'objectif du projet de recherche, ses procédures, ses avantages et ses risques.

2. Invitation à participer

Vous êtes invité à participer volontairement à deux entrevues semi-dirigées qui se dérouleront en ligne sur Zoom, à environ trois mois d'intervalle, et dureront environ 45 minutes chacune. Les discussions porteront sur les informations qui vous ont été communiquées dans les établissements de santé conventionnels d'Ottawa et sur votre prise de décision concernant les options de traitement pour votre enfant autiste. Votre participation consistera à signer ce formulaire de consentement, à remplir un court questionnaire sociodémographique et à prendre part à deux entrevues, à environ trois mois d'intervalle, d'une durée d'environ 45 minutes chacune.

3. But de l'étude

Cette étude vise à explorer les informations disponibles fournies aux parents dans les établissements de santé conventionnels après le diagnostic d'autisme d'un enfant et les perceptions parentales de ces informations par rapport à leur utilisation dans la prise de décision concernant le traitement. Plus précisément, l'objectif est d'évaluer dans quelle mesure il existe un écart entre les informations disponibles et les informations utilisées dans la prise de décision et comment les parents font face à cet écart.

4. Critères d'inclusion

Les participants doivent être âgés d'au moins 18 ans, être parents ou personnes proches aidantes d'un enfant autiste, résider dans la région de la capitale nationale du Canada et avoir un enfant dont le diagnostic d'autisme remonte à au moins six mois. Les participants doivent être capables de comprendre et de parler l'anglais ou le français.

5. Participation

Votre participation volontaire consistera à remplir le formulaire de consentement et un court questionnaire sociodémographique, puis à participer à deux entrevues semi-dirigées en ligne sur Zoom, à environ trois mois d'intervalle, d'une durée d'environ 45 minutes chacune. Veuillez noter que les entretiens seront enregistrés afin de garantir une transcription précise et de permettre une analyse ultérieure des résultats. En outre, pour des raisons de précision, une fois les données de l'entretien transcrites, vous recevrez par courrier électronique un PDF sécurisé de la transcription. Vous serez invité à soumettre vos commentaires de la même manière.

6. Bienfaits

Cette étude donne la parole aux parents/personnes aidants afin d'accroître les connaissances concernant les informations fournies dans les établissements de soins de santé conventionnels après le diagnostic d'autisme d'un enfant et les perceptions de ces informations par rapport à leur utilisation dans

la prise de décision concernant le traitement. Les résultats de ce projet permettront d'informer, ou du moins de guider les responsables du système de soins de santé dans le contexte du diagnostic et du traitement de l'autisme, notamment dans le but de réduire les risques d'interprétations erronées de la part des familles, qui peuvent entraîner une confusion ou conduire à prendre de mauvaises décisions.

7. Risques

Bien que peu probable, il existe un risque mineur d'inconfort psychologique associé à la participation à l'étude. Vous pouvez vous sentir mal à l'aise si certaines des questions vous rappellent des expériences désagréables. Veuillez noter que vous êtes entièrement libre de refuser de répondre à toute question ou de cesser de participer à l'étude. Si vous ressentez une détresse quelconque, je vous invite à communiquer avec la ligne d'urgence en santé mentale au 613-722-6914 ou 1-866-996-0991. La liste complète des ressources disponibles se trouve à la dernière page de ce document.

8. Conservation des données

Les données et les documents de recherche seront conservés pendant cinq ans, comme l'exige le protocole éthique de l'Université d'Ottawa. À des fins d'analyse, les données peuvent être téléchargées sur un ordinateur appartenant à la chercheuse principale. Toutes les données téléchargées sont, en tout temps, protégées par des mesures techniques (p. ex., mot de passe, antivirus) et administratives (p. ex., utilisateurs autorisés seulement).

9. Confidentialité et Anonymité

Les informations que vous partagerez resteront strictement confidentielles. Les données seront utilisées uniquement aux fins de cette recherche. Les seules personnes qui auront accès aux données de recherche sont les chercheurs mentionnés ci-haut et les membres autorisés de leur équipe. Afin de minimiser le risque de failles de sécurité et de garantir votre confidentialité, nous vous recommandons d'utiliser les mesures de sécurité standard telles que la déconnexion de votre compte et la fermeture de votre navigateur lorsque vous aurez terminé le questionnaire démographique et ce formulaire de consentement. Tous les résultats seront publiés sous forme groupée (agrégée) sans informations individuelles. Une série de questions sociodémographiques vous seront posées; cependant, afin de garantir votre anonymat, aucune information clé d'identification (par exemple, nom, date de naissance, adresse) ne vous sera demandée. Si vous pensez qu'une question sociodémographique particulière pourrait fournir des informations permettant de vous identifier, vous n'êtes pas obligé de répondre.

10. Participation volontaire et compensation

Votre participation à la recherche est volontaire. Vous êtes libre de vous retirer à tout moment ou de refuser de répondre à certaines questions, sans subir de conséquences négatives. Si vous choisissez de vous retirer de l'étude, les données recueillies jusqu'à ce moment-là seront détruites. Elles ne seront pas utilisées dans l'analyse ou les étapes ultérieures.

Chaque participant recevra un chèque-cadeau de 40 $ de Tim Hortons pour le remercier de sa participation.

11. Consentement

En signant ce formulaire de consentement, vous acceptez les conditions ci-dessus et de participer à l'étude menée par Marie Dominique Antoine, candidate au doctorat supervisée par Martine Lagacé, professeure au Département de communication de l'Université d'Ottawa. Si vous avez des questions ou si vous désirez plus d'informations sur l'étude elle-même, vous pouvez contacter la chercheuse ou sa superviseure aux numéros mentionnés ici (voir les coordonnées à la première page).

Pour des questions concernant la conduite éthique de cette étude, vous pouvez communiquer avec la responsable de déontologie en recherche de l'Université d'Ottawa au Pavillon Tabaret, pièce 154, 550 rue Cumberland, (613) 562-5387 ou ethics@uottawa.ca.

Nous vous remercions très sincèrement de votre intérêt et de votre considération pour cette étude.

Marie Dominique Antoine, PhD(c)

Chercheuse principale

Université d'Ottawa | University of Ottawa

Formulaire de consentement

☐ J'accepte de participer à cette étude.

☐ Je confirme avoir au moins 18 ans et être parent ou personne proche aidante d'un enfant dont le diagnostic d'autisme remonte à au moins six mois.

☐ Je confirme résider dans la région de la capitale nationale du Canada.

Signature: _____ Date: _____

Liste des ressources

Ottawa ligne de crise en tout temps 24/7
Détresse: 613-238-3311 | Crise: 613-722-6914 ou 1-866-996-0991 | Texto: 313-306-5550 Chat et Texte 10 am to 11 pm
Caring for Caregivers Resources 2.0 (seulement disponible en anglais)
https://www.theroyal.ca/sites/default/files/2021-03/Caring%20for%20Caregivers%20Resources%20March25%2C2021.pdf
Ottawa Autism – Ontario Chapter
ottawa@autismontario.com
poste 318
Trousse d'information pour les familles d'enfants ayant récemment reçu un diagnostic
https://www.ontario.ca/page/autism-ontario
Coalition des centres de ressources et de santé communautaires d'Ottawa
http://www.coalitionottawa.ca/en/find-your-chrc.aspx

Exploring communication and information processes for informed parental decision-making in the context of autism diagnosis.

Sociodemographic Questionnaire

Q1. How old are you? _____

Q2. What gender do you identify with? _____

Q3. What is your occupation/profession? _____

Q4. What is the highest level of education you have attained?

- ☐ Less than high school
- ☐ Completed high school
- ☐ Community college certificate or diploma, CEGEP, ...
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Doctoral degree

Q5. What is your ethnicity? _____

Q6. What is your marital status?

- ☐ Married
- ☐ Common-law
- ☐ Widowed
- ☐ Separated
- ☐ Divorced
- ☐ Never legally married
- ☐ Single/Not partnered

Q7. What is the relationship with the child? _____

Q8. How old is your child? _____

Q9. What is your child's gender? _____

Q10. When was your child diagnosed? _____

Q11. Which autism organization(s) provides services to your child in Ottawa?

_____

_____

_____

Exploration des processus de communication et d'information pour la prise de décision éclairée des parents dans le contexte de diagnostic d'autisme.

Questionnaire sociodémographique

Q1. Quel est votre âge? _____

Q2. À quel genre vous identifiez-vous? _____

Q3. Quelle est votre occupation/profession? _____

Q4. Quel est le niveau d'éducation le plus élevé que vous avez atteint?

- ☐ Inférieur aux études secondaires
- ☐ Études secondaires complétées
- ☐ Certificat ou diplôme d'un collège communautaire, CÉGEP, …
- ☐ Diplôme de baccalauréat
- ☐ Diplôme de maîtrise
- ☐ Diplôme de doctorat

Q5. Quelle est votre ethnicité? _____

Q6. Quel est votre statut civil?

- ☐ Marié(e)
- ☐ En union libre
- ☐ Veuf /veuve
- ☐ Séparé(e)
- ☐ Divorcé(e)
- ☐ Jamais légalement marié(e)
- ☐ Célibataire/Pas de partenaire

Q7. Quel est votre lien de parenté avec l'enfant? _____

Q8. Quel âge a votre enfant? _____

Q9. Quel est le genre de votre enfant? _____

Q10. Quand avez-vous reçu le diagnostic de votre enfant? _____

Q11. Quel(s) organisme(s) d'autisme offre(nt) des services à votre enfant à Ottawa ?

_____

_____

_____

Appendix C - Interview guides

Exploring communication and information processes for parental informed decision-making in the context of autism diagnosis.

Semi-structured Interviews

Time 1 Interview (T1): Initial Post-Diagnosis Experience

1. After your child's diagnosis, did you receive any information from a healthcare professional or organization providing autism-related services?
   (If yes, please describe.)
2. Which healthcare professional or organization provided this information?
3. What types of information or materials did you receive?
   (For example: reports, pamphlets, websites, resource lists.)
4. How was this information provided to you?
   (For example: during an appointment, email, website links.)
5. How did you experience the way this information was communicated to you?
6. Have you made any decisions related to intervention or treatment options since the diagnosis?
   (If yes, please describe the decisions you made.)

Relating to Decision-Making

7. Can you describe any decisions you were facing at that time related to services, interventions, or supports?
8. How, if at all, did the information you received influence those decisions?

Time 2 Interview (T2): Follow-Up and Reflection (Three Months Later)

1. Since our last conversation, have you used any of the information or materials you received after the diagnosis?
   (If yes, please describe how.)
2. Have you accessed any new information or resources since then?
   (If yes, please describe.)
3. Looking back, have your perceptions of the original materials changed over time?
   (If so, in what way?)
4. Have you made any further decisions related to autism care options since we last spoke?
   (If yes, please describe.)
5. Was the information you received helpful in supporting your decision-making?
6. Is there anything you would change about the information you received or the way it was communicated to you?
7. Were there any resources that stood out to you as particularly helpful or unhelpful?
8. Did you seek out information on your own?
   (If yes, did this information complement or differ from what you received from healthcare professionals?)
9. Which sources of information did you find most useful for decision-making?
   (For example: healthcare professionals, online searches, books, peer groups.)

Exploration des processus de communication et d'information dans la prise de décision éclairée des parents dans le contexte du diagnostic de l'autisme.

Entrevues semi-dirigées

Entrevue – Temps 1 (T1) : Expérience initiale après le diagnostic

1. Après le diagnostic de votre enfant, avez-vous reçu de l'information de la part d'un professionnel de la santé ou d'un organisme offrant des services liés à l'autisme?
   (Si oui, pouvez-vous me décrire ce que vous avez reçu?)
2. De quel professionnel de la santé ou de quel organisme provenait cette information?
3. Quels types d'information ou de documents avez-vous reçus?
   (Par exemple : rapports, dépliants, sites Web, listes de ressources.)
4. Comment cette information vous a-t-elle été transmise?
   (Par exemple : lors d'un rendez-vous, par courriel, par des liens vers des sites Web.)
5. Comment avez-vous vécu la façon dont cette information vous a été communiquée?
6. Depuis le diagnostic, avez-vous pris des décisions concernant des interventions ou des options de traitement?
   (Si oui, pouvez-vous décrire les décisions que vous avez prises?)

Questions liées à la prise de décision

7. Pouvez-vous décrire les décisions auxquelles vous faisiez face à ce moment-là concernant les services, les interventions ou les soutiens pour votre enfant?
8. De quelle manière, le cas échéant, l'information reçue a-t-elle influencé ces décisions?

Entrevue – Temps 2 (T2) : Suivi et réflexion (trois mois plus tard)

1. Depuis notre dernière rencontre, avez-vous utilisé l'information ou les documents reçus après le diagnostic?
   (Si oui, pouvez-vous expliquer comment?)
2. Avez-vous consulté de nouvelles sources d'information ou de nouvelles ressources depuis ce temps?
   (Si oui, pouvez-vous les décrire?)
3. Avec le recul, votre perception des documents ou de l'information reçus initialement a-t-elle changé?
   (Si oui, de quelle façon?)
4. Avez-vous pris d'autres décisions concernant les soins ou les services liés à l'autisme depuis notre dernière rencontre?
   (Si oui, pouvez-vous les décrire?)
5. Dans quelle mesure l'information reçue vous a-t-elle aidé à prendre des décisions?
6. Y a-t-il des aspects de l'information reçue, ou de la manière dont elle vous a été communiquée, que vous changeriez?
7. Certaines ressources vous ont-elles semblé particulièrement utiles ou, au contraire, peu utiles?
8. Avez-vous cherché de l'information par vous-même?
   (Si oui, cette information complétait-elle ou différait-elle de celle reçue de la part des professionnels de la santé?)

9. Quelles sources d'information avez-vous trouvées les plus utiles pour prendre des décisions?
   (Par exemple : professionnels de la santé, recherches en ligne, livres, groupes de pairs.)

Appendix D - Study 1 organizational context and resource identification

The tables describe the organizations included in the study and illustrative pathways used to identify relevant public resources during fall 2024, and the screening record for all organizations reviewed. Organizational profiles and language entries refer to information recorded at collection. Resource pathways document how items were presented or linked within organizational websites.

Table D1 Included organizations and recorded service context

Organization	Service context recorded at collection	Recorded resource-page language
ACT Learning Centre	Caregiver-mediated early years programs, core clinical services, and entry-to-school programming	English and French
CHEO	Early years services, foundational family services, school support, and urgent response	English and French
Emerging Minds	Assessment, behavioural consultation and intervention, occupational therapy, and speech therapy	English
Full Circle Therapy	Foundational and social skills programs and individual therapy	English
Fundamentals Child Behaviour Solutions	Psychological and diagnostic assessment, behavioural assessment and intervention, consultations, and workshops	English
Gamache Behaviour Consulting	Focused ABA, behaviour management, skill development, and parent training	English
Horizons Behavior Consulting	Centre-based early intervention using ABA	English
Portia Learning Centre	Comprehensive and focused ABA, small-group ABA, and consultation	English
QuickStart Early Intervention for Autism	Diagnostic assessment support, parent respite, family events, and workshops	English
The Core Learning Centre	Individual ABA therapy, school and life skills, respite, and parent/family coaching	English

Organization	Service context recorded at collection	Recorded resource-page language
Thinking In Pictures Educational Services (TIPES)	Intensive behavioural intervention, school readiness, behaviour management, mental health services, and parent training	English

Table D2 Selected recorded resource-identification pathways

Organization	Recorded route or website section	Examples identified
CHEO	Home → Resources and Support → A–Z Resources → Autism	Books and guides, websites, local contacts, Our ASD Journeys, and videos
Portia Learning Centre	Resources	Parent's Guide to ABA, frequently asked questions, and financial-help information
Fundamentals Child Behaviour Solutions	Links	External professional/resource links and educational articles concerning autism, assessment, ADHD, executive functioning, and related topics
Emerging Minds	Resources	Autism-related educational information and links to Ontario services and supports

ABA: applied behaviour analysis. ADHD: attention-deficit/hyperactivity disorder. Language entries in Table D1 describe the recorded organizational resource page, not every external resource linked from that page. Identification of a recommended or linked item does not indicate full-text analysis of that item.

Table D3 Organizational screening record

Organization reviewed	Recorded public resource-page status	Included in final sample
AAC and Literacy Ottawa	No resource page recorded; some resources identified.	No
ABA Connections	No	No
ABA Services Ottawa	No	No
ACT Learning Centre	Yes	Yes
Active Pediatrics	No	No
Applied Behaviour Consulting	No	No
Aspire Academy	No	No
CHEO	Yes	Yes
Dr. ABA Early Intervention Center	No	No
Edelweiss Private Academy	No	No
Emerging Minds	Yes	Yes
Expanding Horizons Occupational Therapy	No	No
Full Circle Therapy	Yes	Yes
Fundamentals Child Behaviour Solutions	Yes	Yes
Gamache Behaviour Consulting	Yes	Yes
Home Run Pediatric Occupational Therapy	No	No
Horizons Behavior Consulting	Yes	Yes
Howell Occupational Therapy Professional Corporation	No	No
On the Ball Pediatric Physio and Occupational Therapy Clinic	No	No
Pamela Rogoza-Hayward Behaviour Consulting	No	No
Portia Learning Centre	Yes	Yes
QuickStart Early Intervention for Autism	Yes	Yes
Spectrum Intervention Group	No	No
Speech-Language Ottawa	No	No
The Core Learning Centre	Yes	Yes
Thinking In Pictures Educational Services (TIPES)	Yes	Yes

The status entries reproduce the organizational screening record at collection. Final inclusion applied the study criteria described in Section 3.2.3. Organization names follow that record. AAC in “AAC and Literacy Ottawa” stands for augmentative and alternative communication.

Appendix E - Supplementary analytical materials and tables referenced in the chapters

Appendix E supports Study 3 (Chapter 5). Appendix E1 summarizes the relationships stated in the selected contributions, Appendix E2 gives paraphrased summaries of each contribution with its source-group identifier and theme and subtheme assignment, and Appendix E3 cross-references the chapter's reporting against the Reflexive Thematic Analysis Reporting Guidelines.

Appendix E1 Contextual summary of relationships stated in the selected contributions

Entry ID	Group	Relationship stated in text	Role in coding record (unverified)	Age stated in text (range)	Geographic reference
B001	G2	Parent	Not recorded	Under 2	Germany (stated location)
B002	G1	Parent	Mother	2–5	Not stated
B003	G1	Not stated	Not recorded	Not stated	Not stated
B004	G1	Parent	Mother	Not stated	Not stated
B005	G2	Not stated	Not recorded	Not stated	United States (service availability)
B006	G2	Parent	Mother	2–5	Not stated
B007	G2	Mother	Mother	Not stated	Not stated
B008	G1	Parent	Mother	Not stated	Not stated
B009	G1	Not stated	Not recorded	Not stated	Not stated
B010	G1	Not stated	Not recorded	Not stated	Not stated
B011	G1	Not stated	Not recorded	Not stated	Not stated
B012	G1	Not stated	Not recorded	Not stated	Not stated
B013	G1	Parent	Mother	Not stated	Not stated
B014	G1	Parent	Mother	18+ (other child, described as non-autistic)	Not stated
B015	G1	Parent	Mother	Not stated	Not stated
B016	G2	Parent	Not recorded	Not stated	United States (school context)
B017	G2	Parent	Not recorded	Not stated	Not stated
B018	G2	Parent	Not recorded	6–11	Not stated
B019	G1	Not stated	Not recorded	Not stated	Not stated
B020	G1	Not stated	Not recorded	Not stated	Not stated
B021	G1	Parent	Mother	Not stated	Not stated

Entry ID	Group	Relationship stated in text	Role in coding record (unverified)	Age stated in text (range)	Geographic reference
B022	G1	Parent	Mother	12–17 (older siblings); focal child: not stated	Not stated
B023	G1	Not stated	Not recorded	Not stated	Not stated
B024	G1	Parent	Mother	Not stated	Not stated
B025	G1	Not stated	Not recorded	Not stated	Not stated
B026	G1	Parent	Mother	6–11	Not stated
B027	G1	Grandparent	Grandmother	Not stated	Not stated
B028	G1	Not stated	Not recorded	Not stated	Not stated
B029	G2	Not stated	Not recorded	Not stated	Not stated
B030	G2	Parent	Not recorded	Not stated	Not stated
B031	G2	Parent	Not recorded	2–5	Not stated
B032	G2	Parent	Mother	2–5	Not stated
B033	G2	Not stated	Not recorded	Not stated	Not stated
B034	G2	Parent	Not recorded	Not stated	Not stated
B035	G2	Not stated	Not recorded	Not stated	Not stated
B036	G2	Not stated	Not recorded	Not stated	Not stated
B037	G2	Not stated	Not recorded	Not stated	Not stated
B038	G2	Not stated	Not recorded	Not stated	Not stated
B039	G2	Not stated	Not recorded	Not stated	Not stated
B040	G2	Not stated	Not recorded	2–5	Not stated
B041	G2	Parent	Not recorded	6–11	Not stated
B042	G1	Not stated	Not recorded	Not stated	Not stated
B043	G1	Relative (niece)	Aunt	Not stated	Not stated
B044	G1	Not stated	Not recorded	Not stated	Not stated
B045	G1	Parent	Not recorded	Not stated	Not stated
B046	G1	Parent	Not recorded	Not stated	Not stated
B047	G1	Not stated	Mother	2–5	Not stated
B048	G1	Parent	Mother	Not stated	Not stated
B049	G1	Parent	Mother	Not stated	Not stated
B050	G2	Not stated	Not recorded	Not stated	Not stated

Entry ID	Group	Relationship stated in text	Role in coding record (unverified)	Age stated in text (range)	Geographic reference
B051	G2	Not stated	Not recorded	Not stated	Not stated
B052	G2	Not stated	Not recorded	Not stated	Not stated
B053	G2	Not stated	Not recorded	Not stated	Not stated
B054	G2	Parent	Not recorded	6–11	Not stated
B055	G2	Not stated	Not recorded	Not stated	Not stated
B056	G2	Not stated	Not recorded	Not stated	Not stated
B057	G2	Not stated	Not recorded	Not stated	Not stated
B058	G2	Not stated	Not recorded	Not stated	Not stated
B059	G2	Not stated	Not recorded	Not stated	Not stated
B060	G2	Not stated	Not recorded	Not stated	Not stated
B061	G2	Not stated	Not recorded	Not stated	Not stated
B062	G2	Not stated	Not recorded	Not stated	Not stated
B063	G2	Parent	Not recorded	Not stated	Not stated
B064	G2	Not stated	Not recorded	Not stated	Not stated
B065	G2	Not stated	Not recorded	Not stated	Not stated
B066	G2	Not stated	Not recorded	Not stated	Not stated
B067	G2	Not stated	Not recorded	Not stated	Not stated
B068	G2	Not stated	Not recorded	Not stated	Not stated
B069	G2	Not stated	Not recorded	Not stated	Not stated
B070	G2	Not stated	Not recorded	Not stated	Not stated
B071	G2	Not stated	Not recorded	Not stated	Not stated
B072	G2	Parent	Not recorded	18+	Not stated
B073	G2	Parent	Not recorded	Under 2	Not stated
B074	G2	Not stated	Not recorded	Not stated	Not stated
B075	G2	Not stated	Not recorded	Not stated	Not stated
B076	G1	Not stated	Not recorded	Not stated	Not stated
B077	G1	Not stated	Not recorded	Not stated	Not stated
B078	G1	Parent	Mother	Not stated	Not stated
B079	G2	Not stated	Not recorded	Not stated	Not stated
B080	G2	Not stated	Not recorded	Not stated	Not stated

Entry ID	Group	Relationship stated in text	Role in coding record (unverified)	Age stated in text (range)	Geographic reference
B081	G1	Parent	Not recorded	Not stated	Not stated
B082	G1	Not stated	Not recorded	Not stated	Not stated
B083	G1	Not stated	Not recorded	Not stated	Not stated
B084	G1	Not stated	Not recorded	Not stated	Not stated
B085	G1	Not stated	Not recorded	Not stated	Not stated
B086	G1	Not stated	Mother	Not stated	Not stated
B087	G1	Not stated	Not recorded	Not stated	Not stated
B088	G1	Not stated	Not recorded	Not stated	Not stated
B089	G2	Not stated	Not recorded	Not stated	Not stated
B090	G2	Great-grandparent	Great grandmother	2–5 (great-grandchild); 18+ (other relatives)	Not stated
B091	G2	Not stated	Not recorded	Not stated	Not stated
B092	G2	Not stated	Not recorded	Not stated	Not stated
B093	G2	Parent	Not recorded	6–11	Not stated
B094	G2	Not stated	Not recorded	Not stated	Not stated
B095	G2	Not stated	Not recorded	Not stated	Not stated
B096	G2	Mother	Mother	12–17	Not stated
B097	G2	Not stated	Not recorded	Not stated	Not stated
B098	G2	Parent	Not recorded	Not stated	United Kingdom (seeking local contacts)
B099	G2	Not stated	Not recorded	Not stated	United States (another family)
B100	G2	Mother	Mother	Teenage (two children; exact ages not stated)	Not stated
B101	G2	Parent	Not recorded	Not stated	Not stated
B102	G2	Not stated	Not recorded	Not stated	Not stated
B103	G1	Parent	Mother	6–11 (two children; at travel)	Poland (travel destination)
B104	G1	Parent	Mother	2–5	Not stated
B105	G1	Not stated	Mother	2–5	Not stated
B106	G1	Not stated	Not recorded	Not stated	Not stated

Entry ID	Group	Relationship stated in text	Role in coding record (unverified)	Age stated in text (range)	Geographic reference
B107	G1	Not stated	Not recorded	Not stated	Not stated
B108	G1	Not stated	Not recorded	Not stated	Not stated
B109	G1	Parent	Mother	Not stated	Not stated
B110	G2	Not stated	Not recorded	Teenage (person being tutored; exact age not stated)	Not stated
B111	G2	Parent	Not recorded	Not stated	Not stated
B112	G2	Mother	Mother	Not stated	Not stated
B113	G2	Parent	Not recorded	Not stated	Not stated
B114	G2	Mother	Mother	2–5	Not stated
B115	G2	Parent	Mother	Not stated	Not stated
B116	G2	Parent	Not recorded	2–5	Not stated
B117	G2	Grandmother	Grandmother	2–5	Not stated
B118	G2	Parent	Not recorded	6–11	South Africa (stated location)

Appendix E2 Paraphrased inventory of selected contributions, including source-group identifiers and theme/subtheme assignments

Theme 1. Navigating uncertainty in fragmented systems

18 entries: Group 1, 11; Group 2, 7.

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B001	G2	A parent describes concern about a young child's development, slow progress with therapy, and distress following a discouraging professional consultation.	Not recorded	Perceived limitations of professional guidance
B002	G1	A parent reports limited school support for suspected developmental conditions, although staff helped with a referral.	Mother	Delayed access
B003	G1	The writer asks how long a disability-benefit application may take and when payments would begin.	Not recorded	Delayed access
B004	G1	A parent describes changing schools after learning difficulties continued, but reports that the child remains disengaged from schoolwork.	Mother	Delayed access
B005	G2	The writer reports a lack of suitable local childcare and an intention to continue supporting the child.	Not recorded	Delayed access
B006	G2	A parent describes difficulty managing a child's communication and behavioural needs after diagnosis, with little support.	Mother	Delayed access
B007	G2	A mother describes raising a child alone, difficulty accessing therapy, and financial hardship.	Mother	Delayed access
B008	G1	A parent explains that accompanying a school outing requires a background check.	Mother	Systemic opacity

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B009	G1	The writer questions whether a family received sufficient notice to make arrangements and refers to seeking help from local authorities.	Not recorded	Systemic opacity
B010	G1	The writer states that a specialist class requires an accompanying adult.	Not recorded	Systemic opacity
B011	G1	The writer welcomes disability-related financial assistance and wishes it were more widely available.	Not recorded	Systemic opacity
B012	G1	A brief response compliments a child's photograph.	Not recorded	Systemic opacity
B013	G1	A parent asks how to apply for disability-related financial support after a child's diagnosis.	Mother	Systemic opacity
B014	G1	The writer suggests that bullying may help explain a child's behaviour and expresses concern for the family.	Mother	Systemic opacity
B015	G1	A parent asks why differences between assessment scores prevented calculation of an overall score.	Mother	Systemic opacity
B016	G2	A parent describes a prolonged dispute over special-education provision and calls for fair treatment.	Not recorded	Systemic opacity
B017	G2	The writer reports receiving a suggestion to ask an insurer what support it covers.	Not recorded	Systemic opacity
B018	G2	A parent describes increasing difficulty with a child's emotional regulation and seeks support from the group.	Not recorded	Systemic opacity

Theme 2. Making meaning through peer connection

38 entries: Group 1, 18; Group 2, 20.

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B076	G1	The writer asks why ABA attracts criticism.	Not recorded	Collective witnessing
B077	G1	A response rejects ABA on rights-related grounds and makes claims about its history and institutional acceptance.	Not recorded	Collective witnessing
B078	G1	A parent expresses interest in trying an idea with their child.	Mother	Collective witnessing
B079	G2	The writer responds positively to an idea and asks about product contents and purchasing arrangements.	Not recorded	Collective witnessing
B080	G2	A brief statement celebrates achievements that others may overlook.	Not recorded	Collective witnessing
B081	G1	A parent expresses concern after encountering information about a product their children have used.	Not recorded	Emotional disclosure and validation
B082	G1	A brief response expresses appreciation for a moment without explaining its context.	Not recorded	Emotional disclosure and validation
B083	G1	The writer thanks others and says they intend to investigate sensory items.	Not recorded	Emotional disclosure and validation
B084	G1	A brief response offers birthday wishes.	Not recorded	Emotional disclosure and validation
B085	G1	A brief response expresses enthusiasm without further context.	Not recorded	Emotional disclosure and validation
B086	G1	The writer frames a child’s sadness as an opportunity to help the child understand emotions.	Mother	Emotional disclosure and validation
B087	G1	A brief response values a short shared experience or memory.	Not recorded	Emotional disclosure and validation

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B088	G1	The writer thanks others for their contributions and says they intend to explore the information further.	Not recorded	Emotional disclosure and validation
B089	G2	The writer expresses appreciation for advice received.	Not recorded	Emotional disclosure and validation
B090	G2	A family caregiver expresses affection for autistic relatives and appreciation for the recognition offered in the group.	Great grandmother	Emotional disclosure and validation
B091	G2	A brief response acknowledges difficulty without further explanation.	Not recorded	Emotional disclosure and validation
B092	G2	A brief response describes something as difficult without further explanation.	Not recorded	Emotional disclosure and validation
B093	G2	A parent asks for advice about a child's needs and thanks the group for welcoming them.	Not recorded	Emotional disclosure and validation
B094	G2	The writer identifies with another person's difficulties and describes having little help or understanding of a child's moods.	Not recorded	Emotional disclosure and validation
B095	G2	The writer invites others to reflect on what they appreciate in their lives.	Not recorded	Emotional disclosure and validation
B096	G2	A parent describes changes in their relationship with a child and concern about the child's behaviour toward peers.	Mother	Emotional disclosure and validation
B097	G2	The writer thanks the group for admission and asks whether others are homeschooling.	Not recorded	Emotional disclosure and validation
B098	G2	The writer seeks contact with other families in their local area.	Not recorded	Emotional disclosure and validation
B099	G2	The writer asks about help for another parent who lacks support and faces obstacles to employment or education.	Not recorded	Emotional disclosure and validation
B100	G2	A mother describes different triggers affecting her children and suggests routines, clear expectations, and distraction.	Mother	Emotional disclosure and validation

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B101	G2	The writer promotes a hemp product, reports perceived improvements in a child, and directs readers to a seller.	Not recorded	Milestone sharing
B102	G2	The writer celebrates a child's achievement and recognizes the need for permission before sharing images of other children.	Not recorded	Milestone sharing
B103	G1	A parent shares a positive experience of travelling with children and visiting an attraction they enjoyed.	Mother	Milestone sharing
B104	G1	A parent describes a child managing without a comfort item after previous attempts had been difficult.	Mother	Milestone sharing
B105	G1	A parent announces a child's birthday.	Mother	Milestone sharing
B106	G1	The retained entry consists mainly of tags referring to a school transition and family celebration.	Not recorded	Milestone sharing
B107	G1	The writer expresses pleasure in a child's photograph and growth.	Not recorded	Milestone sharing
B108	G1	The writer offers to share a child's artwork and suggests a related creative resource.	Not recorded	Milestone sharing
B109	G1	A parent describes a child recalling written material learned through videos, surprising school staff.	Mother	Milestone sharing
B110	G2	The writer introduces an account of tutoring an autistic young person and mentions shared neurodevelopmental experiences.	Not recorded	Milestone sharing
B111	G2	A parent reports perceived benefits from CBD products and recommends them to others.	Not recorded	Milestone sharing
B112	G2	A mother describes joy at a child initiating an affectionate interaction.	Mother	Milestone sharing
B113	G2	The writer celebrates a child's willingness to try unfamiliar food.	Not recorded	Milestone sharing

Theme 3. Practical wisdom in everyday parenting

57 entries: Group 1, 18; Group 2, 39.

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B019	G1	The writer encourages families to build on children's interests and strengths when considering educational priorities.	Not recorded	Adaptive parenting strategies
B020	G1	The writer describes calmly interrupting a child's hitting or scratching, while acknowledging uncertainty about whether this helps.	Not recorded	Adaptive parenting strategies
B021	G1	A parent describes difficulty helping a child leave a preferred activity, despite trying a transition aid.	Mother	Adaptive parenting strategies
B022	G1	A parent describes supervising children's use of public toilets and sometimes relying on older siblings for assistance.	Mother	Adaptive parenting strategies
B023	G1	The writer suggests gradually reducing use of a comfort item and considering age-appropriate sensory alternatives.	Not recorded	Adaptive parenting strategies
B024	G1	A parent notices that a child repeatedly chooses another language setting on toys.	Mother	Adaptive parenting strategies
B025	G1	The writer describes allowing a child time to settle before offering comfort and asking what is needed.	Not recorded	Adaptive parenting strategies
B026	G1	A parent asks whether others have experienced changes in a child's speech style and what might trigger them.	Mother	Adaptive parenting strategies
B027	G1	A grandmother describes trying sensory activities and noticing the child's enjoyment of water play.	Grandmother	Adaptive parenting strategies
B028	G1	The writer suggests using different textures and materials for sensory play.	Not recorded	Adaptive parenting strategies

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B029	G2	The writer asks for information about stem-cell treatment.	Not recorded	Adaptive parenting strategies
B030	G2	The writer reports a favourable experience with stem-cell treatment and offers private contact and access to information groups.	Not recorded	Adaptive parenting strategies
B031	G2	The writer mentions using mobility and supervision aids with a child.	Not recorded	Adaptive parenting strategies
B032	G2	A parent seeks ideas for reducing a child's intense fear of bathing after previous attempts have been unsuccessful.	Mother	Adaptive parenting strategies
B033	G2	The writer suggests making an activity more enjoyable with toys and bubbles.	Not recorded	Adaptive parenting strategies
B034	G2	The writer describes gradually reducing their own participation in bathing as the child became more comfortable.	Not recorded	Adaptive parenting strategies
B035	G2	The entry raises a question about claimed benefits of camel milk for autistic children.	Not recorded	Adaptive parenting strategies
B036	G2	The entry outlines an activity intended to teach children to ask questions about objects in containers.	Not recorded	Adaptive parenting strategies
B037	G2	The writer encourages recognition of gradual progress, seeking help, and following an associated social-media page.	Not recorded	Adaptive parenting strategies
B038	G2	A short entry identifies a foot-pressure activity as an occupational-therapy goal without further explanation.	Not recorded	Adaptive parenting strategies
B039	G2	The entry introduces parenting tips for mothers of autistic children, but the retained extract does not include the tips.	Not recorded	Adaptive parenting strategies

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B040	G2	The writer seeks a game suited to a child who enjoys exploring virtual environments but may struggle with complex tasks.	Not recorded	Iterative learning
B041	G2	A parent asks whether others have found a commercial reading program useful.	Not recorded	Iterative learning
B042	G1	The writer reports an unfavourable experience with medication side effects and expresses doubt about finding an effective option.	Not recorded	Tactical crowdsourcing
B043	G1	An aunt suggests looking for patterns in a child's behaviour and considering a possible sensory explanation.	Aunt	Tactical crowdsourcing
B044	G1	The writer asks what a communication device is called and how to obtain one.	Not recorded	Tactical crowdsourcing
B045	G1	The writer recommends a harness based on its use with their own child.	Not recorded	Tactical crowdsourcing
B046	G1	A parent asks how to explain a concept that a child can read aloud but may not understand.	Not recorded	Tactical crowdsourcing
B047	G1	A parent seeks advice about reducing pacifier use while managing a child's tendency to put objects in their mouth.	Mother	Tactical crowdsourcing
B048	G1	A parent asks what to expect at an upcoming first paediatric appointment.	Mother	Tactical crowdsourcing
B049	G1	A parent seeks guidance about autism symbols and avoiding imagery that others may find offensive.	Mother	Tactical crowdsourcing
B050	G2	The entry uses a comparison to an unfamiliar activity to express parenting uncertainty and offer encouragement.	Not recorded	Tactical crowdsourcing
B051	G2	The writer calls for continued advocacy, acceptance, and support for autistic people.	Not recorded	Tactical crowdsourcing

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B052	G2	The writer recommends a film promoting a health-related practice and makes a broad claim about its value.	Not recorded	Tactical crowdsourcing
B053	G2	The writer recommends CBD products, claims that they helped a child, and directs readers to a seller.	Not recorded	Tactical crowdsourcing
B054	G2	The writer reports using CBD products with a child, claims benefits, and refers readers to a seller.	Not recorded	Tactical crowdsourcing
B055	G2	The entry promotes an audio-visual learning product and claims benefits for communication and understanding.	Not recorded	Tactical crowdsourcing
B056	G2	The writer recommends an autism-related book and attributes improvements in communication to its guidance.	Not recorded	Tactical crowdsourcing
B057	G2	A brief slogan presents raising an autistic child as a source of positive family identity.	Not recorded	Tactical crowdsourcing
B058	G2	The writer promotes autism-awareness merchandise and includes a sales reference.	Not recorded	Tactical crowdsourcing
B059	G2	The writer encourages attention to autistic children's strengths as well as their difficulties.	Not recorded	Tactical crowdsourcing
B060	G2	A brief awareness message emphasizes family togetherness despite difficulties.	Not recorded	Tactical crowdsourcing
B061	G2	The entry promotes an informational resource about repetitive behaviours and seeking further support.	Not recorded	Tactical crowdsourcing
B062	G2	The entry gives a general description of repetitive behaviours and encourages an understanding response.	Not recorded	Tactical crowdsourcing
B063	G2	The writer describes educational challenges following a child's diagnosis and promotes a longer account of that experience.	Not recorded	Tactical crowdsourcing
B064	G2	A brief statement emphasizes valuing small achievements.	Not recorded	Tactical crowdsourcing

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B065	G2	The writer offers suggestions for managing family visits, including leaving when needed and limiting pressure to stay.	Not recorded	Tactical crowdsourcing
B066	G2	The retained extract begins a general explanation of ADHD but does not contain a complete discussion.	Not recorded	Tactical crowdsourcing
B067	G2	The writer encourages families to consider travel and prepare for their child's needs.	Not recorded	Tactical crowdsourcing
B068	G2	The retained extract introduces a paediatric professional but provides little further context.	Not recorded	Tactical crowdsourcing
B069	G2	A brief awareness message emphasizes acceptance and criticizes judging people for characteristics they cannot change.	Not recorded	Tactical crowdsourcing
B070	G2	The writer asks whether others have read a recommended resource before deciding to use it.	Not recorded	Tactical crowdsourcing
B071	G2	The entry presents general encouragement to resist discouraging attitudes, but the retained passage is incomplete.	Not recorded	Tactical crowdsourcing
B072	G2	A parent seeks advice about supporting a young adult who is struggling with the pace and demands of college.	Not recorded	Tactical crowdsourcing
B073	G2	A parent describes concern about an infant's development and seeks accounts from others with similar experiences.	Not recorded	Tactical crowdsourcing
B074	G2	The entry offers general encouragement and invites readers to follow a social-media account.	Not recorded	Tactical crowdsourcing
B075	G2	The writer expresses sympathy and suggests exploring reasons for a change in a child's behaviour.	Not recorded	Tactical crowdsourcing

Theme 4. Moral labor and invisible strain

5 entries: Group 1, 0; Group 2, 5.

Entry ID	Group	Paraphrased summary	Role in coding record (unverified)	Subtheme
B114	G2	A mother seeks help with toilet training because childcare requirements are affecting her ability to work.	Mother	Tensions between caregiving needs and institutional expectations
B115	G2	A parent suggests monitoring what happens in a classroom and refers to concerns raised by school staff.	Mother	Tensions between caregiving needs and institutional expectations
B116	G2	A parent asks whether using a mobility aid is appropriate for a child who can walk but struggles in everyday situations.	Not recorded	Internalized stress and guilt
B117	G2	A grandmother who has recently assumed care of a child seeks help with unfamiliar support needs and distressing behaviour.	Grandmother	Internalized stress and guilt
B118	G2	A parent seeks advice and support for a child's anxiety and behaviour while describing their own difficulty coping.	Not recorded	Internalized stress and guilt

Appendix E3 Reflexive Thematic Analysis Reporting Guidelines cross-reference

Study 3 Caregiver communication and coping in online peer spaces

This study-specific cross-reference locates reporting relevant to Braun and Clarke's Reflexive Thematic Analysis Reporting Guidelines (RTARG). The areas below are paraphrased and grouped for this study; they are not the authors' verbatim checklist or an assessment of full compliance. Section numbers identify the corresponding locations in Chapter 5.

Study rationale and researcher positioning

Reporting area	**Chapter 5 location**	**Study-specific account**
Context and purpose	Section 5.1	Situates caregiver discourse within existing research on communication, support, and care-related uncertainty. States the interpretive research question.
Theory and assumptions	Sections 5.1, 5.2.1 and 5.2.5	Explains coping theory as an interpretive framework and describes inductive, semantic, and latent analysis. A separate ontological or epistemological position is not explicitly named.
Researcher positioning	Section 5.2.6	Identifies the author as a communication researcher and parent of an autistic child. Describes how familiarity informed attention and required reflexive scrutiny.
Reflexive practice and researcher visibility	Sections 5.2.6 and 5.5	Reports journaling, memoing, supervisory discussion, and reconsideration of early emphasis on vulnerability. The researcher's role is explicit although the chapter uses third-person authorial wording.
Methodological fit	Sections 5.2.1, 5.2.5 and 5.3.1	Uses reflexive thematic analysis to interpret meanings across selected contributions. Distinguishes this task from tracing interactional sequences or demonstrating subsequent outcomes.

Dataset and analytic procedures

Reporting area	Chapter 5 location	Study-specific account
Selection and context	Sections 5.2.2 and 5.2.3	Describes purposive group selection, public access, English-language material, the common collection window, and archived group membership figures. Notes limits to knowledge about moderation.
Dataset extent and rationale	Sections 5.2.3 and 5.5; Figure 5.1	Reports 8,670 raw lines, 793 potentially relevant lines, and 118 selected contributions, with group breakdowns. Explains the bounded period and manageability for manual analysis. Figure 5.1 distinguishes text volume from contribution counts.
Contextual characteristics	Sections 5.2.4 and 5.5; Appendix E1	Separates contextual information from verified demographics. Appendix E1 summarizes stated relationships at entry level rather than counting unique contributors.
Ethics and confidentiality	Section 5.2.6	Reports ethics approval and the consent basis for public material. Discusses sensitivity, withholding group names, paraphrasing, checking meaning, online traceability searches, and restrictions on data sharing.
Collection and preparation	Sections 5.2.3, 5.2.4, and 5.2.6	Describes manual extraction, screening, organization, identifiers, and preparation. The study involved no direct interaction with, or recruitment of, contributors.
Analytic orientation and responsibilities	Sections 5.2.5 and 5.2.6	Describes inductive coding, semantic and latent interpretation, iterative theme development, and subsequent use of coping theory. The author conducted coding; the research supervisor contributed discussion rather than independent coding.

Interpretation and contribution

Reporting area	Chapter 5 location	Study-specific account
Analytic process and supporting inventory	Sections 5.2.5 and 5.2.6; Appendix E2	Explains repeated reading, coding, memoing, and theme review. Appendix E2 records entry summaries and coding assignments; it is not a chronological account of every code-to-theme decision.

Reporting area	Chapter 5 location	Study-specific account
Thematic structure and concepts	Sections 5.3.1–5.3.5; Table 5.2	Presents the thematic structure and explains the interpretive focus of each theme. Subthemes organize aspects of the wider thematic account.
Evidence and interpretation	Sections 5.3.2–5.3.5; Table 5.2; Appendix E2	Pairs paraphrased material with interpretation. Source-group identifiers provide context. The moral-labor account is explicitly grounded in selected Group 2 material rather than a claim of equal representation.
Relation to scholarship	Section 5.1 and Sections 5.4.1–5.4.5	Positions the account within coping, peer support, invisible work, gendered care, and neurodiversity scholarship. Most explicit integration with published theory occurs in the Discussion.
Contribution and practical relevance	Section 5.4, opening discussion; Sections 5.4.6 and 5.6	Draws together uncertainty, practical knowledge, emotional experience, and responsibility. Links practice implications to specific findings without claiming tested intervention effects.
Quality and contextual limits	Sections 5.2.6, 5.5 and 5.6	Explains why coding agreement was not used as a quality criterion. Reflects on selection, platform visibility, timing, researcher interpretation, and limits of nonsequential analysis. Future work follows from these analytic boundaries.

Source: Braun V, Clarke V. Supporting best practice in reflexive thematic analysis reporting in Palliative Medicine: A review of published research and introduction to the Reflexive Thematic Analysis Reporting Guidelines (RTARG). Palliative Medicine. 2024;38(6):608–616. doi:10.1177/02692163241234800. This cross-reference draws on the accompanying RTARG supplementary guidance.