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CHILDREN WITH DEVELOPMENTAL DELAYS AND THEIR
YOUNGER SIBLINGS**

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Honors Thesis

PARENT PERSPECTIVES ON ACCESSING RESOURCES FOR CHILDREN WITH
DEVELOPMENTAL DELAYS AND THEIR YOUNGER SIBLINGS

by
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Submitted to Brigham Young University in partial fulfillment
of graduation requirements for University Honors

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Brigham Young University
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PARENT PERSPECTIVES ON ACCESSING RESOURCES

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ABSTRACT

PARENT PERSPECTIVES ON ACCESSING RESOURCES FOR CHILDREN WITH DEVELOPMENTAL DELAYS AND THEIR YOUNGER SIBLINGS

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The benefits of early intervention for children with developmental delays is widely documented in the current literature (Goode et al., 2011; Koegel et al., 2014; Roberts & Kaiser, 2015; Smith et al., 2000). There is, however, a lack of research on what parents experience when accessing resources for their child with a developmental delay and younger siblings who may be at risk for a developmental delay. Through face to face qualitative interviews, the current study examined parent awareness of and experience accessing desired resources for children with developmental delays and their younger siblings. Through thematic analysis, four themes emerged: (a) positive experiences with external resources, (b) difficulty accessing external resources, (c) negative impact on family, and (d) positive impact on family. Implications, limitations, and directions for future research of the study are discussed.

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PARENT PERSPECTIVES ON ACCESSING RESOURCES

Parent Perspectives on Accessing Resources for Children with Developmental Delays and Their Younger Siblings

Early intervention for children with developmental delays have been found to be beneficial for children and their families (Goode et al., 2011; Koegel et al., 2014; Majnemer, 1998; Roberts & Kaiser, 2015; Smith et al., 2000). In the United States, the prevalence of developmental delays is estimated to be 3.6% for children aged 3-17 years, or about 1 in 25 children (Zablotsky et al., 2015). Furthermore, many developmental delays have heritable components and may be more prevalent in families where one child has already been diagnosed with a delay (Hallmayer et al., 2011). When parents are aware of this increased risk, they may proactively prepare for potential challenges in younger children. For example, a study of parents who had a child with autism spectrum disorder found that parents who are aware of familial risk report being more vigilant to ASD symptoms in younger children, report considering risk in reproductive and healthcare decisions, and enroll in presymptomatic screening tests (MacDuffie et al., 2019). Although familial risk appears to be an important issue for parents in these circumstances, there is limited research on how easily parents access resources for their child with a developmental delay and any younger siblings who may be at risk.

Emerging research has reported that many parents are unaware of resources or experience difficulty attaining it (Raspa et al., 2015). Extending this line of research may help further answer questions such as how parents seek more information, what they experience when consulting with clinicians, or how parents prepare to care for their children remain unanswered. Furthermore, when efforts are made by parents, it is unclear as to what resources were sought and the ease or difficulty of their experience gaining or

not gaining their desired resource. To address these issues and answers these questions, I aim to extend the current research by investigating parent awareness of and experience accessing desired external support and resources for children with developmental delays and their younger siblings. In this study, external support is defined as any support outside of personal and immediate family resources that benefit the family or child. Common resources include school-based resources or respite care, both of which are associated with reduced parental stress (Krakovich et al., 2016; Harper, et al., 2013). Many schools and communities offer support for families facing various stressors, but sometimes this support may be hard to access due to concerns such as limited availability (Costanzo & Magnuson, 2019).

The current study includes participants who are more likely to seek resources and have valuable information regarding their ease or difficulty accessing resources. This may be due to their participation in presymptomatic screening for their child. Because of this knowledge, these parents are more likely to have attempted to access external support for the participating child or other children in their family. Gathering rich qualitative information on potential efforts made by these parents may reveal nuances or potential difficulties to receiving external support currently unstated in the literature. Because there is such strong evidence that early intervention, early identification, and access to external resources are associated with positive outcomes, understanding these nuances could further enhance the development and dissemination of support. Therefore, this study aims to examine what and how this external support is accessed by parents.

Method

Participants

Participants for the current study were recruited from a broader study called *Genetic, Microbial, and Environmental Influences on Visual Reflexive Attention in Infants and Perseverance Screening for Autism in Infants to Facilitate Earlier Identification*. The present study originally included 16 participants. Four were identified as having high familial risk for ASD by having an older child with ASD, eight were identified as having a child with a different developmental delay (five children with speech delays, two children with cerebral palsy, and one child with physical and learning delays), and four had no children with any developmental delays (see Table 1). The eight participants identified as having a child with a non-autism developmental delay were excluded from the broader study but included in the present study.

Table 1.

List of Participants and Type of Child Disability

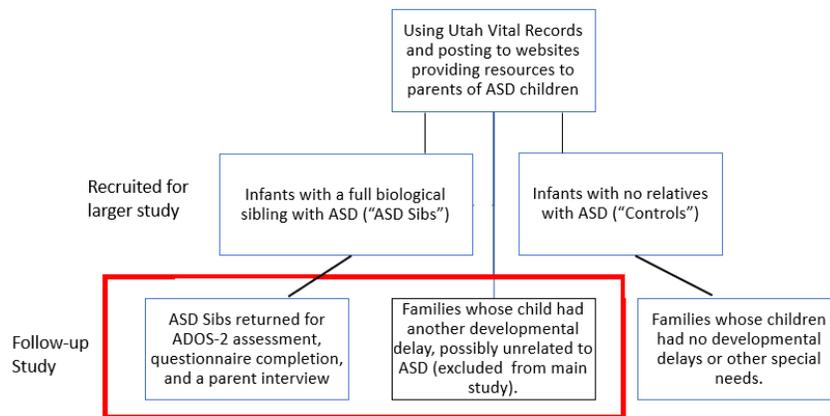
No.	Participant	Disability of Child
1	Greta	Speech delay
2	Martha	Autism
3	Hannah	Physical and Learning delay
4	Lilly	Cerebral palsy
5	Mary	Speech delay
6	Wanda	Autism
7	Lilah	Autism
8	Anna	Cerebral palsy
9	Ruth	Autism
10	Sarah	Speech delay
11	Courtney	Speech delay
12	Eva	Speech delay

Note: All participant names are pseudonyms

The overall study, including the current branch, was approved by Brigham Young University’s Institutional Review Board. For the present study, potential participants were identified through state birth records and local parent support groups as having an infant under the age of 18 months. Potential participants were sent an invitation through mail to participate in the study (see Figure 1 for our sample selection procedures). When the infant was between three and twelve months old, they participated in the larger study previously mentioned. This study consisted of parents completing a demographic questionnaire and infants completing two visual attention tasks. The tasks were modeled after Dannemiller (1998) and Harman et al. (1994) to examine looking preference, including in infants with an older sibling with ASD. The infants also provided a fecal sample for gut microbiome analysis. Age- and sex-matched control participants completed the same tasks and also provided a fecal sample. Then, when the infant was between 1- and 6-years old, parents and children were invited to participate in the current study. Both low and high-risk families were included.

Figure 1.

Sample Selection Procedure



Note: Red box indicates those whose interviews were transcribed.

Procedure

Parents who had agreed to a follow-up appointment during the first appointment were contacted when the participating child was between one and six years old, given a brief description of the current study, and asked if they would like to participate. All parents who came in for the follow-up appointment agreed to participate in all portions of the study.

During the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), the parents completed the Autism Family Experience Questionnaire (AFEQ) and either the Modified Checklist for Autism in Toddlers (M-CHAT-R) or Social Communication Questionnaire (SCQ) depending on the age of the child. Face to face interviews were conducted in the research lab immediately following the administration of the ADOS-2 assessment. Interviews were semi-structured and typically lasted 15 minutes. They were conducted by the author and by other trained research assistants. Participants were paid \$20 for the follow up appointment including the interview. Interviews were video recorded and transcribed. Transcripts were deidentified and stored on a secure server. To maintain focus on parents of children with developmental delays, the four participants who had no children with a developmental delay were excluded from transcription analysis. Twelve total participant transcripts were used.

Measures

Autism Family Experience Questionnaire (AFEQ). An adapted version of the AFEQ measure was used to assess the experiences of parents of children with autism. The original questionnaire had 48 questions. Example questions included: “I feel listened to by professionals,” “I doubt my ability to help my child’s development,” and “My child

is getting the right help.” Responses ranged were based on a 5-point Likert scale from “always” to “never”. For the current study, the adapted version included 13 questions from the original questionnaire along with two questions that were included by the researcher. Please refer to Appendix A for the adapted questionnaire.

Social Communication Questionnaire (SCQ). The SCQ is a screening tool used by clinicians to aid ASD diagnosis. It is completed by parents or caregivers for the child receiving the screening, contains 40 items, and takes approximately 15 minutes to complete (Marlow, Servili & Tomlinson, 2019). Sensitivity and specificity are high for both ASD cases (sensitivity 0.88, specificity 0.72) and autism cases (sensitivity 0.90, specificity 0.86; Chandler et al., 2007). Participants who had children 36 months or older completed the SCQ. The general guideline for a cut-off score is 15, although it can be adjusted lower depending on the age of the child (Marvin et al., 2017).

Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). The ADOS-2 is the gold-standard diagnostic instrument for ASD as diagnostic validity (sensitivity and specificity) is high, as are the interrater and test-retest reliabilities (Luyster et al., 2009). The ADOS-2 is a semi-structured interactive session that allows an examiner to rate the presence of various autism symptoms in the examinee. These ratings are then entered into an algorithm that produces a total score.

Modified Checklist for Autism in Toddlers (M-CHAT-R). The M-CHAT-R is a screening tool used by clinicians to aid ASD diagnosis and is best used for toddlers ages 16-36 months (Sunita, & Bilszta, 2012). It is completed by parents or caregivers for the child receiving the screening, contains 20 questions, and takes approximately 10 minutes to complete (Robins et al., 2009). Sensitivity and specificity are high at 0.91 and a

specificity of 0.96, respectively (Robins et al., 2014). The guidelines for cut-off scores for the M-CHAT are low-risk: 0 – 2; medium-risk: 3 – 7; high-risk: 8 – 20 (Robins et al., 2009). The participant whose child was between 16 and 36 months old took this measure.

Semi-Structured Interview. Interviewing provides opportunities to explore participant perspectives in-depth and gather rich data on lived experiences. Narrative data provides depth and specificity to challenges experienced by participants beyond the descriptive nature of quantitative measures. For this study, an adapted questionnaire was created to guide the semi-structured interview. Questions 1-2 of the interviews were adapted from MacDuffie et al. (2019) and were presented to parents of children with ASD. Questions 3-4 were developed by the author to assess parent access to and desire for external community resources and were presented to all participants. Example questions included:

- What do you know about the risk associated with your youngest child having autism?
- How has the information you know about risk affected you and your family? and,
- Thinking about your entire family, what resources would be beneficial?

Please refer Appendix B for the complete questionnaire used for the interviews of this current study.

Analysis

Analysis of data was conducted through a team-based grounded theory approach comprising of two coders. The first coder and author is an undergraduate student in psychology with previous experiences administering developmental measures for children using observational methods. The first coder had also received training in

research methods and completed coursework on child development, psychopathology, and positive psychology. With interest in child and adolescent well-being, the first coder has worked in settings such as an elementary school, a treatment center, and as a research assistant for a study involving child development. This training and background influenced the first coder to understand the benefit of external resources for children and adolescents and subsequently increase her desire for these resources to be available to parents and their families.

The second coder is an associate professor of psychology, a mother, and a developmental researcher with a doctorate degree in cognitive neuroscience and a focus on cognitive and social development. She received additional training in autism assessment for research purposes, including training for administering the ADOS-2. She is a former licensed professional counselor who maintains interest in clinical issues, including early identification of autism. The training and background of the second coder influenced her to be attentive to the experiences of parents with children with developmental delays and the potential challenges to parents who are seeking help for their children.

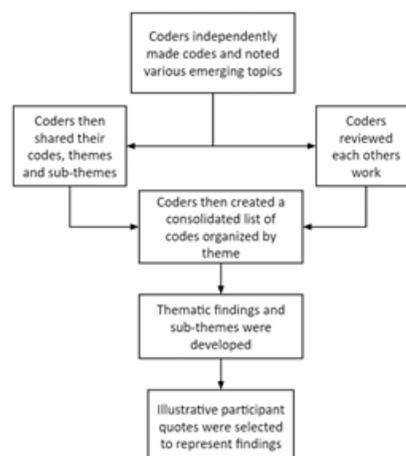
Grounded theory analysis aims to inductively explore the contexts and processes of the phenomenon under investigation. This entails careful reading of transcripts, coding through an iterative process, and consolidating and organizing pieces of information into relevant themes and sub-themes. The coding strategy to achieve these aims involved two stages: open coding and selective coding (Glaser & Strauss, 1967). Open coding refers to the process of assigning codes to units of information. Selective coding is the process in

which open codes are organized into themes that are pertinent to the relevant research question (Urquhart, 2013).

Coding. First, coders read through all transcripts looking for meaningful units of information as described by participants. The first coder read through the transcripts 2-3 times over several days and the second coder also read through each transcript twice. This process was done independently by the coders who arrived at two separate lists of open codes. Next, coders reviewed each other's work and consolidated the list of codes. During the selective coding stage, coders discussed their themes and subthemes with each other to determine final themes to best represent the participants words. These themes were further developed and formed the structure for the findings section. In this article, we emphasize findings from the qualitative interviews. Descriptive findings from quantitative measures are presented for context. To present findings in participant's voices, we selected illustrative quotations, reported below. The coding process is illustrated in *Figure 2*.

Figure 2.

Qualitative Coding Process Flow-chart



Descriptive Findings

Here I present findings from the quantitative measures. Descriptive statistics are reported in Table 2. The mean score for the AFEQ was 2.29 (range 1-5), indicating that, on average, participants felt that they were often or sometimes having positive experiences getting appropriate help for their child with a developmental delay. Financial limitations, strained family relationships, and time management tied as the most reported difficult aspects of having a child with a developmental delay. The most reported positive aspects were also tied between three topics: increased empathy, increased compassion, and expanded community. For the SCQ, the mean score was 7.2 and the range 2-15. Because the recommended cutoff score for this measure is 15, the mean score indicates that the majority of the children in the study fell below a level of concern for ASD (Marvin et al., 2017). Additionally, the mean score for the ADOS-2 was 3.45 and the range 1-6, adding further evidence that the majority of children in the study did not score high enough to be of concern for ASD. The ADOS-2 (Toddler Module) and M-CHAT-R completed for a child between 16 and 30 months respectively indicated a mild-to-moderate and low level of risk for the child having ASD. Three participants had incomplete data for some measures. Two participants had incomplete data for the AFEQ, and one participant had incomplete data for the SCQ.

Table 2.*Descriptive Statistics for Measures used in the Study*

Instrument	<i>M</i>	<i>S.D</i>	Range	Count
Autism Family Experience Questionnaire (AFEQ)	2.29	0.3	1 - 5	10
Social Communication Questionnaire (SEQ)	7.2	4.05	2 - 15	10
Autism Diagnostic Observation Schedule – 2 (ADOS - 2)	3.45	1.86	1 - 6	10
Autism Diagnostic Observation Schedule – 2 (ADOS - 2, Toddler Module)	11	0	11	1
Modified Checklist for Autism in Toddlers-R (MCHAT-R)	0	0	0	1

Note: Three participants had incomplete data for some measures.

Thematic Findings

Through thematic analysis, four themes emerged: (a) positive experiences with external resources, (b) difficulty accessing external resources, (c) negative impact on family, and (d) positive impact on family. Although I paid careful attention to answer the primary research questions of the study, analysis using grounded theory approach resulted in emergent findings which are also reported in an effort to adequately represent participant experiences. These emergent findings will be discussed later in conjunction with implications for external resources. In this section, I present each theme illustrated with participant quotations. Note, when talking about some experiences, parents sometimes referred to other children in their family who had developmental delays. All participant names are pseudonyms. Content analysis with themes and subthemes are summarized in Table 3.

Table 3.*Content Analysis of Themes and Sub-themes*

Themes & Sub-themes	<i>ID</i>	No. of Participants
Positive Experiences with External Resources		9
Feel they have adequate resources	3, 7, 9, 10, 11, 12	6
Feel confident could find resources	1, 9, 10, 12	4
Trust school to find resources/found resources at school	1, 5, 6, 10	4
More aware of resources due to older child with delay	1, 5, 7, 10	4
Generally happy with services when found	4, 5, 12	3
No problem finding resources during preschool age	4, 5, 10	3
Trust pediatrician's referrals	9, 10	2
Difficulty Accessing External Resources		7
Was not aware of developmental delays with first child	4, 5, 6, 7	4
Difficulty finding childcare for children with special needs	2, 7, 8	3
Concerns remain even when child no longer qualifies for services	1, 2, 7	3
Expressed desire for resources to support entire family	1, 6, 8	3
Financial limitations (e.g. to afford a special education school)	6, 7	2
Increased difficulty finding resources during preschool age	2, 7	2
Insurance wouldn't cover desired therapy/evaluation	6, 7	2
Unsure of what resources exist	4	1
Negative Impact on Family		6
Increased emotional difficulties	2, 3, 6, 8, 9	5
Financial concern (for providing appropriate resources)	2, 6, 7	3
Delayed having more children	2, 8	2
Limited career opportunities	2, 7	2
Parent disagreement on how to help children	8	1
Positive Impact on Family		8
Siblings supporting each other	3, 8, 12	3
Positive emotional experiences	3, 8	2
Not deterred from having more children	6, 10	2
Improved parenting for other children	7, 10	2
Expanded friendship networks	4	1

Positive Experiences with External Resources

Nine participants expressed that they found resources to be beneficial or were confident in the resources they attained. One of the parents reported being completely satisfied with the services available to her family, while the other eight expressed a mix of both positive and negative sentiments. The positive experiences of note are described below.

For example, four participants who also had younger children frequently reported being more aware of community and school resources because they had an older child with a developmental delay. This proved to be instrumental in helping younger children get help for potential delays. Additionally, two parents reported using that knowledge to proactively secure resources in the event that a younger child was also diagnosed.

For instance, Greta, a mother of a child who experienced a speech delay mentioned:

His older brother had a speech delay, and so we got information from the speech pathologist from the school because he used to have an IEP through the public school. Anyway, so I've been notified because of that about different workshops and things for students with speech issues or autism things.

Martha, a mother whose oldest child has autism explained about her younger child:

I did put him on the [autism preschool] waitlist, the preschool, but when they called, I was like, "nah."

Interviewer: So, you had the precaution in place,

Martha: I did.

Interviewer: But you didn't feel like it was necessary.

Martha: But I didn't use it. I kept him on both years, and I declined both years.

Six parents reported that the needs of their child have been adequately met through the resources available to them through community and school programs. Some parents expressed highly positive experiences, especially when someone went above and beyond to aid their family.

When asked about getting support at school, Hannah mentioned:

Interviewer: With the help that he gets [at school], how do you feel that it meets his needs?

Hannah: It's great. Yeah, they've done great with him. He does the adaptive PE and he's met a lot of his goals . . . we've just made new goals for him and he's really succeeded a lot of what we didn't think he would do.

Additionally, Lilly, the mother of a child with high-functioning cerebral palsy had this conversation with the interviewer:

Interviewer: How have your experiences been with the therapy that you've done?

Lilly: Across the board, in general, no complaints, we've had really awesome experiences. And so, we weren't, we had some personality differences with the therapist.

Interviewer: That happens.

Lilly: But, overall, the experience has just been fabulous.

Similarly, Mary, a mother of multiple children with speech delays said:

Just the speech help that they've got at our elementary school. [Name of school] has been amazing, 'cause actually when he went into take the test to see if he

qualified, he did well enough in everything else except for speech that they said he didn't qualify. But the lady that had helped my other kids was there and she said, "Nope, we're gonna take him. I don't care what the test says. I know their family and he could use some help and so, we're gonna do it."

Many parents expressed satisfaction or that their expectations had been exceeded regarding the community and school resources available to their child and family. In one account, a parent described amazement at getting help beyond what their child qualified for because of the special attention of someone in their school. Additionally, parents described having increased awareness of resources for younger children. This was reported as helpful whether or not younger children had a developmental delay. Although these parents reported positive experiences accessing resources, these parents and other participants also described negative experiences.

Difficulty Accessing External Resources

Seven participants found external resources inadequate or experienced difficulty accessing external resources. Resources were inadequate when the parent felt that the child's or family's needs were not met sufficiently. Difficulty accessing resources included being unaware of available resources, unaware of their child having a delay, and difficulty finding appropriate care. While all participants were able to discuss some accessed resources, not all participants felt that the acquired resources had adequately met their needs. For example, some participants talked about desired therapy for their child and family that they had never been able to experience. Financial limitations were sometimes mentioned as the cause.

To illustrate, Wanda, a mother of five whose oldest child has ASD explained this:

ABA therapy is really expensive and a lot of the stuff that goes with autism insurance doesn't cover . . . We really wanted to do the ABA therapy because not only would that teach [oldest child's name] how to cope and regulate in a world that won't necessarily bend to him and you know, he's gonna have to figure out how to navigate this world, but it also would've taught us as a family skills to kind of figure things out and have dynamics better. We could never take advantage of that and I think that would've been really good. . . The ABA therapy would've had a practitioner come in and basically not only teach me and my husband how to do stuff, but the siblings as well.

Four of the participants were initially unaware of developmental delays in their child due to difficulty discerning between atypical and typical development. For some of these parents, the lack of awareness resulted in a delay of accessing resources and initiating appropriate interventions. Additionally, parents often found it difficult to find resources or were unaware of resources available to them. These two situations often occurred together, as illustrated below.

Mary, a mother of multiple children with speech delays said:

Interviewer: Thinking about your entire family, what resources would be beneficial?

Mary: I think just knowing about the [community program] sooner, so with my daughter, my oldest son didn't have any speech issues or whatever and so we didn't really pick up on it with my daughter that she was behind.

Interviewer: Because it was the first time.

Mary: Right. And so, we didn't actually get her involved with [community program] until she was almost too old for it. And so, I think just helping new parents know about those programs ahead of time would be great, 'cause then we were able to use it with our next two. And use it earlier, you know, so it could be of more benefit.

Lastly, even when parents were aware of a developmental delay and had access to information about resources, some parents still expressed difficulty finding appropriate care. Lilah, a mother of several adopted children with a variety of developmental delays said this about her child with autism:

And then when we have that little jump in-between when the child is really super tiny and when they jump into school, I couldn't find anything. I could not find what I needed. And I started searching everywhere and I found a neighborhood preschool where the lady had worked with special ed kids before and so I spoke to her and said, "Okay can I talk to you about this." So, he went to her preschool and it helped, but again it wasn't a professional, it was somebody who just had done it before, and had a little knowledge, so, I was searching more for something greater. It wasn't until, he had two years of preschool, so the first preschool was with the neighborhood through 3 years old, so when he turned 4, I started looking for another one and I finally found a special ed preschool, but it had taken me a year and a half to find it.

Parents described having difficulty finding adequate resources for their child or family. Some of the difficulties—financial, primarily—completely prohibited parents from accessing desired resources such as a specific therapy. Other difficulties came

because parents were not aware that their child was experiencing a delay, were unaware of available resources, or had difficulty finding appropriate care. Consequently, for some parents, finding appropriate care was left to happenstance or word of mouth.

Negative Impact on Family

Six participants expressed negative experiences associated with having a child with a developmental delay. Negative experiences included increased emotional distress, interference with work, being deterred from having more children, and parent disagreement on how to help children. Five parents discussed negative emotional experiences associated with having at least one child with a developmental delay. Parents mentioned the experience being ‘traumatic,’ ‘overwhelming,’ or ‘crushing,’ and showed an increased desire for family services to help cope.

Wanda, who was previously quoted regarding her desire for family-based services, also described her experience with the increased emotional distress:

If you asked us maybe eight years ago, this was very traumatic, it was really hard ‘cause it’s ... you just don’t know what you’re dealing with and it’s very overwhelming and we went with the mantra “knowledge is power” and so when we first found out and got over our grief of “our kid’s not normal” that we were just like “okay. we need to educate ourselves to make the best fit for him and also for us” you know, to manage our stress and how to help him. ‘Cause there’s also the statistics that there’s a lot of stress in the family when it comes to dealing with kids that have special needs.

Martha, a mother whose oldest child has autism explained:

‘Cause you--how long are people gonna be mad at him? How long is he gonna get negative feedback? How long until he learns how to make friends?

Interviewer: That’s hard.

Martha: It totally is. I don’t know how people do that multiple times actually, because it’s crushing.

Several parents also mentioned how raising children with developmental delays have interfered with a career or made other work decisions more difficult.

Lilah said:

But the situation we’re in with the special kids needs we have, we have to have a parent at home, we cannot have both of us working, it wouldn’t--wouldn’t be able to handle it. Babysitters cannot handle my kids, they can’t. I’ve gotten used to it, but they cannot.

Martha also explained how their experience deterred her and her husband from having more children:

We couldn’t handle having another one. So, [older child] was not diagnosed when I got pregnant with [younger child] and then I think, I was questioning at that time and then once I actually was pregnant and far enough along to figure out if it was a boy or girl, I felt like during that time I figured out, I was sure there was something wrong with my older one. So, that definitely made me not want to have another kid. ‘Cause it just was that hard. I didn’t have it in me to do another kid on the spectrum. And just knowing that you can’t choose, even if it’s 10%, even if it’s 5%, I just didn’t have that in me.

Interviewer: It's not in your ability to choose but making a decision with what you knew that you had and the life that you had.

Martha: Yeah. So definitely, I would say that's the main reason I didn't have a third kid.

Lastly, some participants reported disagreeing with their spouse on decisions regarding care for their child or children with delays. Anna, mother of a child with cerebral palsy and another child with a speech delay described this experience:

When the speech therapist was coming over for [older child], I mentioned that [younger child] wasn't talking and I was like, "that's fine, right?" and she goes "ummm!" [laughter]. So, she did an evaluation and said that he'd qualify for [inaudible]. My husband didn't want to do it. [Having] multiple kids who weren't okay was too much for him, but it's fine because . . .the preschool he's in, he's getting speech therapy now.

Overall, many parents described negative experiences in their experience with having a child or children with developmental delays. Some of these experiences included negative emotional experiences, interference with work, being deterred from having more children, and parent disagreement on how to help children with delays.

Positive Impact on Family

Eight participants also expressed positive experiences associated with having a child with a developmental delay. Positive experiences included increased awareness of developmental milestones, increased compassion in family, siblings acting as a support to each other, and expanded friendships to parents of other special needs children.

Wanda described her experience being more aware of developmental milestones with her younger children, “Our oldest is the one who is autistic. And so, we keep an eye out for things [in our youngest].” Also, Anna described an observation of increased compassion in her family. She said, “I think that having [a child] have such a visual disability and things have made everyone more compassionate to others. ... which is great.”

Additionally, three parents reported siblings supporting each other. For instance, this was described in a child with a delay supporting a younger child, or a child without a disability supporting a sibling with a developmental delay. To illustrate, Hannah reported her son with a developmental delay supporting his younger sister:

And it helped that he was our first so that we could, we were able to put all the attention on him and help him. And it’s really helped to have his younger sister. They’re about the same level right now and so they teach each other a lot of things. Like when he’s doing his homework, she likes to come over and pretend she’s doing homework too.

Anna shared her experience having another child:

Well, we definitely weren’t gonna have kids for a while. They’re only 19 months apart. [Younger child] was an accident. You know, ‘cause I wanted to give my attention to what he needed. I cried the first trimester [inaudible]. When he was born [my husband] gave him a blessing. He’s like, “You are going to be a protector. You were meant to be here.” ... So, yeah—we definitely were going to hold off on that because, you just don’t know how much he needs and we do think that [younger child] has been able to push [older child] also, physically and

everything. You know, to a higher level than maybe we could have achieved otherwise. . . It was hard! To have them so close together, at the time, but yeah, I'm grateful for it.

About expanded social connections, Lilly mentioned, "One of the best things that have come from a child with a developmental disability was we have an expanded friends' group as part of our therapy."

In summary, participants shared many ways in which having a child with a developmental delay has had a positive impact on their family. Supportive sibling relationships and social networks, awareness of milestones, and compassion were among these positive experiences shared. These experiences were sometimes shared in conjunction with negative experiences. Overall, most parents shared a combination of both positive and negative experiences.

Discussion

The purpose of this study was to explore how parents of children with a developmental delay were able to access resources to meet the needs of their family and child or children with a developmental delay. Through semi-structured interviewing and qualitative analysis, I determined that many parents were able to successfully access desired resources, while others experienced difficulty or found resources to be inadequate. I also identified several themes revolving around positive and negative aspects of having a child with a developmental delay. The findings provide an overall view of the variety of participant experiences but are not necessarily typical of all parents. In this section, I will discuss these findings in light of previous research

literature. Finally, I will present implications of these findings and directions of future research.

Some participants in our study reported that the resources available to them were adequate for the needs of their child and the needs of their family. This is encouraging that research and clinical efforts to improve available information and interventions for children with developmental delays have reached participants in the study (Shonkoff & Meisels, 1990). Because over half of the participants had negative experiences accessing resources, however, the current study indicates an issue in that some families are getting appropriate care while others are not. First, parents expressed uncertainty about what resources were available and reported difficulties accessing resources or finding appropriate care. This lack of knowledge and difficulties finding resources has been documented by parents of children with emotional or behavioral disorders (Rosenzweig et al., 2008). Second, parents reported disparities in finding appropriate care due to insufficient insurance coverage or other financial limitations. Insurance coverage was limited to certain types of therapeutic and clinical services based on the insurance providers, and was especially apparent among parents of children with ASD, therefore limiting their choices for better services. This finding is supported by previous findings that caregivers of children with autism spectrum disorders are more likely to experience difficulty using services and inadequate insurance coverage (Vohra et al., 2014). Together, these challenges faced by parents highlight the dual need to promote awareness of appropriate care services and provide better options through expanded and affordable health and insurance coverage

With regard to positive experiences expressed by parents, participants who had younger children mentioned that having an older child with a developmental delay helped them to be more aware of resources for their younger children. This proved helpful and reassuring whether or not the younger children had developmental delays. This relates to recent research findings that parents were generally not aware of local early intervention programs before their child's delay was identified (Raspa et al., 2015). Research and interventions on this topic are still nascent, however some organizations are advocating for developmental literacy interventions for parents to help parents identify delays earlier (Jeyaseelan & Sawyer, 2017). Because younger siblings are benefited from their parents becoming aware of these resources, these findings suggest that older siblings with delays may experience greater challenges than younger siblings. Taken together, parents frequently expressed positive experiences due to their increased knowledge and connections due to having an older child with a developmental delay.

In addition to being more aware of milestones and resources, parents described positive emotions such as gratitude for the beneficial aspect of the sibling relationship. Building on family strengths and positive family experiences, interventions for families with a child or children with developmental delays can focus on integrating these positive aspects into future intervention programs. This could also help fulfill the desire for more family-based interventions. Interventions that include positive aspects of family relations may be beneficial for early intervention and thus provide better support to children with developmental delays.

Negative experiences of having a child with developmental delays included increased emotional challenges, interference with careers, and being deterred from having

more children. These topics are well documented in the current literature (Estes et al., 2009; Freedman et al., 1995). Previous research has found that parents at a higher risk of having children with a developmental delay express increased complexity around reproductive decision making and face potential determent from having more children (McDuffie et al., 2019; Pond & Dimond, 2018). Having easier access to desired resources may prove to alleviate strains associated with having a child with a developmental delay. Furthermore, parents may be encouraged to pursue their goals and find activities that help them cope and recover from psychological and emotional burdens due to caregiving.

In summary, the present findings contribute to the field of research by providing an initial conversation of accessing resources for children with developmental delays. Additionally, unique contributions such as the supportive sibling relationship can improve the development of family-based interventions. Consequently, findings from this study have valuable implications for policy, service delivery, health care access, and public information.

Directions for Future Research

Findings from the current study suggest that there are several directions for future research. First, more research is needed to understand why some parents are able to access appropriate care while others are not. I hypothesize that the ease or difficulty accessing resources may be community-specific and more research is needed to identify communities with low access to resources and thus isolate areas of improvement specific for that community. Relatedly, future research may examine social disparities faced by various linguistic and racial groups. Additionally, further research is needed to understand the nuanced interplay of positive and negative experiences in family

relationships and how to integrate positive elements into family-based interventions. As this study and previous research demonstrates, challenges faced by parents of children with developmental delays are complex and involve various aspects of familial and community relations (McDuffie et al., 2019; Pond & Dimond, 2018). To navigate this issue, future research can address aspects and issues raised by parents in this study to better understand systemic implications of service delivery and external resources.

Conducting this study using a qualitative approach has inherent advantages. First, the grounded theory approach allows for emergent findings that may not have arisen in a purely quantitative study. Researchers wishing to more fully understand the topics in this study may choose to continue in-depth qualitative interviewing based on specific findings outlined in the study. I suggest that the current findings—and any future findings—be incorporated into future research through measures developed on this new information. With quantitative measures based on the findings in this study, future research would be more easily scaled to a large sample size and also more easily disseminated to communities seeking to understand the ease or difficulty accessing resources for community members with children with developmental delays. Purely qualitative research may limit the scope and implementation of larger or more community-specific future research. In summary, whether for further qualitative or quantitative research, these findings lay the foundation for continued research and measure development on these topics.

Clinical Implications

Clinicians and service providers can emphasize the need for and provide educational opportunities to parents of children with developmental delays. Previous

research has found that parents trust pediatricians to be reliable sources of developmental information and often rely on their guidance for their children (Committee on Children with Disabilities, 2001). Consequently, the current findings reiterate the need for consistent developmental education through pediatricians. Research can also examine best practices for disseminating developmental milestone education for parents, especially those who may not have reliable access to a pediatrician. Increased emphasis on developmental literacy may help parents be more aware of the need to access resources for a child with atypical development, thus increasing the likelihood of improved developmental outcomes for the child. Lastly, policy makers may consider broadening the outreach of various community resources for children with developmental delays for parents to more easily recognize available resources and have improved ease of access.

Limitations

Because participants were recruited from a specific geographic location (Utah County), findings from this study may not generalize to parents in other locations. Additionally, the interview was short and directed parents to think about their experience accessing resources. Therefore, it is not surprising that most of the comments centered on these topics. Participants were recruited from an ongoing study and therefore more likely to be connected to research and other resources, potentially creating a selection effect. For instance, as these participants were aware of certain resources beforehand, they may have thus provided more information during the interview than if they were completely unaware of developmental challenges in their children. Finally, because there were only a small number of participants, the breadth of experiences regarding access to resources by

parents of children with developmental delays may not have been fully represented. This project was also conducted during the COVID-19 pandemic and as a result, the sample size was small and findings from this study may have been influenced by broader social and cultural processes and hence should be taken with caution.

Conclusion

This study provided descriptive and thematic findings of parental experiences of having children with developmental delays. In summary, parents may have either positive or negative experiences accessing external resources for their child or children. Parents who have younger children are likely to be more prepared to access resources and know appropriate milestones for children, resulting in earlier care and improved outcomes. Older siblings with a developmental delay may experience more challenges than younger siblings because parents were not aware of milestones or resources. Finally, siblings were often seen as a support to children with developmental delays. As awareness of milestones and access to appropriate resources becomes more attainable for parents with children with developmental delays, challenges to child and family well-being are more likely to be mitigated.

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Appendix A

EXPERIENCE OF BEING A PARENT OF A CHILD WITH AUTISM

		Always	Often	Sometimes	Rarely	Never	N/A
No	Item	1	2	3	4	5	
1	I lack confidence in knowing how to help my child						
2	I feel listened to by professionals						
3	Working with therapists or professionals helps me feel confident						
4	I am confident that I understand my child's level of development						
5	I feel I know how to help my child progress						
6	I feel I'm getting it wrong						
7	I have realistic milestones for my child's development						
8	I doubt my ability to help my child's development						
9	I feel frustrated at not knowing how to help my child						
10	I have coping mechanisms to help my child						
11	Professionals don't understand my family's needs						
12	It's a continual battle to get the right help for my child						
13	My child is getting the right help						

Open-ended questions:

1. If you think about all the areas of your life (your time, finances, career goals, hopes and dreams, family relationships, friendships, confidence, etc.), what are the hardest three things about having a child with a developmental disability?
2. What are the best things that have come about from having a child with a developmental disability?

Appendix B

Interview Questions

1. What do you know about the risk associated with your youngest child having autism?

1.a. If you had to estimate a percent chance, what would that number be?

2. How has the information you know about risk affected you and your family?

3. In addition to enrolling in this study, have you ever tried to access specific interventions, programs, or other resources for your youngest child?

If yes: What has been your experience? Can you tell me more about that?

If no: If you were to try to access resources for your child, what kind of help would you like to receive?

4. Thinking about your entire family, what resources would be beneficial?