

Special Issue

Recreation in Families with Children with Developmental Disabilities

Caregivers' Use of Online and Offline Support Groups

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Abstract

The purpose of this study was to explore what role online and offline support groups play in the lives of families with children who have developmental disabilities. Eight semi-structured individual interviews were conducted with married mothers who had one to five children. The study revealed that caregivers saw online and offline support groups as playing important but different roles in their lives and the lives of their families. Online support groups were particularly appreciated during the initial steps of learning about a child's disability when caregivers felt isolated and eager to learn more. During that stage, online support groups offered them volumes of valuable information and access to people across the world who go through similar experiences. Offline support groups offered participants of this study a sense of strong connection and belonging, and allowed them to spend time with other adults and learn about resources available in their community. The mothers also appreciated the opportunity provided to the children with disabilities and their siblings to make friends and spend time together.

Keywords

Children with disabilities, developmental disability, e-leisure, family leisure, online leisure

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Introduction

Shared leisure often defines what it means to be a family, offers opportunities to strengthen bonds and build memories, increases happiness of the members, and encourages the development of children (Johnson, Zabriskie, & Hill, 2006; Shaw & Dawson, 2001; Trussell & Shaw, 2009). Not every family and not each family member, however, has equal opportunities to benefit from shared leisure. Research shows that those who serve as family caregivers, especially those who care for children with disabilities, often have limited leisure experiences due to a variety of unique constraints, including an ethic of care (Henderson & Allen, 1991), stress and health problems (Marks, 1996), lack of time and energy due to caregiving duties (King et al., 2000), lack of knowledge (Buettner & Langrish, 2001), and social isolation (Valtchanov, Parry, Glover, & Mulcahy, 2013). Families of children with disabilities are also constrained by community programs that more frequently offer structured, competitive sports opportunities, as opposed to more individualized recreation programming that can accommodate a wide variety of skill and ability levels. The program staff's lack of awareness about disabilities and the community's negative attitudes also create challenges for families with children who have a disability (Jones, 2010; Mactavish & Schleien, 2004). Despite these constraints, parents of children with disabilities found family recreation to be the "catalyst for skill, interest and self-development" and "the most accepting and enduring social and recreation outlet for children with a developmental disability" (Mactavish & Schleien, 1998, p. 207). As a result, the opportunities for recreation among these families are often family-initiated, informal, and take place either within the family or the community (Mactavish, 1997).

One of the potential solutions to this issue of limited leisure opportunities might be online and offline community groups that provide families with leisure opportunities and ideas for leisure, as well as a close connection to others in similar life circumstances. For the purpose of this study, online and offline groups were defined as community-building groups of people with similar experiences created and maintained either in online spaces (Facebook, websites) or in person, and offering participants support and advice. Seeking encouragement and leisure ideas from other community members who face similar challenges has been shown to be beneficial. Sharing leisure experiences with those who can relate to an individual's life experiences, whether in person or in online spaces, has been shown to provide dignity, hope, and transcendence (Parry & Glover, 2010), as well as to allow for the development of camaraderie and sense of belonging (Parry, Glover, & Mulcahy, 2013). Moreover, technology-mediated leisure among those who are constrained by caregiver responsibilities may provide opportunities for leisure that otherwise would be unavailable. Due to limited and fragmented time available for leisure, caregivers may experience leisure by connecting with someone online to share and receive information and support, or to escape the reality of their situation.

Since engagement in online and offline leisure with people of similar backgrounds seems to play an important role in the lives of people with challenging life circumstances (Parry & Glover, 2010; Parry, Glover, & Mulcahy, 2013), this study aimed to explore what role online and offline support groups play in the lives of families with children who have developmental disabilities. More specifically, the objectives of this study were to explore: a) the role that online support groups play in the lives and leisure of

caregivers in families with a child who has a developmental disability and b) the role that offline support groups play in the lives and leisure of caregivers in families with a child who has a developmental disability.

Literature Review

Leisure in Families with a Member who Has a Disability

Existing research that focused on leisure opportunities among caregivers discussed multiple constraints faced by this population (Buettner & Langrish, 2001; Henderson & Allen, 1991; King et al., 2000; Marks, 1996; Valtchanov, Parry, Glover, & Mulcahy, 2013). Among the unique constraints experienced by these families are the lack of appropriate leisure opportunities and relationship-building programs, inadequate staff training, and a lack of understanding of people with disabilities by members of the community (Jones, 2010).

Leisure time for many families is compromised by a lack of time and resources needed to ensure the entire family is engaged together (Shaw & Dawson, 1998). Families that have a child or children with a disability have limited leisure opportunities because many factors must be accounted for in order for leisure to happen, including extensive pre-planning for leisure activities and securing assistance from others, including family members and support staff (Mactavish & Schleien, 2004). Parents of children with disabilities find it challenging to create an experience or opportunity where everyone in the family is able to participate due to skill variation, age variation, and limited community programs for the entire family (Mactavish & Schleien, 2004). Thus, leisure in these families is often compartmentalized, with each individual engaged in leisure activity separately rather than collectively as a family unit.

Other studies suggest that nearly 35% of families with a child with Down syndrome have no leisure time in their daily lives, which impacts the quality of life in the family (Brown, MacAdam-Crisp, Wang & Iarocci, 2006). These families claimed that they had no or few activities that would improve the family's well-being. Participants in this study also mentioned that if they had access to additional caregivers or support staff, they would have more opportunities for a variety of activities.

While families do feel constrained regarding access and time to be actively engaged in family leisure, they also indicate that family leisure time is the most important leisure experience for their families, particularly for their child or children with a disability (Mactavish & Schleien, 1998). Like other parents, parents of children with disabilities felt that family leisure had a positive impact on the physical and mental well-being of their children, and provided a fun way for their children to work on improving their social and emotional skills (Mactavish & Schleien, 1998). In recognition of the importance of leisure in the lives of families who have a member that has a disability, it is necessary to explore what role an online and offline settings play in facilitation of leisure among these families.

E-leisure and Families

Some of the unique constraints for leisure and recreation among families with members who have a disability could be partially addressed through online leisure experiences, or e-leisure. E-leisure can be defined as any activity performed in cyberspace for leisure purposes (Nimrod & Adoni, 2012). Nimrod and Adoni (2012) were the first to conceptualize e-leisure and compare it to traditional offline leisure. They suggested

that since e-leisure can be accessed any time from anywhere, it “significantly decreased the distinctiveness of leisure as time” (p. 34). Moreover, e-leisure introduced an infinite number of activities in which to participate and “decreased the importance of physical place and space” (p. 37). As a result, following a Symbolic Interaction Framework (White & Klein, 2008) and using the definition of leisure as a state of mind (Kelly, 1987), we relied on the perception of our participants when it came to a definition of online leisure related to support groups. Any technology-mediated activity (whether passively scrolling through the page or actively interacting with other members) that the caregivers perceived as leisure experiences was included as leisure with an online support group for the purposes of this study.

It is important to remember that just as with offline types of leisure, e-leisure might be constrained by a multitude of factors, including a lack of time, money, and access; insufficient skills and knowledge; and a lack of motivation (Nimrod & Adoni, 2012). Considering that in 2016, 87% of the U.S. population used the internet regularly (Anderson & Perrin, 2016) and that Americans of all gender, age, racial, or social backgrounds are using technology (Anderson, 2014), more attention should be given to e-leisure experiences.

Previous research showed that e-leisure might play an important role in the lives of families by influencing intimacy and communication between family members, as well as interaction between family members and society (Sharaievska, 2017). In some cases, family members were able to stay closer with each other by using cellphones when a child left for college (Lee, Mezaros, & Colvin, 2009), or by using Skype when relatives lived in a distant location (Horst, 2010; Ivan & Hebblethwaite, 2016). Bargh and McKenna (2004) discussed how couples in romantic relationships felt closer to each other due to their ability to text more often during the day, while Hertlein (2012) explained that couples felt closer because technology required them to express their feelings without relying on body language, as well as allowed time to phrase their concerns in a more constructive way. Moreover, in cases of individuals with hearing impairments and those who belong to the Deaf community, technology (texting and emailing) allowed them to feel closer to their family members due to their ability to communicate without mediation of the relay services (Valentine & Skelton, 2008). Exploring experiences of caregivers, Parry, Glover, and Mulcahy (2013) described how new mothers used the online community sites to connect with other mothers in the community, developed a sense of camaraderie, and, as a result, felt less isolated in the experiences of motherhood. Moreover, in a study by Jang and Dworkin (2014), when mothers felt comfortable with technology, they used it for parenting purposes and to establish and maintain their social capital that was otherwise limited due to caregiving responsibilities.

Despite the multiple benefits of e-leisure for families, there are also several challenges that technology might introduce into the family unit. Among those challenges are blurred boundaries between work and family time due to access to smartphones and emails (Chelsey, 2005), cyber affairs (Groves, Gillespie, Royce, & Lever, 2011), cyber-bullying and stalking (Burke, Wallen, Vail-Smith, & Knox, 2011), unsafe driving while texting (CDC, 2017), Internet addiction (Li, Garland, & Howard, 2014), and a decrease in face-to-face communication in families with higher levels of conflict (Mesch, 2006).

Despite an increase in research that focuses on technology-mediated leisure, research focused on technology use by contemporary families is still relatively limited and needs more attention within the leisure and therapeutic recreation field. Spracklen (2015) suggests that e-leisure has a potential to either help or damage someone's freedom, identity, and leisure. Therefore, we suggest that further exploration of this area of study can help professionals working with the families of persons with disabilities to better understand what factors may encourage the beneficial use of e-leisure and lower the potential harm associated with it.

Parents of children with disabilities in this study developed online support groups. Typically, these groups were developed after a parent created a blog and built a list of followers. Information about blogs and online support groups was shared by word of mouth, including suggestions from physicians. The members of the groups connected to share information on various topics related to developmental milestones, needed resources, and general encouragement. Other parents would seek out Facebook groups focused primarily on having a child with Down syndrome or other developmental disabilities. In addition to these outlets, the parents used websites such as BabyCenter.com to gather information about what to expect in their children's development. The community developed in these settings were focused less on connecting people with one another and more on creating a place to gather information.

The offline support groups were established by parents who took part in this study to seek opportunities to connect with other families in similar circumstances. These support groups met once a month to discuss various topics or host events for families to engage in leisure. The in-person support groups had less frequent interactions with members due to conflicting schedules, distance traveled, and multiple family commitments. The members of offline support groups also met with one another outside of scheduled meetings for more intimate interactions over lunch, coffee, or dinner.

Theoretical Background

The Symbolic Interaction Framework (White & Klein, 2008) employed in this study posits that individuals' perception of reality is constructed through their interaction with people and objects around them. As a result, the physical and social environments of an individual shape his or her world. For many people, family represents a large portion of this immediate environment and helps them to develop values and beliefs through shared time and experiences (White & Klein, 2008). However, in contemporary society, technology allows family members to access various groups and explore diverse values and beliefs outside of the family circle. Thus, a caregiver, who in the past might have been limited to the social circle of his or her immediate family and potentially homogeneous neighborhood, now has access to a variety of sources of information, support, and friendships. Moreover, a sense of isolation often experienced by new mothers can be minimized and their well-being can be improved due to their access to a variety of people and information sources via technology (McDaniel, Coyne, & Holmes, 2012). Considering the relative novelty of modern technology and e-leisure, The Symbolic Interaction Framework may be helpful in exploring what role both online and offline leisure play in the lives of families with a child with a developmental disability. Moreover, since individuals experience their environment differently and

interpret events through their own minds, it is important to explore the experiences of people in similar life circumstances.

Methods

Upon IRB approval, the project was conducted during 2014 in two rural communities in New Jersey and North Carolina. Using a purposive sampling (Bernard, 2000), potential participants were approached through several online and local support groups for families with children who have Down syndrome or autism, as well as personal contacts of the researchers. Eight primary caregivers of children with developmental disabilities took part in the study. All of them participated in both online and offline support groups and were Caucasian married mothers of middle class background with one to five children.

Semi-structured individual interviews were conducted over the phone or in person at locations convenient for the participants. The interviews lasted approximately 40 minutes and the participants received a \$10 gift card for their participation. The interview script included a series of questions related to leisure opportunities for families who have a child with a developmental disability and the role that online and offline support groups play in the lives of caregivers for a child who has a developmental disability. The interviews were recorded with the participants' consents and later transcribed verbatim using pseudonyms.

The data analysis began after the first several interviews were conducted and lasted until agreement about themes was reached. The data were analyzed by using initial, focused, axial, and theoretical coding (Charmaz, 2006). During the initial coding stage, the codes were generated by reading through the data. During focused coding the data were sifted through to construct vivid categories. The axial coding stage involved development of the categories, subcategories, and links between them. Lastly, during theoretical coding, existing categories and relationships between them were conceptualized (Charmaz, 2006). To ensure the trustworthiness of the study, the authors followed the set of Charmaz's (2006) questions to evaluate their work on credibility, originality, resonance, and usefulness. The researchers developed expertise in the area of the study by reviewing existing literature on this subject, and conducted member checks with participants who were asked to review transcripts for accuracy and additional information.

Results

Four distinct categories emerged from the data, including a) leisure opportunities for families with a child with a developmental disability, b) the role of online groups for caregivers of children with developmental disabilities, c) the role of offline groups for caregivers of children with developmental disabilities, and d) ways to improve leisure opportunities for families with children who have a developmental disability.

Leisure Opportunities for Families with a Child with a Developmental Disability

Caregivers who took part in this study varied in the way they perceived leisure opportunities available within the community for their families. Several of them believed such opportunities were limited. For example, Ashley shared,

There are very few [recreation opportunities] that I'm aware of. There have been a couple and the same group that did the adapted baseball last year has done a couple of activities throughout the year. They did bowling and a couple of other things so there've been some limited things through that one group. That's about the only thing that I know of. Yeah, there really hasn't been much.

As a result of the lack of organized programing for their families, participants and their children spent time in family-organized activities, such as playing with toys and jump around the house and backyard, reading, listening to music, going to the beach, going on walks with siblings, watching TV, and going out to eat. Moreover, caregivers networked with other families who had a child with a developmental disability to organize play dates and go to social events with peers.

However, there were also mothers who felt their leisure experiences were not significantly different from families who did not have a child with a disability due to the young age or high functionality of their children. As Hanna, described,

I'm not afraid to get out there just because he has a disability, I want him to have the same kind of life and socialization as my older child has. [...] He's still very young so we take part I guess in what's age appropriate, but I'm pleased so far.

Lastly, some mothers put the responsibility for creating leisure opportunities for their families on parents rather than community, indicating that parents needed to seek out these leisure opportunities on their own. Hanna explained that her family had great opportunities for recreation thanks to her efforts:

I think as a parent, it's what you make of it; I have never been one to sit in the house with my kids. When my first child was born, I joined a local mom's group community to meet other kids, to meet other moms, and to get out there to do things. I think the community as a whole really does have nice things to do for families. They have specific town themes or events that you can choose to do or not do. I think overall as a family, we take part in what we can and I'm happy with that.

Although they have different perceptions about the leisure opportunities available within their communities, all of the caregivers in this study appreciated what both online and offline groups offered to them and their families.

Role of Online Groups for Caregivers of Children with Developmental Disabilities

Reflecting on the role that both online and offline groups play in their lives and their leisure activities, the caregivers in this study claimed that both groups had equally beneficial but different roles. The participants reported that online groups were especially important during the overwhelming and isolating experience of learning their child had a disability. For example, Hanna explained how communicating with other parents online helped her to feel less alone in that stage full of worries and concerns.

You think you live in a very small part of the world, but when you see something like that and you join all these pages and there are people from all over the country, or world rather, that have children with Down syndrome or special needs, it's just a nice feeling that you are not alone.

Samantha shared this sentiment of isolation during the initial stages following a diagnosis and an appreciation of online interactions and support, "When I just had my son I started using online [support groups] because I was worried and I didn't know anyone. In the beginning, it was crucial since you don't know anyone." One of the mothers stated that she would have been lost without the online support groups and could not imagine what people did without the internet when they received a diagnosis about a child's disability.

In addition to support provided during the initial isolating stages as a caregiver of a child with a disability, the participants of the study appreciated online groups for several reasons. These online communities provided parents with an opportunity to interact with a more diverse group of parents than the members of their communities; allowed easy and fast access to support groups and social circles; and offered a wealth of information about disabilities, useful parenting techniques, auxiliary resources such as healthcare information, and leisure opportunities. For example, Ashley expressed her appreciation of communicating with a variety of people,

We have access to a lot more people who had a lot more experiences, so I think it's easier to find somebody who's had a similar situation with whatever you're dealing with, especially with something that's new and you really are questioning, "How do I deal with this? What do I need to do?" I think it's much easier to find someone who had a fairly similar experience. You have more exposure to a wide variety of ideas on how to solve a situation and I think that can be very good.

Hanna explained how online sources were helpful due to the variety of information available,

I think I gain knowledge from it which is definitely helpful. [...] Anything that is going to help him grow socially, developmentally, physically. Like if there is a latest trend out there that is going to help him through physical therapy or if there is a new speech tool that somebody tried that they got good results with, anything medically. If I read something and take it to my doctor, I ask them questions like what should we do next.

In addition to information about healthcare and other valuable resources, the mothers in this study stated that although leisure information was not the main reason for going online, they often found some ideas to engage their children. As Samantha stated, "Once a month [I go to online group] to see links on Facebook for activities, TV shows, articles."

Online support groups were also praised for the convenience of fast access to people and information. As Amber stated, "Online communities/support groups also save time that in-person support groups cannot because they do require a great deal of

work and effort. Online support is quicker and easier—in-person is harder because of all the other life commitments.” Emily also explained,

It is easier with online support groups because you don't have to be somewhere at a certain time. Children with Down syndrome get a lot of special services so it makes it difficult to be anywhere besides home getting PT, Speech, OT, and all the other things. I think it really helps to not be isolated.

Online support groups were perceived by mothers in this study as a valuable source of fast and diverse information, support, and encouragement that was easy to access and did not require significant effort. Although mothers reported finding some ideas for recreation in their online communities, searching for this information was not their main priority.

Role of Offline Groups for Caregivers of Children with Developmental Disabilities

The participants had predominantly positive views of offline support groups and saw their purpose differently from the role of the online groups. The caregivers considered offline groups especially important for creating a sense of normalcy and developing strong intimate and meaningful connections with other families in the community. As Ashley stated “You know it [online support groups] can be really helpful but it's not a real close, personal connection. [...] You just can't get the close friendship online I think that [you] can develop face-to-face.”

Conversely, mothers saw offline groups as an opportunity to build relationships with similar families in the community that could lead to leisure time for their children and themselves. Through participation in the offline groups, the caregivers in this study felt more positive about their children's development, observed other children with a disability and their siblings grow and develop, and offered their support and knowledge to other caregivers in the community. In Samantha's words,

When I had my son I received a lot of negativity from all of the doctors and I was worried that this support group will only perpetuate this attitude. I thought there will be a group of depressed people crying and complaining to each other. But it was just the opposite—uplifting and positive.

Emily also explained,

There is usually one mom there to give you the long view. Her son is older than 10. [...] When I first had [my daughter] I really didn't know what to expect and it was nice to see how other people's kids were doing (as a 3-, 7-year-old etc.). Knowing she was doing the 90% normal thing was very reassuring.

Emily also shared that spending time with families in similar situations helped her escape the awkwardness of everyday interactions, and allowed her to feel understood:

The first is to be around people who understand what you have been through. To be around other people [who think] that this is just normal. In the real

world, it is the norm to be around people who haven't experienced it. Many people are very awkward. They have weird questions or make weird statements.

Mothers in this study also believed that offline support groups were a great way to help their children (both with and without disabilities) to build friendships, provide opportunities for the family to participate in leisure, and learn information about resources relevant to their community. As Hanna stated, "From there [offline support group], I had created another network of friends and I wanted him to be around kids that were like him. My son has friends at the age of 2." Similarly, Amber shared the importance of organizing activities in which siblings with or without disabilities could participate, "It is family-focused group that included opportunities for siblings." Samantha also explained that the information she learned through her offline support group was different from the information she could find online since she could learn about opportunities and resources unique to their community,

I joined this group when my son was just three months old and I have been a member for almost six years. I have gained so much from it! Friendship, doctor's recommendations, information about early intervention school, various programs (Christmas party, challenger league, sports league). Many of those programs are not advertised and you know about them only through word of mouth. Many responses to my questions—you can ask anything, just knowing that someone has your back, they know what you are going through, they know and understand.

The quote above brings attention to multiple benefits of the community-based groups that meet the unique needs of families with a child who has a developmental disability. These groups serve as a source of sense of community, valuable information, friendships, and ideas for leisure and recreation.

Lastly, an opportunity to take a break from a role of caregiver was named as one of the benefits of the offline support groups. As Lilly said, she was meeting with other parents from the support group so that her brain "doesn't turn to mush from being around a baby all day." Ashley, a mother of children with developmental disabilities who was also a part of a group offering babysitting services stated,

I love watching the parents' faces. When they come at 5:30 they look stressed and tired and, when they come back a couple hours later, they have gone out to dinner together; they come in, they're smiling, they're holding hands, and you know it's just really nice so that's been wonderful for us to be a part of as well and I hope for the other families.

Mothers in this study enjoyed being part of an offline support group since it provided them and their children with close friendships and leisure opportunities, as well as informed them about resources available in their own community.

Ways to Improve Leisure Opportunities for Families with Children with Developmental Disabilities

Mothers who took part in the study provided ideas on how online and offline groups could be even more beneficial for families with children who have developmental disabilities. Therapeutic recreation specialists could employ this feedback to improve leisure and recreation opportunities offered to these families. The caregivers suggested that administrators of online resources should encourage more positive communication and provide a sense of community, ensure positive representation of families, and focus on making connections with local resources. One such resource could be a therapeutic recreation specialist in the community who may collaborate with families during the planning, organizing, and delivery stages of a recreation program and assist with event management. As some of the mothers in this study stated, it was important for them to have more assistance and support from various professionals due to the unique needs of their families. For example, Sarah highlighted, “I would prefer a support group that focused on finding people what they need rather than focusing on a diagnosis.”

In addition to the assistance of professionals, several participants mentioned they would like to see more representation online and see families like theirs to be presented on websites such as those of community recreation organizations in more positive ways. As Amber suggested, “portrayal of them [children with and without disabilities] together; something that represents our time together” could send a message about individuals with disabilities being valuable members of community and welcomed participants of the programs. Moreover, Samantha stated that even name “support group” could be adjusted to have more positive connotation,

I think “support [group]” is a good word, and you do get support from being a part of this group. But the name “support group” just has very negative connotation. [...] I know about this phone group, they don’t meet, they just share information and support with each other. It is called “Parent-to-Parent Network.” I think this name would be better.

The participants recommended that community-based groups ensure more organized distribution of information and more locations for participation. Since opportunities to offer specialized programs might be limited due to lower demand and insufficient funds, adjusting existing programs to make them more inclusive and integrative could be a viable solution. For example, Ashley offered suggestions for people in the community explaining how easy it could be to create healthier and more welcoming recreation programs,

To not go in with a lot of prejudices and assuming things about the kids but just come in and meet them as kids and find simple ways to engage them and to include them in the activities and you know if they’re willing to do that they’ll be blessed as well. It’ll be a good experience for them and for the kids and it’s usually not that hard to do. Um, you know everybody responds to a warm smile and a welcoming heart so...

Both online and offline support groups were important to caregivers in this study who have a child with a disability, however they played different roles. While online support groups offered easy, always available resources for support and information, offline groups provided opportunities for more meaningful and deep connection, friendships, local resources, and leisure opportunities.

Discussion

The study revealed several important findings about the perception of recreation opportunities available to children with disabilities and their families, as well as the role that online and offline support groups play for families with a child who has a developmental disability. The caregivers in this study varied in their perceptions of the recreation opportunities available to their families in their communities: while some parents believed that those opportunities were abundant, others thought that they were rather limited. All caregivers, however, viewed online and offline support groups as playing important but different roles in the lives of their families. Online support groups provided extensive, valuable information and helped mothers to feel a sense of community with people around the world who shared similar experiences. Moreover, those online spaces offered easily accessible support that was important during the initial steps of learning about a child's disability when caregivers felt isolated and eager to learn more. While these groups were considered to be a valuable resource, they did not provide deep personal connections with other families in similar situations or contribute to a more diverse and significantly expanded leisure repertoire of children with disabilities and their families.

Offline support groups offered mothers a sense of strong connection and belonging, allowed them to spend time with other adults, and provided them with an opportunity to learn about resources available in their community. Moreover, mothers in this study appreciated the ability to see other children with disabilities growing up, as well as the opportunity for their own children to make friends and spend time with their siblings. Spending time with families in similar situations allowed mothers to feel understood and more positive about their children, and provided them with a chance to share their experiences with other parents.

While the sense of belonging associated with being a member of online or offline communities was discussed in previous studies (Parry & Glover, 2010; Parry, Glover, & Mulcahy, 2013), the other findings prompt further research in this area. Among some suggestions for future research is the exploration of experiences that families with members with disabilities have in leisure and recreation settings. While focusing on this subject, it is important to employ the concept of intersectionality (Cho, Crenshaw, & McCall, 2013) and take into consideration the various identity-forming experiences of individuals in the family. As the results of this study suggest, the age and ability level of the child might influence recreation opportunities available to the family in the community. Moreover, while this study was mainly focused on the experiences of families with a child who has a disability, other factors such as race, social class, or cultural background may influence the experiences of these families.

We also encourage further research exploring how technology can be used to facilitate leisure and well-being in families, particularly among members of communities who have a disability and their caregivers. Technology-based leisure

has the potential to significantly influence intimacy, communication, and leisure in families (Sharaievska, 2017), empower people and help them develop their identity (Spracklen, 2015), and promote health and well-being (Street, Gold, & Manning, 2013). The caregivers in this study reflected on the important role of online groups during the initial stage after learning about their child's disability. Like the participants in Parry, Glover, and Mulcahy's (2013) study, mothers in this study felt sense of community with other people who shared their experience during this isolating time and expressed appreciation for easily accessible support and the wealth of information available to them via online sources. Although participants did not go online to specifically look for information about leisure opportunities for the entire family, they often found some ideas for leisure with their children. Such experiences of community building, learning new information, and receiving and providing support may significantly improve the well-being of caregivers whose opportunities for leisure are often limited due to their everyday responsibilities. Looking at this data through the lens of Symbolic Interaction (White & Klein, 2008), it is possible that through these experiences, the caregivers are making sense of their new reality. Since their immediate environment and social circle have limited information on the new condition in their lives (their children's disabilities), the caregivers are searching for a wider community that can provide them with a sense of clarity, support and belonging. Further research is needed to explore how those online communities can be used by therapeutic recreation specialists to learn more about needs of families with a child who has a developmental disability, as well as to provide better services to these families.

The participants of this study provided several suggestions on how online and offline communities could be improved to accommodate the needs of their families. Among those recommendations were more positive representation of families with members who have a disability, a more solution-oriented approach, providing the assistance of professionals, and better education about disabilities among members of the community. Thus, there are multiple practical implications of this study. Due to the important role that both online and offline groups play for the families, the administrators of local recreation organizations could ensure access to recreational opportunities for all families in the community by offering hybrid, locally based online communities. Those hybrid programs could provide a space in recreation facilities in the community to meet in person, as well as to ensure an online presence to encourage sense of belonging among the members who are more constrained due to multiple caregiver responsibilities. These programs could offer opportunities for positive communication and the representation of families, as well as connections to local resources and other families with children with or without disabilities. Such online spaces could offer easily accessible and local, yet professionally facilitated and organized, environments where parents could build connections, plan and organize leisure for their families, and request the support of local organizations. These spaces could be used by Therapeutic Recreation professionals as a platform to learn about the specialized needs of the families in the community, as well as to provide caregivers with advice and assistance relevant to their community.

Another area for improvement would be the implementation of more expanded training of employees in local recreational organizations, as well as the education of the wider community. The caregivers in this study reflected on their unpleasant

experiences in the community due to lack of understanding and, as a result, strived to escape uncomfortable interactions by spending time with families in similar situations. While offering programs focused on families with children with developmental disabilities is important, it might be impossible to fund and administer a wide variety of choices and locations due to the limited demand. Thus, the existing programs could hire therapeutic recreation professionals to encourage more integrative and inclusive practices.

While this study introduced several valuable findings, it has some limitations. First, more interaction between researchers and participants of the study, and even potential membership in support groups, could encourage better rapport and a deeper understanding of the challenges faced by the families in the study. Although such engagement was not possible, the participants expressed interest in participation in the project, and were genuinely interested in sharing their knowledge and experiences. Future studies could employ netnography or ethnography as a methodological approach to explore the experiences of this unique population (Berg, 2012; Kozinets, 2015). Second, only mothers' responses were used to form the snapshot of experiences of the entire family. Considering that gender differences may influence one's leisure experience, the father's or a male's experience as a caregiver should be given more attention. While including only mothers in this study might be a limitation of the study design, it is an acceptable approach to exploring caregivers' perceptions of the roles online and offline support groups have on their lives because nearly 70%–80% of women are caregivers (Rabins, 2016). Lastly, we understand that the results of this study cannot be generalized, and thus, we suggest future research to employ mixed methods and quantitative approaches to start forming and examining theories, and to conceptualize relationships between family and technology.

Leisure experiences of children with disabilities, their caregivers, and the entire family can be limited by the specialized set of constraints. This study provided a glance into the leisure experiences of these families and offered several suggestions for therapeutic recreation and recreation professionals who aim to improve the experiences of this population. The practical application of the findings and further research in this area will ensure more inclusive and integrating communities and a higher quality of life for all its members.

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