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Related Service Providers' Perspectives on Everyday Life Participation of Children and Youth with Disabilities

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Related Service Providers' Perspectives on Everyday Life Participation of Children and Youth with Disabilities

Abstract

Background: The purpose of this qualitative study was to investigate the perspectives of related service providers on everyday life participation of children and youth with disabilities that they serve.

Method: A qualitative design was used to guide interviews that elicited the participants' perspectives working with children and youth with disabilities.

Results: Five themes emerged from the qualitative analysis: (a) each child's individual experiences and quality of life; (b) linked to home, school, and community life; (c) child or youth driven; (d) provider collaboration and carryover; and (e) distinct professional provider views.

Conclusion: Insights into related service providers' perspectives on participation for children and youth with disabilities indicated that while each professional participant defined participation somewhat differently, all agreed that participation in home, school, and community life is critical for quality of life for children with or without disabilities. They reported benefits and barriers to participation that are important to consider for various settings. Providers often work collaboratively with families and other professions to enhance participation. There is a need for more research on how related service providers and other professionals define participation and how they enhance participation through interactions with children and families and the community.

Comments

The authors report they have no conflicts of interest to disclose.

Keywords

participation, childhood, youth, disabilities, provider perspectives

Cover Page Footnote

We would like to thank Dr. Keli Mui for his expertise and assistance with this study as well as the providers who shared with us their time, insights, and perspectives about participation.

Credentials Display

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Background and Literature Review

Participation in daily life is known to be significant for children's physical and emotional development and well-being (Anaby et al., 2014; Axelsson, Granlund, & Wilder, 2013). Participation in activities can foster in children and youth a sense of competency and fulfillment that leads to continued positive development into adulthood (Bedell et al., 2013). Moreover, participation offers children opportunities for development, a sense of belonging, and a strong sense of self (Petrenchik & King, 2011).

Individuals working with children and youth with disabilities note that improved participation in daily life is an important health and educational goal (Adair, Ullenhag, Keen, Granlund, & Imms, 2015). Moreover, in rehabilitation care, enhanced participation is considered one of the more important outcomes for children (Vargus-Adams & Martin, 2010). For children with severe disabilities, social participation and support for social interactions and relationships is often lacking (Adolfsson, Westerberg, & Moller, 2014). A study by Tan et al. (2016) noted that children with cerebral palsy who also had epilepsy and speech impairments were at a greater risk for restricted social participation. According to Dang and colleagues (2015), the degree or lack of childhood participation was a major indicator of adolescent participation in children with a diagnosis of cerebral palsy.

Other researchers have reported that children with disabilities participate less in physical recreation, social, and leisure activities than children without disabilities (Bult, Verschuren, Lindeman, Jongmans, & Ketelaar, 2014; Gilboa & Fuchs, 2018; Woodmansee, Hahne, Imms, & Shields, 2016). In addition, children with disabilities engaged in these activities with adults rather than with their peers without disabilities (Solish, Perry, & Minnes, 2010). Based on a systematic review by Bult, Verschuren, Jongmans, Lindeman, and Ketelaar (2011), the frequency of leisure and social activity participation for children with disabilities was linked to factors such as age, gender, gross motor function, manual ability, cognitive ability, and communication skills. As reported by Bedell et al. (2013), "children with disabilities participated less frequently, were less involved, and had less environmental support in the community than children without disabilities" (p. 315).

The World Health Organization's (WHO) *International Classification of Functioning, Disability and Health* (ICF) defines participation as engagement in activities and situations of everyday life (WHO, 2018). Examples of everyday life activities for children might include learning, self-care, community life, school events, leisure pursuits, social interactions, and communication (WHO, 2018). Along with the ICF, the *International Classification of Functioning, Disability and Health for Children and Youth* (ICF-CY) further elucidates the nature of participation, everyday living situations, and the relevant physical and social environments that impact a child's participation and development (WHO, 2007).

Participation, however, is a complex concept, and some view the WHO definition of participation as vague and difficult to operationalize for research purposes (Adair et al., 2015; Axelsson et al., 2013; Imms, 2016). Participation is considered to be a multidimensional concept in which personal factors related to the child and family, such as income, interact with community environmental barriers and supports (Anaby et al., 2014). Elucidation of the interactions among participation and intrinsic and extrinsic factors is needed to develop a clearer picture of participation and its influences (Imms et al., 2016).

In terms of assessment and intervention outcomes related to participation with children and youth with disabilities, a systematic review by Adair et al. (2015) identified a variety of assessment

tools, such as the Canadian Occupational Performance Measure, Goal Attainment Scaling, the Children's Assessment of Participation and Enjoyment, parent surveys, and child and student perceptions of change in participation. Further, King, Imms, Stewart, Freeman, and Nguyen (2018) noted the significance of assessing children in real-life contexts and of a focus on children's behaviors in dynamic and challenging life experiences.

Adair et al. (2015) noted a lack of rigorous intervention studies that report favorable participation results for children with disabilities. Direct, individually tailored programs with both individualized and group-based approaches for children with disabilities and multiple approaches to improving participation were considered most effective (Adair et al., 2015). In addition, a systematic review by Maxwell, Alves, and Granlund (2012) noted that most published studies on participation highlighted participation in relation to availability and accommodability, and that few studies examined the important aspects of accessibility and affordability to participation. Moreover, environmental and context-based interventions are promising, as they can be adapted, unlike interventions that target children's impairments and functioning (Anaby et al., 2014). Interventions that build on a combination of youth strengths with supports from the environment enabled those with intellectual disabilities and autism to thrive or to experience well-being and contribute to society in a meaningful way (Weiss & Riosa, 2015).

The social and physical environment can act as a barrier or a support to participation for children and youth with disabilities. Coster and colleagues (2013) reported that environmental features are more likely identified as barriers to participation with the most frequent barriers related to physical, cognitive, and social aspects of the environment. A systematic review by Shields, Synnot, and Barr (2012) suggested that more research is needed on the facilitators of physical activity, as most research has focused on barriers. Inadequate, inaccessible, or a lack of facilities and transportation were barriers to participation, and a lack of staff, negative staff attitudes, and costs were policy and program barriers (Freehan et al., 2012; Lim, Law, Khetani, Pollock, & Rosenbaum, 2016; Shields et al., 2012). Social barriers may include a lack of friends with whom to participate or unsupportive peers and a lack of knowledge by staff about disability or a staff's negative attitudes about disability (Lim et al., 2016). Having a social interaction component as part of an interactive physical activity was a strong theme that emerged as a facilitator, or as a barrier, if found to be deficient (Shields et al., 2012).

Participation in the community is an important aspect of the WHO's taxonomy of participation and activity for children with disabilities (WHO, 2007). More research is needed on interventions to enhance community participation by meaningful child and youth activity analysis along with an environmental modification analysis (Bedell et al., 2013). Occupational therapists can play an important role in improving environmental modifications, as they are skilled in activity analysis in real-life contexts (Brammer et al., 2015). A stronger focus on the promotion of community participation for children and youth with disabilities is needed (Anaby et al., 2014).

Part of community participation involves engagement in school and school-related activities for children with disabilities. Related services are those that assist children and youth with disabilities to benefit from special education. Related services can include, but are not limited to, speech-language pathology, vocational rehabilitation, special education, and physical and occupational therapy (Individuals with Disabilities Education Improvement Act, 2004). Therefore, related service providers are those who provide related services as defined by this act. In this study, the participants were related

service providers from the professions of occupational therapy, physical therapy, special education, and speech-language pathology.

As noted by Feehan et al. (2012), physical and occupational therapists working with children can assist children and families with resources and strategies to promote participation. They are part of the related service provider team that can encourage children with disabilities in activities outside of the home, in the school, or in the community to foster healthy development alongside their typically developing peers and encourage social interactions and friendships (Palisano et al., 2012; Solish et al., 2010).

Supporting children and youth in their participation in inclusive environments, such as in school and in the community, is an important role of occupational therapists and other related service providers (Lim et al., 2016; Schranz & Sane, 2017). However, little research is available on the perspectives of related service providers, including occupational therapists, who serve children with disabilities, and how they view the participation of children and youth with disabilities. Law and colleagues (2006) noted the importance for occupational therapists to review literature on childhood participation to plan appropriate interventions. Understanding of therapists' perspectives on participation may assist in the development of context-based strategies for improved participation for children and youth and advocacy for positive changes in the environment (King et al., 2018). More information is needed about what related service providers know about participation and how they incorporate participation for children and youth into practice. Therefore, the research question for this study was: What are related service providers' perspectives in enhancing participation for children and youth with disabilities in their homes, schools, and communities?

Method

Because of the lack of research about related service providers' perspectives on childhood participation, this study used an exploratory qualitative design (Stebbins, 2001). This initial exploration of related service providers' views will offer them an opportunity to describe, in detail, their thoughts about and experiences working with children and youth related to improving participation. In this study, we used strategies based on Saldaña (2016) to examine and analyze text data collected via interviews. Qualitative analysis was based on descriptive coding processes to convert meaningful interview text passages into key words and phrases that will later be organized into patterns and themes (Miles, Huberman, & Saldaña, 2014; Saldaña, 2016).

Participants

We used the term related service providers to represent professionals recruited for this study. Related services can include, but are not limited to, speech-language pathology, physical therapy, and occupational therapy services that meet the needs of children and youth (U.S. Department of Education, 2004).

The target population were related service providers who work with children and youth with disabilities as their primary work role under the Individuals with Disabilities Education Improvement Act (IDEA) and who were practicing in a Midwest city with approximately 500,000 residents. The inclusion criteria required participants to be aged 21 years or older; proficient in English; and a licensed related service provider from the professions of occupational therapy, physical therapy, speech-language pathology, or special education, which allowed us to obtain representation of various related service providers who address participation with children and youth with disabilities. In addition, the inclusion criteria required the participants to treat children and youth aged 0 to 19 years and to have at least 1 year

of experience providing these services. These criteria were chosen based on the ages of children served by related service providers and the need for some practice experience to describe participation, assessment, and evaluation in service settings. Those providers who did not meet the inclusion criteria were excluded from the study.

Snowball and purposive sampling are used in qualitative research to recruit participants who can provide meaningful and saturated information about a phenomenon (Depoy & Gitlin, 2016). We used this sampling method to recruit participants through distribution of an informational flyer about the study distributed to multiple health and school settings in the city where related service providers practiced. Purposeful sampling was used to enroll eight participants: two occupational therapists, two physical therapists, two speech-language therapists, and two special education teachers.

Procedures

We obtained institutional review board approval prior to initiating this study. To establish a rich and deep understanding the participants' experiences, two researchers engaged the participants in face-to-face, in-depth interviews of 60 min to 80 min. The interviews were conducted alone, at the participant's requested work setting, to gain a contextual experience of the participant's practice (Silverman, 2014). One investigator engaged the participants in the interview questions, and the other collected field note data and assisted with clarification questions. To protect the participants' privacy and to elicit responses, the interviews occurred in a secure, comfortable location at a mutually agreed on site in the participants' work settings. To protect the participants' rights, we obtained informed consent and permission to audio-record the interviews.

The recordings were transcribed verbatim to enhance the data, and the text data were stored electronically in a password protected file accessible only to the researchers. A pseudonym was used to identify each participant (Miles et al., 2014). A text data coding system of first and second cycle coding and use of qualitative software along with inter-rater coding was established to enhance qualitative reliability (Morse, 2015; Saldaña, 2016).

Instrument and Measures

A semi-structured interview guide was used to gain an in-depth understanding of the meaning of participation for children and youth through the perspectives of the related service providers (Seidman, 2013). Semi-structured questions were used to gain narratives with a rich description of how the participants viewed and used participation strategies with the children and youth they served (Silverman, 2014). The interview questions in the guide were developed from a literature review of research studies and theoretical articles on childhood participation (Adolfsson, Malmqvist, Pless, & Grandlund, 2011; Coster & Khetani, 2008; Solish et al., 2010).

The main interview question for each participant was: What are related service providers' perspectives on enhancing participation for children and youth with disabilities in their homes, schools, and communities? Additional prompts during the interview were:

- What is the meaning of your work in improving participation for your clients?
- Tell me about ways you assess participation.
- In your everyday practice, describe facilitators and barriers to participation and a meaningful life for your clients.

Interview questions were pilot tested with five related service providers experienced in working with children and youth from the various recruited professions to establish peer review and clarity of questions (Morse, 2015).

Data Analysis

Qualitative analysis began with the development of a codebook of transcribed text data from the interviews and the field notes from the researcher and interviewee from each interview (Miles et al., 2014; Saldaña, 2016). The research investigators individually engaged in first-cycle coding of responses to the semi-structured interview questions for identification of words or phrases (data chunks) that were essence-capturing, relevant feelings, or the participants' thoughts (Miles et al., 2014; Saldaña, 2016). In a second cycle of coding, the researchers reviewed initial coding and analyzed the responses for patterns or general themes (Miles et al., 2014; Saldaña, 2016). These themes were compared to words and phrases generated through use of ATLAS.ti qualitative software to enhance analysis and rigor (ATLAS.ti, 2014). Finally, categorical themes were developed through investigator inter-coder agreement to enhance the validity (Morse, 2015). To improve the trustworthiness of the results, the investigators' field notes were triangulated into data analysis. Member-checking from six of the eight interviewees was used to confirm themes, and an expert consultant in the field of qualitative research reviewed and confirmed the data analysis (Creswell & Poth, 2018).

Results

Eight related service providers participated in the study. Two were from occupational therapy, two were from physical therapy, two were from speech-language pathology, and two were from special education. All of the participants had at least a master's degree in their respective professions, while three of the eight had a doctorate degree. In terms of practice settings, half of the participants worked or had worked in the school setting, one participant had experience in the hospital setting, one participant had experience in the home health setting, and half of the participants had experience in an outpatient clinic setting. In terms of working experience with children and youth with disabilities, five of the participants had experience with children under the age of 1 year, five participants had experience with children aged 1 to 3 years, four had experience with children aged 4 to 6 years, four had experience with children aged 7 to 9 years, four had experience with children aged 10 to 13 years, seven had experience with children aged 14 to 16 years, and four had experience with children aged 17 years and older.

Table 1 represents the six themes that emerged from the qualitative analysis of text data related to participant interview responses. The themes are: (a) The aim of the provider? Increase participation, leading to enhanced quality of life; (b) each child's individual experience impacts quality of life; (c) linked to home, school, and community life; (d) child or youth driven; (e) provider collaboration and carryover; and (f) distinct professional provider views.

Table 1

Qualitative Analysis Themes

-
1. Aim of provider? Increase participation, leading to enhanced quality of life
 2. Each child's individual experience impacts quality of life
 3. Linked to home, school, and community life
 4. Child or youth driven
 5. Provider collaboration and carryover
 6. Distinct professional provider views
-

Aim of provider? Increase Participation, Leading to Enhanced Quality of Life

The goal of the therapeutic process for all related service providers appeared to be to increase participation to enhance quality of life for the child. Regardless of the related service providers' definitions of participation, the providers viewed their roles as assisting children and families to increase a child's positive interactions in everyday activities and routines that can lead to children who feel engaged in life with others. Maria reflected on the therapeutic process in this way:

I think it's easy to get caught up in working on just performance skills and not really looking at if there is improvement or no improvement in that area affecting participation. We need to be intentional with finding out if it's impacting their participation, but sometimes we forget to bring it back full circle to function and participation and what matters most to them.

Quality of life related to participation in terms of the meaning the activities had for the child and the family. Activities chosen by the related service providers in this study were based on the child's strengths and areas to improve, but were also adapted and modified to lead to a sense of competence and satisfaction for the child, and often applied to real-life settings. For example, Maria stated, "I think that if you can build in ways they [children] can feel successful . . . if you can plug it in to what they like to do and what is meaningful to them, then they are more likely to do it again." In addition, when the related service providers investigate the rhythm and routines of a child's life, this can lead to enhanced participation opportunities. Exploring the ebb and flow of a child's or youth's day can indicate the quality of participation. As Marta reported, "whatever the family typically does in the community, from doing church activities to summer rec programs . . . I look at how we can modify bike trailers for [the] kid and do a lot of connecting families with community-based activities for kids with disabilities."

Each Child's Individual Experience Impacts Quality of Life

The study participants described that participation for children and youth is different, depending on the physical and social context of the child's life experiences. The uniqueness of each child and family experience in daily routines and tasks were important to capture for optimized participation. For example, Marta stated,

I would say participation is participating in their home life, participating in their school, if they are a child, participating out in the community with leisure activities with extended family, like, I think it's very multi, like just lots of factors involved. I think participation can look very different for the same child based on who they are with.

The quality of the child's participation in natural environments also seemed important to related service providers in promoting skills for children with disabilities. Although the functional skills were important, how the skills lead to a quality of experiences for the child that lead to competence and quality of life was more important. Alicia explained:

It's probably a little harder to quantify exactly, but it's fairly easy to measure by the people who know that child well. You know, for example, are they now able to sign up for that community soccer activity, are they able to visually keep up with the kids on the playground, you know, those sorts of things, so, yeah, I would say that it impacts, I'm sure, the quality of life, you know, for that child and [his or her] enjoyment of [his or her] surroundings and ability.

Linked to Home, School, and Community Life

The related service providers discussed the importance of inclusion with family and peers in school routines that foster participation. They discussed with parents and other providers the importance of home and community routines to improve participation in meaningful activities. The related service

providers mentioned the importance of scheduling therapy or school sessions around home and school rhythms and routines to optimize participation, which was key to working with children with disabilities, as illustrated by the following quote from Maria:

So, one routine would be getting out of bed, getting dressed, feeding themselves. All those routines that are happening not only at home but will be carried through at school. So, their home routines are going to look like, you know, getting up, dressed, uh, eating breakfast, and then getting ready to go to school. And then their school routine will look like circle time, then center time, then we have clean-up time, then gross motor routine, get where I'm going?

Peer interactions and social relationships as part of home life, school life, and community life were important skills to foster for participation for children with disabilities. Improved participation involved development of self-confidence and social skills with peers and adults, as delineated by Hailey:

I think any sort of social clubs where they are learning social skills and especially nonverbal cues is probably, with the kids I am working with, is most important. So, I really encourage my kids to be a part of different clubs here at school for some of the not sporty kids.

In terms of community participation, the related service providers agreed that a barrier to participation was that communities may not know how to accommodate for children and youth with disabilities, but also that parents may not know what activities the community offers for their child. As delineated by Sally, parents often need assistance in finding appropriate resources that meet their child's needs:

I think one [barrier] is people's access to community outings, which would obviously be in their physical or geographical location, financial situation, the ability to participate in various community outings. It also depends on how knowledgeable the parents are about community resources.

In addition, other barriers to participation related to family carryover, attitudes, funding, reimbursement, and time. In terms of carryover of routines and habits of participation at home, daycare, and school, Leslie noted, "I am going to work on things that are going to be functional, to know the difference between shampoo and conditioner . . . Whatever is meaningful for that child and family is what guides my therapy." Attitudes in the community can also be viewed as a barrier to participation. For example, Leslie commented:

I think people see what a person can't do before [they see] what a person can do. So, they're not open to allowing a person to come to a place of business or to give that person an opportunity to go it alone. I think those really do create barriers and problems, and it takes down their participation.

This was supported by other related service providers who described other physical and social environmental barriers as well as funding constraints. Funding was noted as a significant barrier to enhance participation in the community, as noted by Marta:

We have parks and recs that have a pretty big program for kids with disabilities. But they have gotten more selective on who they allow to participate, which has become frustrating for some of my families. There's quite a bit of Medicaid waivers support for childcare respite and funding to help with community-based, but you must have a significant physical disability to qualify.

There's not a lot of support for kids with cognitive disabilities.

Marta asserted, "I think intentions are there but funding and manpower are not there."

In addition to funding, the related service providers noted that families struggled with scheduling sessions and collaborating on the providers' intervention plans due to time barriers. The related service providers noted the importance of being aware of and respecting family routines and rhythms and use of time to enhance participation. Alicia commented,

I mean, you know, time is always an issue for everybody. Nobody has enough of it, families of children who have a lot of appointments, and they often have lots of places to go, so not only is it burdensome on their third-party payer, but it's also just a lot on their own time and effort and energy.

Child or Youth Driven

A third theme identified was that participation is child or youth driven. All of the related service providers stated that participation increases when the child is motivated to perform a task and has self-determination. Motivation is also individualized, and it is important that related service providers identify what will sustain the child's attention and encourage him or her to participate. As Marta clarified, "kids are driven by different things, and we need to find something that meets their interest and then adapt it so they can participate with their peers."

Motivation for therapy or school was discussed as driven by the child and may lead to better participation and learning. As Jean reported, "Everything is about their ability and how much they participate, and so if I have a kid who is not really motivated, then I will find things that motivate them and use that to participate." Moreover, participation in therapy and school sessions leads to more independence, while the opposite is also true: more independence leads to better participation in therapy and school. It is often the goal of the family and child that the child be as independent as possible. As Marta elucidated,

Usually, we are working on something that is important to them [child and family] as well. If it is going to increase function, they are excited about it. Like taking a bath! I do see kids, like, when working on power mobility with their chair, then we will go to community places or the park. I want them to see what it is like to self-determine where you move and what that means and what you can do with it.

Provider Collaboration and Carryover

Another provider theme was collaboration and carryover between the clinic, home, and school life for better outcomes and increased participation for children with disabilities. The participants indicated that collaboration can and should involve many parties: the parents and caregivers, the related service provider, and the child. Parent or caregiver involvement in therapy or school sessions is critical for understanding the needs of the parent and the child to create common goals, which may lead to better parental involvement in the therapy process. While collaboration with parents was viewed as critical, collaboration with other related service providers, and understanding that person's role in working with a child, is also important for better outcomes. Sally asserted:

What makes you an outstanding therapist is the ability to work with the child, and even more importantly, to work with the people who are a part of their daily routines because they are the ones who will carry out those therapeutic strategies throughout all aspects of their child's life. So, if I am not successful with working with the teacher, parent, sibling who has way more contact hours or time with the kid, then we are not doing anything.

While it is important to have related service provider collaboration, the child's skill carryover from one setting to the next helps to encourage repetition and practice to reinforce that skill. Parents and other

service providers who support and encourage the use of skills in activities are often a focus of therapy. This is further reinforced by Maria, who stated,

I think . . . if you [as a provider] find something that seems really practical and you really feel that with having them [the family] build it into their routine [that] can make a difference. If they aren't willing to, or if they can't do it, that is tricky. Same in the school system.

Most of the participants agreed that the amount of carryover ultimately depends on the family, other providers or caregivers, and the facility's resources to incorporate other provider's ideas in service provision. Carryover between home and school or therapy sessions increases the amount of repetition, and therefore, facilitates better outcomes. Better outcomes can lead to better participation for children with disabilities, as Maria explained:

We help identify, maybe, the areas we can help them improve, but we have to show the parents how to help them on a daily basis, because it has to become part of their lifestyle if it's going to make a difference. Once a week therapy is not going to make a change, or not make changes very quickly.

Collaboration and carryover among related service providers also related to social participation outcomes for children and youth throughout their lives. Working with families, and with each other, the related service providers look to achieve participation outcomes that leave children feeling like they are socially engaged and have the skills to foster participation. The intervention outcome for a child or youth was often described in terms of skills for future participation in life that would allow them to flourish and engage with others, as explained by Alicia:

In my interactions with a variety of children with disabilities, most of them just want to have friends, and they just want to be liked and involved and be part of something, whatever that is. And I hope that they can have some tools to do those sorts of things.

Distinct Professional Provider Views

The special education teachers voiced a different view of participation based on the learning environment. They identified community as the school community and, therefore, participation as skills needed to participate in, as stated by Hailey, "anything in the learning environment." Participation, from the viewpoint of special education teachers, can involve anything from "listening, to speaking, to reading," according to Lisa. The overarching goal for participation in the school setting is success in academics, whereas other professions may address similar skills for different settings.

The occupational therapists noted that participation is linked to a child's involvement in his or her daily activities. These daily activities were identified as, "self-care things, getting dressed, brushing teeth, feeding themselves, taking a bath or shower, [or] hand washing," according to Maria. While both therapists defined participation similarly, Sally described it as "a child's ability to participate in [his or her] daily routines; whether that be independently or with assistance, but that's functional occupational therapy," and Maria asserted that "the biggest key to pediatric OT is the participation key."

The physical therapists placed a focus on independence, mobility, and adaptive equipment in describing strategies to optimize participation. Alicia stated the goal for participation is to "help kids directly do physical activities, recreation activities, [and] some skill-based activities." The physical therapists agreed that the focus for intervention is based on the child's needs and what factors need to be addressed to be successful in every environment. Marta noted that "I do try my best to look globally at that child." They both agreed that this is needed to provide equipment and skills for the child to be able to maneuver around to access all places and spaces.

Although viewpoints on participation may vary across professions, all of the related service providers acknowledged that participation and real-life, authentic experiences are crucial for all children and youth with or without disabilities. Assessment of participation was primarily achieved from observation of participation and developmental tools. For example, Jean explained, “So I am looking at developmental norms, but I am also looking at what is going to be functional for their environment.” Leslie described assessment as: “Participation can come in many different forms with speech-language because any communication intent can be participation.” Hailey remarked,

In terms of real-life experiences, there is constant learning from their everyday choices: When I do this, this is what happens, when I don’t do this, this is what happens. Sometimes, they just have to make mistakes to realize the consequences of them.

As Lisa elucidated, “hopefully [they will] be prosperous and integrated into the community as they get older and become an adult.” This shows the related service providers’ desires that their therapeutic interventions will have a lasting impact on the child’s life.

While levels of independence may vary from child to child, most of the related service providers agreed that self-advocacy is important for maintaining the ability to participate. Self-advocacy will look different for each child, depending on the type of disability, but it is important for every related service provider to equip the child with tools and skills that will allow him or her to meet participation goals. Maria explained, “We are really trying for kids to advocate for themselves eventually, so avoiding learned helplessness type of behavior. Have them start early by allowing them to participate as much [as] they can in every way they can.” Alicia asserted that the role is to “become, you know, their own advocate, and proponent in enhancing participation.”

Discussion

In this study, we explored the perspectives of related service providers from various professions in a Midwest city in enhancing the participation of children and youth with disabilities in their homes, schools, and communities. The key findings for our study noted six themes that resonated with participants: (a) the aim of the provider? Increased participation, leading to enhanced quality of life; (b) each child’s individual experience impacts quality of life; (c) linked to home, school, and community life; (d) child or youth driven; (e) provider collaboration and carryover; and (f) distinct professional provider views.

The related service providers indicated that although they did not have a clear definition of participation, their descriptions of participation and intervention outcomes often related to their professional focus of practice; for example, communication for speech-language providers. However, all related service providers acknowledged the importance of participation, meaningful activities, and quality of life in their work with children and families.

Although there is a little research on related service providers’ perspectives on childhood and youth participation, our findings are consistent with the study by Adolfsson, Grandlund, and Pless (2012) and the literature on childhood participation. Adolfsson et al. noted that professionals’ views of children’s everyday life situations related to participation in which intervention plans build on a child’s and parents’ input and the child’s motivation. The finding of the importance of a focus on increasing participation and the child’s quality of life related to a systematic review of studies in which participation in leisure and everyday activities was viewed to promote quality of life (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012). These authors emphasized that “professionals need to consider complex social, emotional, and physical outcomes such as leisure participation and quality of life when

planning interventions and programs. Participation in different leisure activities is central to promoting quality of life” (Dahan-Oliel et al., 2012, p. 437).

Additional themes for our study included: (a) each child’s individual experience and quality of life was essential to optimal engagement in participation; and (b) participation is closely linked to home, school, and community life. These themes were similar to the priority participation outcomes noted by service users and researchers in working with children with disabilities. Willis et al. (2017) stated in a scoping review on community and leisure activity that understanding the child’s experiences, motivations, and self-determination were important elements of leisure participation. Other authors noted the importance of a child’s preferences, such as feeling listened to, feeling they belong to a group and are challenged, and that they are achieving, as aspects of participation priority areas of self-care, friends and social activities, physical activities, community leisure, and sleep (McAnuff et al., 2016).

The related service providers’ emphasis on the theme of participation as being child or youth driven resonated with the work of Petrenchik and King (2011), who asserted the importance of motivation, choice, and feelings of inclusion and positive social interactions for children to participate in everyday activities essential for development. In addition, a theme of child-driven participation involvement was also noted in enhancing leisure experiences for children with movement disorders in which the child’s choice of activity and sense of fun and safety were important (Kanagasabai, Mulligan, Hale, & Mirfin-Veitch, 2018).

In defining participation, the participants paused and took time to ponder a definition. The complexity of participation and its definitions seemed to echo what researchers and related service providers have noted as the difficulty with operationalizing the term participation into the context of research and practice (Immes, 2016). Although participation is defined and classified by the WHO, some of our participants were not aware of this definition or did not use this definition in their practice. In addition, although assessment tools are available to measure childhood participation dimensions, more work is needed to understand the nature of participation with children in a variety of settings and how related service providers view, assess, and evaluate participation. Occupational therapists view participation as an essential outcome of occupational engagement.

In terms of occupational therapy practice, the occupational therapists in this study discussed participation in the context of daily activities of self-care, home and school routines, and family and community activities. They viewed participation as the key to pediatric occupational therapy, which aligns with the *Occupational Therapy Practice Framework: Domain and Process*, which states that occupational therapy services focus on enhancing engagement in occupations that promote participation in desired or needed life activities (American Occupational Therapy Association [AOTA], 2014). In addition, in AOTA’s *Vision 2025*, a statement of future directions for occupational therapy, facilitation of participation through everyday living, and quality of life are key elements of visionary practice for the future (AOTA, 2018). More research is needed to describe both how occupational therapists working with children and families view participation and the strategies they use to enhance participation as part of practice. These perspectives are important to uncover, as occupational therapists develop, implement, and evaluate strategies to optimize meaningful participation.

The findings of this study also have implications related to related service provider collaboration and carryover with families and other providers. Our study showed that although professionals often work collaboratively with families and other professions to enhance participation and improve outcomes, more collaboration is needed. This finding corresponds with early intervention occupational

therapy services that focus on collaboration with families to enhance their participation with early intervention services (Stoffel et al., 2017). One of the participants noted, “Once a week therapy is not going to make a change or not make changes very quickly.” It appears that meeting participation goals requires a team effort of related service providers, families, and other providers for collaboration and carryover. More studies are needed on how occupational therapists working with children and youth view collaboration and carryover and strategies to improve communication, collaboration, and carryover to meet enhanced participation. Moreover, there is a need to further study collaboration and carryover between related service providers to better coordinate treatment and lessons that will optimize participation in children with disabilities.

The participants in this study also shared stories of numerous benefits and barriers for child and youth participation related to personal factors of the child and external factors of the physical and social environment. The related service providers noted that there are environmental benefits related to engagement in participation, including family and social supports, that provide opportunities for children to engage in activities that are motivating, allow them to make mistakes, and involve social interactions.

In addition, the participants identified several community barriers to participation, including a community’s limited knowledge about childhood disability and ways to enhance participation. Other barriers were community attitudes toward disability, time and scheduling conflicts, and a lack of family knowledge about opportunities for inclusive community experiences. Further research is needed to assess children and youth with disabilities and their parents’ perspectives on participation in terms of assets and barriers and how related service providers can be more helpful in strengthening assets and diminishing barriers.

Limitations

There were several limitations to this study. The participants represented a small, purposive sample, which may not be applicable to other related service providers. The participants’ perspectives may not reflect the diversity of views of child and youth participation from related service providers from other regions and professions.

Conclusion

This study elucidates the perspectives of related service providers on what participation is; its role in therapeutic interactions; and its role as part of the routines and rhythms in the home, school, and community life of children and youth with disabilities. Views on childhood participation shape related service providers’ strategies to enhance child-driven goals and influence the habits and routines of children and families to participate more fully in life activities. Assets and barriers to childhood participation, along with collaboration with carryover to home, school, and community settings, are important to address across practice settings and among related service providers.

Eliciting perspectives from various related service providers about participation shows the need for practice services that clearly address participation. This study highlights participation as part of occupational intervention that professionals can improve to demonstrate outcomes related to optimizing occupation with children and youth. Occupational therapists can be prominent in communicating the value of participation, its assessment and evaluation, and the outcome for enhancement of quality of life for children and youth.

References

- Adair, B., Ullenhag, A., Keen, D., Granlund, M., & Imms, C. (2015). The effect of interventions aimed at improving participation outcomes for children with disabilities: A systematic review. *Developmental Medicine & Child Neurology*, 57(12), 1093-1104. <https://doi.org/10.1111/dmcn.12809>
- Adolfsson, M., Grandlund, M., & Pless, M. (2012). Professionals' views of children's everyday life situations and the relation to participation. *Disability and Rehabilitation*, 34(7), 581-592. <https://doi.org/10.3109/09638288.2011.613519>
- Adolfsson, M., Malmqvist, J., Pless, M., & Grandlund, M. (2011). Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disability and Rehabilitation*, 33(13-14), 1230-1244. <https://doi.org/10.3109/09638288.2010.526163>
- Adolfsson, M., Westerberg, C., & Moller, K. (2014). Everyday life situations of school-aged children with severe disabilities: What are the goals for the future? An exploratory study. *Journal of Intellectual Disability, Diagnosis and Treatment*, 2(1), 21-32. <https://doi.org/10.6000/2292-2598.2014.02.01.3>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1-S48. <https://doi.org/10.5014/ajot.2014.682006>
- American Occupational Therapy Association. (2018). *Vision 2025*. Retrieved from <https://aota.org/Publications-News/otp/Archive/2018/Vision-2025.aspx>
- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L., & Teplicky, R. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Archives of Physical Medicine and Rehabilitation*, 95(5), 908-917. <https://doi.org/10.1016/j.apmr.2014.01.005>
- ATLAS.ti (2014) *ATLAS.ti qualitative* software. Retrieved from <http://www.atlasti.com>
- Axelsson, A. K., Granlund, M., & Wilder, J. (2013). Engagement in family activities: A quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. *Child: Care, Health and Development*, 39(4), 523-534. <https://doi.org/10.1111/cch.12044>
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y. C., Teplicky, R., . . . Khetani, M. A. (2013). Community participation, supports, and barriers of school-age children with and without disabilities. *Archives of Physical Medicine and Rehabilitation*, 94(2), 315-323. <https://doi.org/10.1016/j.apmr.2012.09.024>
- Brammer, W., Malshuk, E., Robertson, L., Rubin, B., Rios, D., & Jirikowic, T. (2015, October). Improving functional motor skills and confidence. *OT Practice*, 20(18), 5-12.
- Bult, M. K., Verschuren, O., Jongmans, M. J., Lindeman, E., & Ketelaar, M. (2011). What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Research in Developmental Disabilities*, 32(5), 1521-1529. <https://doi.org/10.1016/j.ridd.2011.01.045>
- Bult, M. K., Verschuren, O., Lindeman, E., Jongmans, M. J., & Ketelaar, M. (2014). Do children participate in the activities they prefer? A comparison of children and youth with and without physical disabilities. *Clinical Rehabilitation*, 28(4), 388-396. <https://doi.org/10.1177/0269215513504314>
- Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation*, 30(8), 639-648. <https://doi.org/10.1080/09638280701400375>
- Coster, W., Law, M., Bedell, G., Liljenquist, K., Kao, Y. C., Khetani, M., & Teplicky, R. (2013). School participation, supports and barriers of students with a without disabilities. *Child: Care, Health and Development*, 39(4), 535-543. <https://doi.org/10.1111/cch.12046>
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Dang, V. M., Colver, A., Dickinson, H. O., Marcelli, M., Michelsen, S. I., Parkes, J., . . . Fauconnier, J. (2015). Predictors of participation of adolescents with cerebral palsy: A European multi-centre longitudinal study. *Research in Developmental Disabilities*, 36, 551-564. <https://doi.org/10.1016/j.ridd.2014.10.043>
- Dahan-Oliel, N., Shikako-Thomas, K., & Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: A thematic analysis of the literature. *Quality of Life Research*, 21(3), 427-439. <https://doi.org/10.1007/s11136-011-0063-9>
- Depoy, E., & Gitlin, L. N. (2016). Naturalistic designs. In *Introduction to research: Understanding and applying multiple strategies* (5th ed., pp. 158-172). St. Louis, MO: Elsevier.
- Feehan, K., O'Neil, M. E., Abdalla, D., Fragala-Pinkman, M., Kondrad, M., Berhane, Z., & Turchi, R. (2012). Factors influencing physical activity in children and youth with special health care needs: A pilot study. *International Journal of Pediatrics*, 2012, 1-11. <https://dx.doi.org/10.1155/2012/583249>
- Gilboa, Y., & Fuchs, R. (2018). Participation patterns of preschool children with intellectual

- developmental disabilities. *OTJR: Occupation, Participation and Health*, 38(4), 261-268. <https://doi.org/10.1177/1539449218766888>
- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2016). Participation, both a means and an end: A conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine & Child Neurology*, 59(1), 16-25. <https://doi.org/10.1111/dmcn.13237>
- Kanagasabai, P. S., Mulligan, H., Hale, L. A., & Mirfin-Veitch, B. (2018). "I do like the activities which I can do..." Leisure participation experiences of children with movement impairments. *Disability and Rehabilitation*, 40(14), 1630-1638. <http://doi.org/10.1080/09638288.2017.1303093>
- King, G., Imms, C., Stewart, D., Freeman, M., & Nguyen, T. (2018). A transactional framework for pediatric rehabilitation: Shifting the focus to situated contexts, transactional processes, and adaptive developmental outcomes. *Disability and Rehabilitation*, 40(15), 1829-1841. <https://doi.org/10.1080/09638288.2017.1309583>
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., . . . Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology*, 48(5), 337-342. <https://doi.org/10.1017/S0012162206000740>
- Lim, C. Y., Law, M., Khetani, M., Pollock, N., & Rosenbaum, P. (2016). Participation in out-of-home environments for young children with and without developmental disabilities. *OTJR: Occupation, Participation and Health*, 36(3), 112-125. <https://doi.org/10.1177/1539449216659859>
- Maxwell, G., Alves, I., & Granlund, M. (2012). Participation and environmental aspects in education and the ICF and the ICF-CY: Findings from a systematic literature review. *Developmental Neurorehabilitation*, 15(1), 63-78. <https://doi.org/10.3109/17518423.2011.633108>
- McAnuff, J., Brooks, R., Duff, C., Quinn, M., Marshall, J., & Kolehmainen, N. (2016). Improving participation outcomes and interventions in neurodisability: Co-designing future research. *Child: Care, Health and Development*, 43(2), 298-306. <https://doi.org/10.1111/cch.12414>
- Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, 25(9), 1212-1222. <https://doi.org/10.1177/1049732315588501>
- Palisano, R. J., Chiarello, L. A., King, G. A., Novak, I., Stoner, T., & Fiss, A. (2012). Participation-based therapy for children with physical disabilities. *Disabilities and Rehabilitation*, 34(12), 1041-1052. <https://doi.org/10.3109/09638288.2011.628740>
- Petrenchik, T., & King, G. A. (2011). Pathways to positive development: Childhood participation in everyday places and activities. In S. Bazyk (Ed.), *Mental health promotion, prevention, and intervention with children and youth: A guiding framework for occupational therapy* (pp. 71-94). Bethesda, MD: AOTA Press.
- Saldaña, J. (2016). *The coding manual for qualitative researcher* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (4th ed.). New York, NY: Teachers College Press.
- Shields, N., Synnot, A. J., & Barr, M. (2012). Perceived barriers and facilitators to physical activity for children with disability: A systematic review. *British Journal of Sports Medicine*, 46(14), 989-997. <https://doi.org/10.1136/bjsports-2011-090236>
- Silverman, D. (2014). Credible qualitative research. In *Interpreting qualitative data* (5th ed., pp. 76-107). Thousand Oaks, CA: Sage Publications, Inc.
- Solish, A., Perry, A., & Minnes, P. (2010). Participation of children with and without disabilities in social, recreational and leisure activities. *Journal of Applied Research in Intellectual Disabilities*, 23(3), 226-236. <https://doi.org/10.1111/j.1468-3148.2009.00525.x>
- Stebbins, R. A. (2001). *Exploratory research in the social sciences*. Thousand Oaks, CA: Sage Publications, Inc.
- Stoffel, A., Rhein, J., Khetani, M. A., Pizur-Barnekow, K., James, L. W., & Scheffkind, S. (2017, October). Family centered: Occupational therapy's role in promoting meaningful family engagement in early intervention. *OT Practice*, 22(18), 8-13.
- Tan, S. S., van der Slot, W. M. A., Ketelaar, M., Becher, J. G., Dallmeijer, A. J., Smits, D. W., & Roebroek, M. (2016). Factors contributing to the longitudinal development of social participation in individuals with cerebral palsy. *Research in Developmental Disabilities*, 57, 125-135. <https://doi.org/10.1016/j.ridd.2016.03.015>
- U.S. Department of Education. (2004). *Individuals with Disabilities Education Improvement Act of 2004* (IDEA 2004) (Pub. L. 108-446, 20 U.S.C. §§ 1400-1482).
- Weiss, J. A., & Riosa, P. B. (2015). Thriving in youth with autism spectrum disorder and intellectual disability. *Journal of Autism and Developmental*

Disorders, 45(8), 2474-2486.

<https://doi.org/10.1007/s10803-015-2412-y>

Wills, C., Girdler, S., Thompson, M., Rosenberg, M., Reid, S., & Elliott, C. (2017). Elements contributing to meaningful participation for children and youth with disabilities: A scoping review. *Disability and Rehabilitation*, 39(17), 1771-1784.

<https://doi.org/10.1080/09638288.2016.1207716>

Woodmansee, C., Hahne, A., Imms, C., & Shields, N. (2016). Comparing participation in physical recreation activities between children with disability and children with typical development: A secondary analysis of matched data. *Research in Developmental Disabilities*, 49-50, 268-276.

<https://doi.org/10.1016/j.ridd.2015.12.004>

World Health Organization. (2007). *International classification of functioning, disability and health: Children and youth version (ICF-CY)*. Geneva, Switzerland: Author.

World Health Organization. (2018). *List of official ICF updates*. Retrieved from

<http://www.who.int/classifications/icfupdates/en/>