Intellectual and Developmental Disabilities

Seeking social learning: Online self-education in parents of children with intellectual and developmental disabilities.
--Manuscript Draft--

Manuscript Number:	IDD-D-20-00089R2
Article Type:	Research
Keywords:	Social learning; Parent; qualitative; Internet; Online
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Keywords:

Social learning

Parent

Qualitative

Internet

Online

Introduction

As with any child, children with intellectual and developmental disabilities (IDD) require knowledgeable, warm, and consistent support from caregivers to reach their full potential. IDD is characterized by significant limitations in intellectual functioning and adaptive behavior across developmental periods, which require varying levels of support to promote functioning (Schalock et al., 2021). As such, parents are especially influential in promoting positive developmental outcomes for children with IDD, both through parenting and ensuring access to services. Parents identify many positive aspects to parenting their child with IDD, such as increased spirituality, pride in their child's accomplishments, and more meaningful relationships (Beighton & Wills, 2017). At the same time, parents of children with IDD are also at risk of experiencing chronic stress and poorer quality of life (Mugno et al., 2007). Parents have the primary responsibility to mitigate behavioral, academic, mental health, and physical health challenges that a child with IDD is at a higher risk of experiencing due to complex circumstances (Bethell et al., 2012; Einfeld et al., 2011; Pinborough-Zimmerman et al., 2007). Moreover, there are significant barriers to accessing services and resources (Osborn et al., 2020) and parents are also tasked with identifying and communicating their child's strengths to providers and educators. Taken as a whole, parents of children with IDD may experience both added caregiver burden as well as well as more joy and satisfaction in their caregiving role.

The role of a parent often includes addressing unmet needs for their child with IDD, requiring expertise and advocacy skills parents may not have. Parents use the internet to fill gaps in knowledge, services, and supports. For example, a systematic review highlights that internet communities provide parents of children with IDD a sense of agency and social support, but also noted the sparse literature in this area, with only eight reports meeting the inclusion criteria

(Caton et al., 2019). Most parents of children with IDD use parenting websites and social media as sources for parenting information, with parents facing multiple risk factors the most likely to seek parenting information online (Baker et al., 2017). These risk factors include difficulty with finances, living alone, limited education, and having a child with elevated challenging behaviors. Another risk factor is being from a minoritized or marginalized race, these intersectional identities are often associated with increased social disparities, health disparities, and experiences of racism and exclusion (Ford & Airhihenbuwa, 2010). Understanding how parents currently use the internet is critical to supporting equitable and effective access to a burgeoning online knowledge and information base.

Online delivery of research-based interventions can leverage the prevalence of the internet. Notably, parents of children with challenging behaviors prefer internet-based intervention delivery (i.e., videos, websites) over face-to-face methods (i.e., parenting groups, home visits; Metzler et al., 2012) as with parents of adolescents with traumatic brain injury (Wade et al., 2019). Internet-based interventions are not only preferable, but also show comparable efficacy to face-to-face methods for interventions involving parents, in multiple systematic reviews on the use of telehealth (e.g., Knutsen et al., 2016; Sutherland et al., 2018). Online parenting interventions have also served as a resource for accessing social support through discussion boards and forums (Nicholl et al., 2017). Yet, the effective design of online interventions requires an understanding of how parents typically use the internet to seek out information and support.

As noted, internet-based resources vary in levels of interactivity, from a source of static information (e.g., webpage on developmental milestones), to a source of social support and community (e.g., online interventions, discussion boards; Hall et al., 2016). As internet use

entails an interactive process, theories on social learning processes may partially explain

mechanisms by which parents select resources and learn information on the internet. The basic

tenets of social learning theory posit that cognitive, behavioral, and social processes mutually

influence each other to support learning in the real world (Bandura, 1985; Bandura & Walters,

1977). Broadly construed, cognition comprises the mental actions to acquire knowledge, and

behavioral learning includes reinforcement and punishment contingencies for behaviors which

could be from direct experience or from observing other social agents. Indeed, social learning

theory has influenced behavioral parenting interventions (O'Connor et al., 2013) and translational

neuroscience-based interventions (Fisher & Skowron, 2017), and may provide a framework for

designing informational and support-based online interventions for parents of children with IDD.

To better understand how parents of children with IDD use the internet, we convened a

series of focus groups. The purpose of the groups was to gain opinions and perspectives from

parents on how they accessed internet services related to their children's disabilities and the

content that they found most valuable to understand their child's condition. Specifically, we

aimed to identify 1) how parents of children who experience IDD typically access the internet as

a resource related to their child, and 2) explore how parents apply internet-based information to

learn how to meet the needs of their child with IDD.

Methods

Ethics Approval and Consent

The research was approved by the Institutional Review Board of the University of

Oregon [IRB # 09142018.017]. Prior to participating in focus groups, participants provided

written informed consent, including consent to record focus group proceedings.

Settings

To access perspectives of persons in both urban and rural settings in two states, researchers convened a total of four focus groups in early 2019, two in Ohio and two in Oregon. The Ohio focus groups were held at a large children's hospital with clients from a large urban area as well as rural Ohio, Indiana and Kentucky. The Oregon focus groups were convened at a research office on a public university campus in a medium sized city.

Sampling Approach and Recruitment

We used purposeful sampling to select participants, which allowed for the exploration of variables of central importance (Patton, 2015), including differential effects of diagnosis associated with IDD (autism, communication disorder, genetic condition, mental health condition), geographic location, school programing, racial/ethnic background and other demographic factors. We sought to include 8-12 participants in each group, a number recommended as large enough to allow for diversity of perspectives but small enough to provide adequate time for each participant to respond to questions (Krueger & Casey, 2009; Morgan, 1988; Yin, 2009). In Ohio, participants were recruited by hospital staff from clinics and preschools held at the hospital. In Oregon, participants were recruited through emails and informational flyers at local developmental disability parent support groups and early intervention centers.

Participants

A total of 24 participants took part in four focus groups (Oregon N = 16; Ohio, N= 8). Demographic information for participants and information about their child's condition are detailed in Table 1.

Procedures

The focus groups were convened in central locations and at times that were convenient

for parents. One group was held in the early afternoon, with the other three held in the evening. Food was provided, and participants were compensated $70 to cover their time and any costs associated with transportation or childcare. Groups met for about an hour and a half each. Facilitators included at least 1 PhD level researcher with extensive experience in IDD research, 1 PhD level researcher with a background in technology, as well as PhD graduate students with 2 or more years of experience conducting clinical interviews and working with individuals with IDD.

Facilitators followed a semi-structured protocol in order assure coverage of topics across all groups, but participants were encouraged to expand on topics or raise related topics. Discussions began with introductions in which participants talked about themselves, their families, and described their children with IDD. Facilitators then briefly reviewed the purpose of the discussion and engaged participants to share their thoughts on what makes internet resources useful and accessible. Example topic questions included, "What have your experiences been like using the web as a format to gain more information? What are some common formats that have been helpful for learning information online? What are some common challenges your child or family experiences?" Discussions were wide ranging, with participants describing both positive and negative aspects of internet interactions as they related to parenting their children with IDD. Facilitators used a balance of follow-up questions and reflections with following the flow of relevant group conversation to gain more information about participants' internet use and preferences.

Data Analysis

All focus group recordings were transcribed verbatim and anonymized. We used a multiple-phase thematic analytic process as our primary framework (Braun & Clarke, 2006;

Clarke & Braun, 2013) and included methods derived from grounded theory (Corbin & Strauss, 2008; Miles et al., 2014). These methods included coding the data, identifying patterns, and exploring emerging themes. Two PhD level researchers and four PhD graduate students with a research focus on families with IDD coded the data. The coding process was led by one of the PhD researchers with an extensive background in qualitative research related to special education and cognitive disability. Senior researchers explored, identified, and interpreted broader themes with assistance from graduate student coders.

Coding involved first reading and rereading the data, then developing a set of broad descriptive codes based on the focus group protocols. The coders met weekly to compare codes on specific transcripts and to discuss differences in coding terminology. When parameters and names of codes were agreed upon, these codes were used to label specific sections of the data, with new and more specific codes emerging during the process.

After the first level of coding the authors generated a summary report that included all the text coded within each transcript, and for each focus group participant, sorted by major categories. Sorting of data in this manner was aided by Dedoose, a qualitative data management and analysis program (Salmona et al., 2020). An in-depth report for each participant was created, providing a summary of each individual's experiences, background and opinions. Cross-case explanatory methods (Miles et al., 2014) were used in a detailed analysis of reports and transcripts to identify patterns or themes that appeared across participants, and to test the degree to which these patterns were consistent across demographic variables. The themes were then summarized and supported with statements from the transcripts. Because focus group participants were not available to review and comment, the summaries were distributed to research team members who had attended the focus groups. These research team members were

asked to comment on the degree to which the themes were valid representations of the views expressed in the focus groups. Finally, the team of authors discussed possible unifying frameworks, discovering that the themes that emerged aligned with social learning theory (Bandura, 1985).

Results

Our analysis revealed that parents took an active role in using the internet to support their own learning and for accessing support. Four themes emerged from focus group discussions of internet usage: (1) the importance of factual knowledge gained from the internet as a source of information for parents of children with IDD, (2) the importance of social models (other parents with similar experiences) to apply and evaluate knowledge, (3) the importance of the internet as a source of social support from parents with similar experiences, and (4) the importance of evaluating the validity of knowledge accessed through the internet through scrutiny of the source of the information.

Theme 1: Importance of the Internet as a Source of Factual Information

Information about Diagnosed Condition

At the time of child diagnosis, which in some cases occurred over a period of years, parents reported that information from medical professionals was often incomplete, confusing, vague, or outdated. Furthermore, these professionals were not readily available to answer parents' questions as they arose. Other parents talked about feeling rushed through medical appointments without an opportunity to have all their questions fully answered. One parent reported:

> We came in on a Friday at 4 PM and nothing was available so they're like, "Okay, he has
>
> autism." And we're like "Okay great it's Friday at 4 PM. This is super helpful." So we

just, like sat on it for a weekend. …They give you this huge packet, but it was pretty

overwhelming, honestly. (OH111)

Parents reported that they supplemented the information from their medical team with

information from the internet to explore what they might expect from the diagnosis they were

given. Parents of children with low-incidence or complex disabilities found the internet

indispensable:

[My daughter] has a condition that less than one in a million people have. …Certainly I

used the internet, and it was a huge resource for me, but in a little bit different ways. …It

took until she was five before we got the actual correct diagnosis. …It took us a long time

to get the correct care for her. …It ends up there's a hospital in [a Northeastern state]

with some of the world's specialists in this area and they have on their website links for

all these different conditions and then general information about them. (OR114)

Once this parent found expertise related to her child's condition online, she found other

resources online to provide travel funds to *access* treatment. Because the condition is so rare, this

parent prints information about her daughter's condition from credible websites to give to local

medical professionals. The parent continues:

[The internet] has made all the difference. I've talked to other parents who[se children]

have conditions like my daughter's who are older than my daughter and I've just been

like "What did you do before the internet? How did you find anybody who had that

condition?" The internet can be a pain, but it has really, really helped in our situation.

(OR114)

Information about Child's Condition and Treatment Options

Parents reported that as they learned more about their child's condition, they sought

factual information about treatment options. "This is what I need help with: What programs are going to be the best for my child? What is going to be the most successful?" (OR119). In making treatment decisions, parents considered their child's diagnosis, age, developmental stage, and functioning level and tried to match these with the overwhelming amount of information they found on the internet about treatment options. One participant reported, "It's like channeling a firehose, deciding whether it will work, how to evaluate it." (OR121)

The number of treatment options combined with arguments, data, and rumors about effectiveness and possible side effects creates pressure for parents to make decisions that may have lifelong consequences for their children. One parent reported that she continually asks herself, "Am I doing enough?" questioning whether she is providing the best intervention at each developmental stage. She explained:

> At eighteen months I am monitoring her speech, I'm monitoring her development, she tip-toe walks, um, she's got about six words and I'm like, I'm watching and I'm sitting here going, "'kay. I know I'm in my eighteen- to twenty-four month window before either she's really gonna pick up or I'm gonna have to start receiving more services." (OR107)

Information about Resources

After deciding on a treatment, participants said they use the internet to seek resources that will help them access or implement the treatment. They look for "solid information on how to do it" as well as materials such as templates, charts and data forms to facilitate implementation. Parents also discussed using the internet to address common problems such as navigating the education system, finding therapists, accessing respite care or other assistance, and dealing with insurance issues.

Much of the conversation about resources centered on the need for more complete, better-organized compilations of resources online. As one participant stated: "There are so many resources that people don't know about" (OR103). They shared experiences of missing out on classes or information sessions or recreational opportunities for their children because there are no comprehensive resource guides or event calendars. For example, one parent explained:

There's groups you can join, there's like play groups, you know, you can get into. …
You don't have to go through [the hospital-based program for rehabilitation services].
There's other places you can go to [for] these services. There's like grants that will give
you money. Like all these things that sometimes you don't find out about. … [We need]
almost like a calendar where you can list those meetings or groups that meet up.
…There's like a million…But something that kinda links everything together for people
to know that the resources are there. (OH111)

In addition to factual information about diagnosis, treatment, and resources, parents want to learn from other parents in a similar situation. Social models, examples of other parent experiences accessed through the internet, were important to parents (Theme 2). We also noted that in each of the focus groups, when conversation turned to the topic of resources, participants spent several minutes sharing information with each other about local resources and events.

Theme 2: The Importance of Social Models

Some parents said the information they look for online is not factual but experiential. They looked for parents in similar situations and how they had applied knowledge in their own families. Participants also accessed other parent perspectives to normalize and better understand their own experiences, to be inspired by others, to see how different life circumstances lead to different approaches to parenting a child with IDD, or to learn from parents of older children

what they might expect as their children grow up. Several participants talked about following

blogs posted by parents of children with IDD, which allowed them to compare their family's

experiences and perspectives:

> I didn't really seek out the … information sites [related to Down Syndrome]. I was more
>
> looking for what people's experiences were. …I found a handful of blogs that had some
>
> aspect that I could relate to, but when I found a blog that resonated with me, I went back
>
> to the first post and I read it like a book. (OR103)

For some participants, learning about the parenting experiences of others was the primary way to

gain an applied perspective on the conflicting studies and treatment claims they were learning

about online. Participants trusted the practical, applied, information they acquired from other

parents' experiences. One parent stated, "No offense to anyone going to school, 'cause education

is good, but you can't beat everyday real life practical. There's a ton of moms [online] that are

24/7 experts on their children" (OR123). Another parent stated:

> [I go online] to get tips, tricks, you know just sometimes you're just at the end of your
>
> rope and it's just like OK, what do I try now? So then someone says, "Hey!", you know?
>
> Or somebody says "Hey I found weighted blankets over here and I found chewies on sale
>
> today." (OH112)

On the other hand, for parents of children with low-incidence disabilities, seeking out the

experiences of others had a slightly different purpose. With little information available on

treatments or treatment outcomes, these parents rely on each other for guidance on specific

medical issues:

> From the rare disease perspective…what happens is [a medical professional]
>
> recommends a surgery, so typically a parent or an adult who has the condition will write

into the Facebook group, "This is what's going on…what do you guys think?" Or

"Anybody have experience with it?" and then people write in all these different things,

and that's kind of the only way to really get information besides whatever your doctor is

telling you. …The way that I ever even got to the correct diagnosis was the social forums.

(OR114)

As discussed below (see Theme 3), these social media conversations focused on

experiential information sometimes evolve into online relationships from which parents derive

not just information but also highly valued social support.

Theme 3: The Internet as a Source of Social Support

For most participants, the value of online connections with other parents of children with

IDD went beyond sharing information. These connections were also valued as sources of social

and emotional support. Many of the participants spoke of feeling socially isolated because of

lack of understanding of their families' situations or their children's behaviors:

My sister is fully supportive, but she will be the first to tell you she has no idea what I'm

talking about. 'Cause if it's not in your daily experience you're not really gonna get it.

Doesn't mean you don't love them or care about them or support them, but if you're not

experiencing it, then you're not really gonna understand it. (OH114)

In contrast, online contact with parents in similar circumstances was an important source of

connection and emotional support:

Early on, for us, we didn't know anybody and because of the issues we were dealing with

we were basically homebound and so the only access that we had was online. The people

that were around us, they may have compassion, but they can't understand, fully

understand, or offer advice or anything, so it was nice whenever we could…even if the

person was over in Europe or the other side of the country or where, just to get the

emotional support. (OR101)

Participants discussed why these remote interactions with strangers had such a powerful effect

on their well-being:

Sometimes it helps just reading that so and so is having the same issue with their kid. It

helps sometimes just knowing that somebody else out there, even if they're like across

the world is going through the same thing, 'cause it give you just the "Ok, I'm not alone

in this." (OR115)

Online relationships sometimes developed into lasting friendships. One parent reported, "Our

son has autism, so obviously now it's fairly common, but I've made the same kind of strong

connections on Facebook with people who just understand and just get what you're saying

(OR118). Another parent reported:

I found a handful of blogs that had some aspect that I could relate to. There was a

particular mom in Oakland, and I'm actually from the Bay Area originally, and we have

actually become friends in real life now. We visited her a couple of times and, they

actually moved to Oregon now. (OR103)

As relationships developed, participants felt safe bringing up topics that they might avoid talking

about in other contexts. As one parent put it: "[The internet/social media] is a place to discuss

sensitive issues that are very much a taboo subject for a lot of people. It's a place to go for

support, mobile support" (OR119). Another parent expressed that breaching taboo topics helped

them feel empowered to help their son:

When [our child] started getting violent, we didn't know that that was part of autism, and

we got online and there was nothing about it, and it was like hush-hush you don't talk

about your child being violent. So now that [we are communicating with other families

online] we know that that can be part of it, now we're better equipped to help our son and

help other families that are seeing that (OR102).

Again, for parents of children with low-incidence or complex disabilities, social media filled a

need that literally could not be met in the local community: "There's lots of people … that have

spina bifida, lots of people that have autism, there's not many that have both, and in addition to

that there's not that many people that have my child's exact function level" (OH109).

Social support in the context of online interactions was important to parents. However (as

shown in Theme 4) parents also take an active role in critically evaluating the validity of the

ostensibly factual information on websites as well as experiential advice offered in online

forums.

Theme 4: Assessing the Validity of Internet Content

Although the internet was a valued resource for factual information, social models, and

social support, participants agreed that determining the validity of the information they found

online was both critically important and extremely challenging. One participant summed it up:

"It's my kid! I want to trust what I read, and that's difficult" (OH117). Participants reported that,

over time, they had become more selective about the resources they consulted online:

When we were first diagnosed I read all thirty [sites that came up in a search]. Like I

would spend all night until I fell asleep reading them all. You know, of course I was

looking for the research-based ones 'cause that's what I do. But nothing was kind of off

limits when I first got that diagnosis. I went through everything. You know you go

through if you believe it or not and I'm reading like everything. Everything. (OH109)

Over time, participants said they found a few websites they trusted.

I'm not big on random websites. I would only look at ones that I would know and

typically the ones I would know are the first ones that come up or the highlighted ones or

sometimes even when you type something in it prompts you to add other words and that

will clear up, clarify that search a little bit more. I don't go rogue and read all thirty that

they give me I just read like one or two or three. (OH111)

Evaluating Trustworthiness

When pressed to talk about how certain websites gained their trust, participants had

several responses. Participants investigated what organization offered the information and what

resources they used to back up their argument. Participants said they tended to trust websites

linked to hospitals or universities, academic journals or other trusted institutions or that they

learned about from trusted professionals:

The lineage, or the heritage of the website itself makes a difference. You know, if it's a

known research site, if it's tied to a journal, for me, you know, those are the things a lot

of times… you know you'll read articles that are in mainstream media like *Wall Street*

Journal, New York Times or even, *The Guardian*, right? And they'll have links that tie

back to things and that's really what I'm looking for. (OH116)

Participants agreed that they embark on internet searches with "a healthy amount of skepticism,"

for example:

The hard part is once you begin to find things that tell you what you want to hear. That

for me is always a huge red flag, 'cause my then goal is to try to refute it, try to find the

other side. Like, what am I missing here? (OH116)

One participant avoids using the word "best" in searches, having found that sites that claim to

have "the best" advice or treatment tend to present one-sided arguments. These parents also

avoid sites that have something to sell: "As far as trying to get validity, any time there's a cart, I don't buy it. It's instantly distrustful" (OR117).

Participants were also distrustful of sites that engaged in a "hard-sell" approach:

> I do have some favorite websites that talk about different therapies that I go to, and I like those, but with respect, they are promoting their therapy and their therapy is the best and this is why everyone else is wrong, and … I'm like, I don't want that. Show me what you're doing, you know. …You don't have to convince me that your bubbles are the best bubbles, just show me what your bubbles look like. I'll be my own judge. (OR123)

Another participant agreed that websites with something to sell are less trustworthy than those that offer help unconditionally: "If they had a section [to] give us resources [in] our area, that you know, kinda non-affiliated, that would be helpful to, kind of give you that sense … that this is a site that's actually wants to help, not trying to sell something." (OR117)

Dealing with Conflicting Information

To deal with the "absolutely overwhelming … amount of information" (OR118) on the internet, parents said they look for websites that present balanced evidence on different sides of issues:

> It's very difficult to put your trust in anything because anything that's out there you will have people that have the exact opposite opinion and I think that one of the things that would be particularly valuable in a site … would be ... to be very clear about the controversial aspects of everything that is discussed and to say, you know, here's the current thinking on this, here are reasons why people think yes, here are reasons why people think no. So that you can give to reader the access to the facts that have been observed and the ability to make their own conclusions. (OR112)

Parents in these groups did not discuss, or were not aware of, websites that take this kind of even-handed approach to presenting conflicting information about parenting children with IDD. However, one parent talked about finding this kind of help in a book:

It is absolutely overwhelming, the amount of information out there. There's this one book I had and I would like to see [it in] kind of a web format, and it was about different autism therapies, because there are so many things that people do. And what I really liked about the book, was the ones that it had listed, it gave a little bit of information without pushing one way or the other. (OR118)

Lacking websites that summarize arguments supporting different views, participants described a process of researching questions related to their children's health and education, tentatively selecting a treatment or approach, then vetting that approach through further internet research. In the vetting process, parents also considered whether a given practice would be compatible with their family's daily life and their child's individual characteristics. This process often led them to seek advice from other parents:

So when you find things where you're getting some evidence, but you need to vet it, that's sometimes where you have to just do an internet survey. That way you ask people. You go into forums. You try to filter through comments people are saying. … And it's not the best evidence but it's really all that's out there. 'Cause you're trying to find other people who are in the same situation as you, who are trying to consider the same things … whether it's behaviorally based, whether it's pharmacologically ... just trying to find out what's out there and trying to develop your own confidence in that. That's the challenging part. (OH116)

Yet they also perceived that this advice may not be comprehensive:

It's complicated because you can look at a therapy authoritatively or experientially. So

hearing the stories of others, about their experiences. … I mean, Facebook is wonderful,

and I've found more answers there than I've found other places, but I would also like a

solid resource to go to. (OR118)

Participants said that the advantage of using internet forums to further investigate

treatments and parenting approaches is that they can judge whether the people who had success

with the approach were dealing with similar family dynamics, behavioral issues and other

personal and highly individual factors. This could give them more information about whether a

particular approach would be successful or helpful, although, as this parent noted, this kind of

social vetting is not foolproof:

That's the hardest part. Especially with autism. Every kid is so different, and you really

can't say "Okay, this person did this, I'm gonna do exactly what they did and I'm gonna

be great." It's not gonna work that way. (OH111)

One serious downside of joining a forum, participants noted was the tendency for the discussion

to go off topic and devolve into arguments. "[In some discussions] if anybody disagrees, I mean,

they get nasty!" (OR101). Participants generally agreed that social media forums are best used

for vetting local service providers, rather than complex, controversial questions:

I appreciate when someone asks like a certain question and people answer, but it'll get

deviated… I mean recently there was like a whole vaccine post and I was like, "I just

don't want to read this" and like, people just get so heated about it and it's just like, this

just shouldn't be what we need to talk about. … I come in here when it says, "Is there a

great speech therapist?" "Who has a good dentist?" Like those are the kinds of questions

I, or like someone is asking question like "what school district? Do you have any

experience with this school district?" Those types of questions I'm totally cool with.

(OH111)

Parents in these focus groups accepted that, although the internet gives them access to a vast amount of information that might help them parent their children with IDD, this information is not organized in a way that is easy to evaluate. This requires parents to continually reassess the internet resources they rely on. One parent summarized his approach:

When you go to a hospital, you know the doctors, even if you may not like the doctor, you know they're properly credentialed. So you come in with a certain baseline level of trust. So the same thing if you have a website and you can establish that baseline level of trust, like yeah, we'll still show you like all the sources, but if you go in knowing that's there you have a home, right? An informational home … because right now all of our informational homes, it's like Google, first … and we use different things for different purposes. We use it 'til it proves, unworthy (laughs) and then we pivot and figure out what the next step is from there. (OH116)

Discussion

The conversations in the focus groups provided important information about the critical roles the internet plays for parents of children with IDD. Parents from different parts of the country, with varying levels of education and socioeconomic circumstances, agreed that they use the internet in similar ways to help them care for their children with IDD. Parents used the internet to access knowledge, compensating for difficulties accessing information from local medical and educational professionals. Moreover, participants described relying on internet resources to access other parents with similar experiences so they can apply information from the time they first became aware of their children's disabilities. They continued to rely on the

internet to evaluate interventions and treatments, and to acquire training and resources to implement them. Accessing other parents also addressed isolation and uncertainty through supportive social relationships in an online environment. However, parents were judicious in evaluating the trustworthiness of information accessed online. In the analysis of the interviews for themes, we were struck by the layered approach that parents created for themselves.

We noted that parents used cognitive, social, and behavioral processes that mutually influenced each other. Parents used sophisticated cognitive strategies to gain and evaluate knowledge as well as social-emotional strategies to apply and evaluate knowledge through the experiential learning of others. Through our analysis we noted the value of interpreting these patterns through the lens of social learning theory, a view which emphasizes learning as both the product of direct experience and the product of social observations of the behavior of others (Bandura, 1985; Bandura & Walters, 1977). Social learning seems particularly relevant for parents of children with IDD, where direct experience with their child's particular diagnosis and individual challenges may not be available. This theory has also been used in conceptualizing internet-based interventions that have a strong social support and community based discussion component (Healy & Marchand, 2020). The social models sought out by parents online served multiple purposes, namely, application and organization of knowledge as well as evaluative and sources of support and reinforcement.

Cognitive Learning

In evaluating knowledge about their child's condition and treatment options, participants said they look first for evidence of the effectiveness of the treatment, employing several strategies to judge the trustworthiness of the information they find. These included considering the reputation of the source, weighing supporting and disconfirming evidence, and skepticism of

the "hard sell."

Social and Behavioral Learning

Evidence of effectiveness was not the only consideration for these parents. Their primary

concern was: "Will it work for my family?" To answer this question participants said they

consult with other parents of children with IDD. The internet allowed them to draw on a much

wider population than the one available locally, making it possible to find families whose

circumstances are similar to their own, even if their child has a low incidence or complex

condition. Parents were able to learn through the experiences of others, even when specific

problems they faced were taboo or rare in the general population.

Social Support

Notably, parents reported that the internet was an important source of support to address

unmet social-emotional needs. Parents reported feelings of isolation and stigma related to their

child's disability, coupled with increased logistical demands and lack of understanding by others

(Faw & Leustek, 2015). Social support has the potential to buffer these impacts (Halstead et al.,

2018), as well as the impact of other psychosocial risk factors such as poverty (Morris et al.,

2017). For example, higher levels of social support have been shown to relate to more positive

parenting, and lower levels of parenting frustration (Lee et al., 2009). Parents in the present study

were proactive in seeking this support from other parents with experience.

Multiple Strategies

Parents assumed and accepted that they were ultimately responsible for the health,

development, and happiness of their children with IDD. Although they, like most parents, felt

this responsibility for all their children, the presence of disability added complexity and a need

for parents to gain knowledge and skills and emotional strength beyond that required to care for

typically developing children. Participants expressed both gratitude for the access that the internet provided and frustration that the internet was not an easier resource to trust. Along with the vast quantity of information came an obligation to first understand their child's condition, then learn about all sides of a number of treatments and issues in order to decide if an approach was effective, safe, and feasible in their specific situation.

Advice for Online Resources for Parents

Participants offered suggestions for how internet resources could be improved for their purposes. Several participants mentioned the need for trusted websites that offer balanced, reliable information on all sides of issues, showing which approaches have supporting evidence and which lack evidence, but not pressuring parents one way or the other. They also pointed out that although there are resources available for children and families, they know of no websites that provide well-organized, up-to-date information about how to access these resources. Furthermore, parents offered suggestions to improve online forums to avoid having discussions devolve into arguments or angry screeds. Participants gave examples of internally moderated forums that self-monitor and steer discussions to helpful topics and avoid emotionally charged controversies.

Limitations

The findings are based on discussions among a small sample of 24 participants. They do not constitute a representative sample of the general population in terms of racial or cultural diversity. For example, all participants were non-Hispanic and represented only four racial categories (White, Black, Native American, and Pacific Islander). Participant incomes for most of the sample were above the median household incomes in Ohio and Oregon. Age was another limitation. Parents were, on average, 42 years old, which does not capture lifespan variation that

is known to be salient for experiences with the internet as individual goals and support needs shift (Perkins & LaMartin, 2012). Furthermore, the conditions their children experience do not represent a full range of IDD. Moreover, the discussions are limited in time, they took place before the COVID-19 pandemic that shifted many services to remote. Parent needs for online learning and support has only been exacerbated by the pandemic (Jeste et al., 2020), a topic of a separate study by our research group.

Future Directions

This study offers initial guidance on how parents use the internet to learn about their child's condition and to meet unmet needs. Social learning theory could provide a framework to aid in the design of internet resources for families with children with IDD. Cognitive learning could be supported by presenting thorough, balanced explanations of complex issues related to parenting of children with IDD, linked to free sources of information from trusted institutions. Behavioral learning could be reinforced with real experiential models to illustrate potential applications of information or treatments within a social context, such as case-studies and interviews to present information in a way that is readily evaluated and applied by parents in a social-learning context. Social learning and social-emotional support could be sustained by websites that feature discussions or social-support forums. Future research can investigate ways to effectively monitor discussions to assure that discussions stay informative and fulfill the support needs of users, especially if moderated with clear community guidelines. The impact of group dynamics in internet communities could also be a fruitful future direction (Wallace, 2015).

Conclusions

Parents of children with IDD report that the internet is a critical resource. Parents rely on the internet to gain knowledge and make informed decisions about their children's care. They

seek the experience of other parents to apply this knowledge to behaviors. The internet is a

valuable source of social support as parents navigate decisions that impact their child and family.

Through engaging with perspectives from parents on their internet preferences and use,

researchers and organizations can create internet-based tools that meet the needs of families.

Table 1
Participant Demographic and Family Characteristics (N = 24)

Parent Age in Years (Mean± SD, Median)	(42 ± 8.1, 44)
Mothers	75%
Race	
White	75%
Black/African American	12.5%
Native American/Pacific Islander	8.3%
Ethnicity/Non-Hispanic	100%
Employment	
Full-time	41.7%
Part-time	16.7%
Student/At-home	29.1%
Unemployed/Disabled	12.5%
Income	
Less than $19.9K	8.3%
$20K - $39.9K	21%
$40K - $59.9K	8.3%
$60K - $80K	29.2%
$80,000 or more	33.3%
Region	
Urban	33.3%
Suburban	58.3%
Rural	8.3%
Education	
High School/Some College/Associates	58.3%
College Degree	12.5%
Graduate Degree	29.2%
Child Diagnosis	
Autism Spectrum Disorder	67%
Communication Disorder	17%
Genetic/Health[a]	25%
Behavioral/Mental Health[b]	13%

Child Age in Years (Mean ± SD, Median)	7.8 ± 5.3, 5

Note. [a]This category included the following conditions: Down syndrome, stroke lesions, collagen disorder, spina bifida, achondroplasia; [b]This category included the following conditions: ADHD, anxiety, ODD. Due to diagnostic comorbidities, child diagnosis categories total more than 100%.

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