

# Social Participation Experiences of Families Raising a Young Child With Autism Spectrum Disorder: Implications for Mental Health and Well-Being

Julie Smith, Nicole Halliwell, Amy Laurent, Jessica Tsotsoros, Katelyn Harris, Beth DeGrace

**Importance:** Social participation (SP) is an important facilitator of positive mental health for children and families. Children are dependent on their families to mediate SP, yet families of children with autism spectrum disorder (C-ASD) seemingly limit SP because of behavioral and functional challenges in community environments. The resulting isolation can affect the child's and the family's mental health.

**Objective:** To distill the essence of everyday SP experiences in the community of families raising C-ASD.

**Design:** Data collected via in-depth, semistructured interviews with a purposive sample and analyzed in the phenomenological tradition.

**Setting:** Community.

**Participants:** We recruited seven families with English-speaking parents (ages 18–64 yr) raising one C-ASD (age 2–8 yr). Families with more than one C-ASD or those whose C-ASD was diagnosed with complex medical condition or a neurological or genetic disorder were excluded.

**Results:** The essence of experiences of SP emerged in the form of three themes depicting the mismatch between societal expectations for SP and families' experience: (1) "the struggle," (2) "it's hard to feel like you belong," and (3) what we "have to do."

**Conclusions and Relevance:** As a collective, families expressed desire for everyday community SP and could do so only in select environments with core groups. The findings, as interpreted through the lens of mental health promotion, reveal opportunities to reduce barriers and to promote meaningful family SP so as to facilitate positive mental health and well-being through the transactional intersecting characteristics of the child with ASD, the family, and the community.

**What This Article Adds:** This study illuminates the experience of SP of families raising a young C-ASD, highlighting both supports and barriers. Practitioners can use this information to potentially prevent isolation and promote both child and family mental health and well-being.

Smith, J., Halliwell, N., Laurent, A., Tsotsoros, J., Harris, K., & DeGrace, B. (2023). Social participation experiences of families raising a young child with autism spectrum disorder: Implications for mental health and well-being. *American Journal of Occupational Therapy, 77*, 7702185090. <https://doi.org/10.5014/ajot.2023.050156>

**P**articipation is a construct defined by the *International Classification of Functioning, Disability and Health—Children and Youth* as "involvement in life situations" (World Health Organization [WHO], 2007, p. 9), which, for a child, is primarily mediated by interactions with and through the family (WHO, 2007). Participation is well recognized as essential to positive child development, quality of life, health, and

well-being, and there is no question that, family participation must be considered as the primary portal for children's social participation, including connecting with others, participating in community life, and negotiating friendships (American Occupational Therapy Association [AOTA], 2020; WHO, 2007). AOTA's (2020) *Occupational Therapy Practice Framework* (4th ed.; AOTA, 2020), the primary document governing

the practice of occupational therapy practitioners, defines the occupation of social participation as comprising meaningful engagement in opportunities that prompt social interactions with others. Social participation has also been demonstrated to be a key element of mental health and well-being across the lifespan (Bramston et al., 2002; Ooi et al., 2016; Piškur, 2013). As such, young children are dependent on their families, which serve as mediators of social participation, to either limit or facilitate these social opportunities (Law, 2002).

Everyday family activities form the foundational context of social participation opportunities for learning and developing social interaction skills, social relatedness, emotional connectedness, self-esteem, and role identity (Law, 2002; Lawlor, 2003; Weiss et al., 2013), which contribute to quality of life, positive mental health, and emotional well-being (DaWalt et al., 2019; Ooi et al., 2016; Rosenberg et al., 2013). Social participation facilitates the development of social support, a well-established mediating factor of family hardiness that can affect families' perceptions and experiences of distress (Weiss et al., 2013). *Family hardiness* can be described as the ability to cope with and mediate stress related to stressors and the confidence to overcome challenges and experience positive outcomes as a family unit (McCubbin & Thompson, 1987, cited in Weiss, 2013). It follows that if social participation supports family hardiness and development, it may be especially important for families of children with disabilities who experience developmental delays to engage in more social participation to help enhance outcomes. This consideration is particularly relevant for families of children with disabilities that feature social communication difficulties as a hallmark of diagnostic criteria, such as autism spectrum disorder (ASD; American Psychiatric Association [APA], 2013).

The linkages of participation, both as a means and an outcome, with mental health have been documented with older children with disabilities (Bramston et al., 2002; Edwards et al., 2020; King et al., 2021). A scoping review of arts-based programs that have explored the participation of children in performing and visual arts suggested that art-based interventions positively influence psychosocial well-being (Edwards et al., 2020). Furthermore, older children with disabilities who participate in transition programs focused on life skills show positive changes in both self-determination and self-efficacy, suggesting improvements in mental health and well-being (King et al., 2021). However, the influences of interventions that promote participation of children with disabilities in everyday life by supporting family social participation remain unknown.

Children with disabilities are known to have greater restrictions in community-based participation compared with their typically developing peers (Arakelyan et al., 2020; Golos et al., 2022; Khetani et al., 2013; LaVesser & Berg, 2011). Recent research suggests that

because of the impact of environments on supporting the unique participation profiles associated with children with disabilities (including ASD), additional considerations should be given to the specific environments encountered (Di Marino et al., 2018; Yee et al., 2017). However, despite the complexity of participation for this population and the increased need for social participation experiences to improve development, the literature indicates that families of children with ASD seemingly limit their social participation rather than increase it, primarily because of their children's sensory, behavioral, and functional challenges (DeGrace, 2004; Germani et al., 2017; Golos et al., 2022; Gray, 1994; Larson, 2006; LaVesser & Berg, 2011; Little et al., 2015; Myers et al., 2009; Woodgate et al., 2008).

This reduction in social participation has been shown to begin in young childhood because of these noted difficulties, but reduced participation continues across the lifespan (DaWalt et al., 2019). As a result of this withdrawal from or reduction in participation, families of children with ASD experience a sense of isolation from family, friends, and society, with the families often being misunderstood and stigmatized in addition to experiencing long-term social exclusion because of their persistent caregiver roles (Marsack & Perry, 2018). Social exclusion in turn leads to a lack of social support, which is a key mediator of perceptions of hardiness and family distress and contributes to positive mental health and well-being for both the child with ASD and the family (Weiss et al., 2013). Many children with ASD depend on continued parent support and facilitation of social experiences into mid-life adulthood and, as such, their risk of social isolation increases with age (Myers et al., 2015).

With regard to the mental health implications of this social restriction, the evidence suggests that people with ASD face lifelong challenges to participating in social activities, which affects resilience, coping, and the family's well-being (Gunty, 2021; Ooi et al., 2016). Limited social participation reduces opportunities for children with ASD to learn and practice social skills, which, coupled with limitations in social interaction—the hallmark characteristic of ASD (APA, 2013)—results in potential negative effects on the trajectory of the person's social and mental health development. Thus, the impact of ASD appears to have lasting effects on social participation as well as potential implications for mental health for the individual and the family. Therefore, we argue that the social participation of families raising a young child with ASD is a family occupation that can significantly affect mental health and well-being and thus demands attention.

When considering implications for mental health and well-being, an examination of the earliest origins of limited social participation is warranted because of the established link between social participation and development (Moore et al., 2015; Ooi et al., 2016; Piškur, 2013). To our knowledge, no study to date has

primarily explored the essence of the everyday experience of social participation in the community by families raising a young child with ASD—an important indicator for the development of social connections—and interpreted this experience through the lens of child and family mental health. Given that early exposure and experience afforded by families influences child development, including social and emotional development, understanding the meaning of social participation for these families is crucial. Firsthand in-depth accounts from families are critical to this understanding because they may reveal information not previously considered about the meaning families raising young children with ASD assign to social participation.

## Method

### Design

We selected a phenomenological approach to uncover deep understanding and distill the essence of experience using Moustakas's (1994) traditions to highlight “‘what’ [participants had] experienced and ‘how’ they experienced it” (Creswell & Poth, 2016, p. 110). We did this by means of in-depth semistructured interviews to reveal the meaning that families ascribe to their experiences of social participation in the community. *Family* was understood to be a group of individuals related to one another by blood, legal ties, or committed relationships; who lived together; and who had a shared past and shared future. The University of Oklahoma Health Sciences Center (OUHSC) institutional review board (IRB) approved this study, and participants provided consent.

### Participants

We used purposive sampling to identify families raising a young child with ASD, recruiting them through personal contacts, state agencies, autism organizations, and community providers by telephone, email, flyers, and website and social media postings. Families were eligible to be included if the family was raising one child with ASD; the parent was between ages 18 and 64 yr; the parent read, wrote, and spoke English; and the child with ASD was between ages 2 and 8 yr, reflecting the years during which social patterns are typically established. Exclusion criteria included a family with more than one child with ASD and a family with a child with ASD who also had a diagnosed complex medical condition or neurological or genetic disorder.

In qualitative research, rules regarding sample size have not been strictly established, but researchers, when considering sampling and recruitment, must keep in mind the purpose of the study and how to use purposeful sampling strategies that will provide in-depth information to answer the research questions, and they must also factor in the practicalities of time and financial resources (Durdella, 2019). Seven

families participated in the interviews with data saturation of their experiences of social participation as a family helping to address the adequacy of range as established by other phenomenological studies of occupation in the field (DeGrace, 2004; Fletcher et al., 2012; Segal et al., 2002). All families signed the IRB-approved consent form and reported their child's ASD diagnosis. All families were two-parent households, with an age range of 31 to 59 yr. The children with ASD were between ages 3 and 7, and they had a variety of communication abilities as identified by the families using the categories in the SCERTS (Social Communication [SC], Emotional Regulation [ER], and Transactional Support [TS]) model, which was incorporated into the demographic data collection sheet (Prizant et al., 2006). There were up to three siblings in each household. Additional demographic information is summarized in Table 1.

### Procedure

Using a piloted, semistructured interview guide (see the Appendix), the first author (Julie Smith) conducted one in-person interview, lasting between 80 and 105 min, with each of the seven families. Families were asked to describe their experiences of doing things as a family in the community and were prompted to describe feelings and experiences related to belonging or connectedness. Families were allowed to choose the setting for their interview, with six selecting the home and one selecting a public library. After each interview, parents completed a brief demographic survey. Interviews were audio recorded and then transcribed verbatim and de-identified by a transcriptionist. Smith corrected errors in the transcripts by comparing each transcript with the audio recording.

### Data Analysis

The data analysis team, which consisted of Smith (a doctoral student), one postprofessional doctoral student, and one entry-level occupational therapy student, was trained by an experienced qualitative researcher (Beth DeGrace). The team held sixteen 2-hr meetings by video conference for the purpose of data analysis and followed the four phenomenological processes Moustakas (1994) described: (1) *epoche* (the act of reflecting on and setting aside one's beliefs, judgments, and assumptions about social participation by families raising a young child with ASD), (2) *phenomenological reduction*, (3) *imaginative variation*, and (4) *synthesis*. Before conducting the analyses, the team members met to discuss and engage formally in *epoche*. This process was maintained throughout the analysis process both as a group and individually by the research team members.

During phenomenological reduction, the relevance of every statement made by each individual in the transcript was considered in reference to the family's experience of social participation. Relevant statements

**Table 1. Participants' Demographic Information**

Family No. and Parents' Age, Yr	Parents' Ethnicity	Parents' Education	Parents' Employment Status	Household Income (\$)	Age of Child With ASD, Yr	Partner Stage of Child With ASD <sup>a</sup>	Sibling's Age, Yr
1				70,000	4	Language partner	
Mother, 33	White, non-Hispanic	Associate degree	Part time				6
Father, 36	White, non-Hispanic	Master's degree	Full time				1
2				Unknown	3	Language partner	
Mother, 39	Asian	Bachelor's degree	N/A				11
Father, 53	Asian	Associate degree	Part time				9
3				99,999	3	Social partner	
Mother, 36	Asian	Some college	N/A				N/A
Father, 59	Black, non-Hispanic	Some college	Full time				
4				Unknown	5	Social partner	
Mother, 35	Black, non-Hispanic	Bachelor's degree	Full time				N/A
Father, 44	Black, non-Hispanic	Bachelor's degree	Full time				
5				89,999	4	Conversation partner	
Mother, 31	White, non-Hispanic	Some college	Full time				4
Father, 33	White, non-Hispanic	Some college	Full time				3
6				≥100,000	7	Conversation partner	
Mother, 42	White, non-Hispanic	Master's Degree	Full time				N/A
Father, 41	White, non-Hispanic	Doctorate	Full time				
7				≥100,000	7	Conversation partner	
Mother, 39	White, non-Hispanic, American Indian	High school graduate	N/A				17
Father, 48	White, non-Hispanic, American Indian	Some college	Full time				18

*Note.* N/A = not applicable.

<sup>a</sup>SCERTS (Social Communication [SC], Emotional Regulation [ER], and Transactional Support [TS]) language levels: social partner = pre-symbolic language, language partner = emerging language, conversational partner = conversational language.

were identified and associated with a word or phrase that captured the ideas conveyed for coding purposes. The team established reliability by collaboratively coding the first transcript as a group. After this, team members independently coded the remaining six transcripts, holding detailed meetings to discuss findings until a consensus was reached. Smith created and updated a codebook and a table listing the codes that were used across families to establish an audit trail. After all interviews had been coded, the statements in the codebook were reviewed by the team, and related codes were combined, with retention of only notable statements central to understanding the experience of social participation. The retained statements were next clustered for similar meanings, characterized with thematic labels, and then validated against the original transcripts to ensure compatibility. Verbatim statements were considered related to what each family had experienced and, through imaginative variation, the experience of each family was contemplated for possible meanings. Last, the experience across families was synthesized, giving rise to the overall essence of the experience of social participation.

### Trustworthiness

Trustworthiness was addressed in the analysis process by considering credibility, dependability, confirmability, and transferability (Durdella, 2019). Several techniques were used to ensure the findings were credible, including repeated reading, peer debriefing, and adequate referencing to the original family statements and audio recordings. Credibility and dependability were established through the triangulated use of consistent methods whereby multiple researchers analyzed and compared the same data and findings for coding. Confirmability speaks to the neutrality of the findings on the part of the researchers. Fifty percent of families participated in member checks, and all affirmed that the results resonated with their experiences. In addition, an audit trail provided a clear record of decisions made about the methodology, analysis, and findings. Code tables and codebooks were maintained throughout the data analysis process, inclusive of descriptions of techniques, to address generalizability, by Smith. Epoche discussions were conducted throughout the analysis process to control for researcher bias.

### Results

This study distilled the meaning ascribed by families raising a young child with autism to their experiences of social participation in the community. The essence of these experiences was captured by these three themes, expressed through direct quotes made by the families: (1) “the struggle,” (2) “it’s hard to feel like you belong,” and (3) what we “have to do.” In the next few sections we consider these identified themes further in the context of implications for positive mental health.

### Theme 1: “The Struggle”

“The struggle” symbolized the families’ difficulties in meeting the societal demands of engaging in social participation because of the relentless and competing demands related to watching over the child with ASD because of a mismatch between the environment and the child’s capabilities. Families depicted the experience using phrases that described behaviors related to vigilance, such as “you’re always on alert, on call”; “watching and following him wherever he goes”; and needing to “keep a close eye on him.” Challenging behaviors, which were most often noted in specific environments (e.g., during church services, eating out, or shopping), included repeating phrases “over and over and over again,” singing and talking “very loud[ly],” and screaming out. Families also reported behaviors such as “running around”; “lying on the floor”; and “ripping things off the shelves, taking things out of the cart, and chucking them.” One family reported that they stopped going to church because “the struggle” was too great to manage; the disconnect between the child’s abilities and the environment’s demands were too great. Families struggled to conform to community environmental expectations because they were either anticipating or addressing behavioral challenges, and the families had a constant feeling of being on guard and worried their child would get hurt, elope or wander off with strangers, or potentially hurt other children. “The struggle” left families feeling fatigued, overwhelmed, worried, and stressed, with a lack of enjoyment and engagement. One family shared the following anecdote:

Father: [We would get] really engaged in a conversation . . . just kind of forget about her for a minute, she might climb in their oven, or she might open up their fridge and take all their eggs and break them. . . .

Mother: And you turn away for two seconds and she could be really hurt. (Family 1)

“The struggle” exemplified the physical and mental energy required to be social participants: “I’ve been beat down for two hours wrestling a kid that doesn’t want to be here” (Family 1). Another family described, “We’ve tried everything under the sun,” but the child continued to run around in public:

He’s pretty impulsive, so you’ve got to constantly stay on your toes with him. And, I think a lot of people look at it as the overprotective, helicopter parent, but it’s more of a, I know that if I give this kid an inch, he’s going to take a mile. And, if I don’t constantly have an eye, then he’s going to be gone in a flash. (Family 5)

Families struggled to meet the societal expectations for interacting with others and being a part of activities. A father shared, “[If you] go to someone else’s house . . . you don’t get to unwind, you don’t get to deep breathe and just talk to somebody” (Family 1). Collectively, these unrelenting, taxing, and competing



experiences exemplify “the struggle” of families to be present and socially participate in the community.

## Theme 2: “It’s Hard to Feel Like You Belong”

All families referenced the experience of social participation as isolating and repeatedly expressed feeling separate. One father sadly likened autism to leprosy and being an outcast (Family 2). Another family expressed feeling like “we’re sort of doing our own thing” and made the following solemn comment:

Mother: It’s like we’re isolated in the midst of whatever’s going on around us, and, like, people are being friendly, but I don’t feel like [statement finished by father]

Father: . . . part of a group, the community or something like that. (Family 6)

The sense of a lack of belonging and feelings of isolation stemmed from others outside the family not understanding autism and the struggle to participate. Families suggested that they felt their circumstances could not be fully understood “until you are experiencing it . . . until you’ve lived it” (Family 5) and that “empathy [for their lived experiences] is not there” (Family 2). A mother reflected, “I feel like it’s hard to feel like you belong. Because no matter how people are understanding or, like, trying to understand, I think it’s still somewhat overwhelming. Like, a lonely feeling of, a feeling like nobody really understands” (Family 1).

Families expressed feeling a sense of being judged because of their differences, which reduced the experience of belonging to and having connections within the community. For example, the families frequently described people “looking,” “staring,” making comments about their child with ASD being different, or being openly blamed as the parents for the children’s behavior and delayed development, with one family reporting being told that their child “just needs a good old-fashioned spanking” (Family 7). The families frequently felt judged, which caused feelings of anger, sadness, and annoyance, while at the same time causing an urge to apologize, explain, and put others at ease. Tearfully, one mother expressed,

I feel like I have to say “Sorry” . . . because even if I shout or tell it to everyone that this is what’s going on, this is what happened, they will not understand me . . . They are not in my shoes to understand me . . . I have to deal with that . . . every time we go out. (Family 3)

However, in an interesting and important contrast, each family also shared at least one experience when they “felt [they] belonged” (Family 4), felt “like everybody else” (Family 1), or had “feelings of being accepted, of being included” (Family 5). These moments of acceptance occurred in places and environments that matched the children’s skills and behaviors, such as parks, indoor play areas, and a

children’s area in a museum. In these “judgment-free” environments, no one worried about the child with ASD because the child looked and behaved like other children. One parent remarked, “My kids run crazy, your kids run crazy; just let them play” (Family 7). Unlike in other places, where the differences of the child with ASD caused them to stand out, in these places, both the families and the children felt more accepted, relaxed, and at ease.

In addition to those particular environments, families described feeling greater acceptance and a higher sense of belonging when they were in the community with friends or extended family. These individuals were described as people who “get it [because they] know her” (Family 1), “they make an exception” (Family 6), or “they are aware of his diagnosis [ASD]” (Family 4). Families were able to find these core groups in places like church or in cultural groups with other members described as friends who were as close as family. One mother shared,

Just being part of a group and being fully accepted . . . I was always very committed in the community, and just thought, am I just going to have to hide in the house? You know, am I not going to be able to take my kid anywhere? But being part of the group really helped. (Family 4)

Families reported a sense of belonging and support from their core groups more so than in the community as a whole or even autism-related support groups. One family discussed how they had considered participating in an autism-related parent support group but decided against it because their child was labeled “high functioning” and they felt “stuck between those two worlds” (Family 6): one for families of children with special needs and one for families with children developing typically. This feeling of being trapped between two worlds contributed further to their feelings of isolation in what would have been expected to be a supportive situation. The experiences of isolation for these families, and the rare occasions when the families felt like they belonged, reveal the potency of involvement in an understanding and supportive environment for family social participation as a facilitator of mental health that can help offset or counter feelings of isolation.

## Theme 3: What We “Have to Do”

The final theme revealed that families found it necessary to mediate social participation for their children and emphasized their mindset that it is essential to be social participants, despite the many challenges, to avoid total isolation and its negative effects on well-being; it’s what we “have to do.” Each family expressed that they felt they had to expose their child to experiences outside the home even though it was difficult: “It doesn’t matter if it’s going to be hard in the moment . . . we want to create experiences for them” (Family 1). One mother shared, “The energies that

we're putting toward our child and getting through those activities that we think are important for him to be part of . . . require a lot of energy, planning" (Family 6). All families emphatically shared that they had to plan strategically and carefully, evaluating the environment for potential triggers and using key items (e.g., favorite toys, food, electronics, strollers, and carts) to minimize the child's challenging behaviors. Families stated, "There's the backup to the backup plan" (Family 1) and that "We have . . . Plan A, Plan B, Plan C . . . any time you go out, you have to battle-plan it. You have to say what could go wrong, and you have to have an exit strategy" (Family 5).

Another strategy was making compromises by doing things differently from other families, often in a way mismatched with societal norms. To visit friends, one family described both arriving late and leaving early because

If you mess that up, you mess up the whole next day . . . and [friends] don't understand that because they might go to bed at 10:00 with their kids . . . well, we don't do that . . . that's not an option. (Family 1)

Another family said felt they had to make exceptions to the rules during religious services by allowing the child to eat, listen to music, and leave the room to avoid disruptions. Families also felt they had to limit the child's opportunities with, for example, organized sports because the child may not understand how to play the game.

In addition to strategizing, planning, and compromising, part of what families "have to do" is rely on family teamwork or recruit help to manage family social participation experiences in the community. One mother stressed, "It takes one person for him when he has, you know, one of his episodes . . . it's just too hard to go to into public without additional help" (Family 5). The family's core groups that demonstrated acceptance were often the same ones that helped facilitate social engagement, with the families feeling that the experience of being in the community was easier when others helped. One mother stated, "I don't feel like when we go out with friends or to a community event like we're parenting alone . . . that takes burden off us as his parents" (Family 4).

Nearly all of the families described the experience of what they "have to do" as reframing their outlook toward acceptance of their family's life situation. This often meant accepting limited family social participation and, for some, it meant knowing that people might always treat the family or the child with ASD differently: "This is how it is, you know? Kind of sad, but kind of resigned to the fact that this is reality. This is how people are . . . it's going to be a hard life for him" (Family 6). For other families, it meant accepting that people might never understand what living with autism is like: "It's just reality. . . . they just don't understand how taxing it is" (Family 1). Part of the difficulty for these families in learning to mediate their

children's social participation was coming to terms with the special challenges they face while at the same time using that reframed perspective as a way to help them cope with those difficulties.

## Discussion

The purpose of this study was to distill the essence of everyday experiences of social participation in the community by families raising a young child with ASD. Our findings suggest that, despite the struggles associated with a difficulty, or sometimes even an inability, to meet societal expectations in social settings, all families had a strong desire for social participation and worked to provide those opportunities using core groups and environments that were conducive to positive experiences. These findings as related to the struggle for meaningful engagement rang true across participants, regardless of differences in the child's abilities or the family's demographics. Families described experiences of social participation as being centered on the child but also as stressful, tiring, and worrisome, which often led to feelings of social isolation. These feelings of social isolation can have potential negative mental health effects on both the child with ASD and their family, and this study's results suggest that all families desired to overcome the struggle to engage in more positive family social participation. This reveals a potent opportunity for occupational therapy practitioners to better facilitate positive child and family mental health by helping families reframe their perspectives toward social interaction, identify and join core groups, and seek out environments that are conducive to positive social experiences.

Our finding that families want to be a part of everyday community life are consistent with those in the established research literature, and they reinforce the power of belonging afforded by social participation as inherent to mental well-being (DaWalt et al., 2019; Ooi et al., 2016; Rosenberg et al., 2013). Without opportunities for meaningful social participation, families experienced isolation and stigmatization, which undermined their sense of belonging and connectedness beyond just their experience of the stigma from a societal lack of understanding of ASD (Farrugia, 2009; Fletcher et al., 2012; Gray, 1993; Marsack & Perry, 2018; Woodgate et al., 2008). When social support as a protective factor is limited (Weiss et al., 2013), a sense of social isolation is often experienced and is attributed to the increased vigilance necessary for the child's safety (Larson, 2010). Our findings align with the those in the existing literature and suggest that when families responded to safety concerns during social participation by being on alert, they dealt with stigma and judgment as a result.

Our findings provide an interesting glimpse into the positive influences of family resilience and hardiness (Gunty, 2021; Weiss et al., 2013). The families in our study reported a desire to pursue social

participation, despite difficulties, that differs from the previously reported family coping strategy of social withdrawal (Gray, 1994; Marsack & Perry, 2018). In our study, only one family reported that they had stopped participating in a community ritual because of challenges; all the other families worked to find strategies that would enable participation. Because our study was of families with young children with ASD, we are cautious about making any strong inferences related to family resilience and hardiness. However, our findings do suggest that indicators of family resilience and hardiness are demonstrated in the families who took part in this study and warrant further investigation, in particular about how these characteristics may change over time as a family navigates the social participation opportunities as the child with ASD ages.

Gunty's (2021) review of the literature found that families build resources to minimize the impact of stressors and develop resilience over time. Families in the identified studies also felt judged or blamed for the child's behavior, and their attempts to inform others about ASD in response to being judged or blamed resonate with other existing research (Farrugia, 2009; Marsack & Perry, 2018; Woodgate et al., 2008). It is interesting that, despite the young ages of the children in our study, a number of families reported that when they encountered negative social feedback such as being stigmatized and judged, they tried to ignore it but still described experiencing negative feelings in response. Similar to previous research, the families in our study made compromises and structured their opportunities around the needs of the child (DeGrace, 2004; Larson, 2006; Schaaf et al., 2011). As other researchers have noted (Anaby et al., 2014; Rosenberg et al., 2013), the community is a complex physical and social environment layered with attitudes and activity demands, and it can be difficult for families to navigate and mediate opportunities. This finding is echoed in our results, which indicated that families formulated numerous plans and exit strategies to participate in community and social outings. In addition, families recruited help from trusted family and friends and participated in groups that were inherently more understanding and accepting and thus frequently used, indicating the positive effect of inclusive settings and core groups on mental well-being: "everybody's happy" (Family 2), "it really makes me happy" (Family 3), "really nice" (Family 4), and "see how happy he is. . . . watching him be [in] just total bliss" (Family 7). Other researchers have noted families' use of planning and teamwork as coping strategies leading to positive results (Bagby et al., 2012; Gray, 1994; Halliwell et al., 2021; Kuhaneck et al., 2010; Lussenhop et al., 2016). Considered collectively, these strategies illustrate the families' attempts to participate socially in the community so they can benefit from social participation in support of their child's overall mental well-being (DaWalt et al., 2019; Ooi et al., 2016; Rosenberg et al., 2013; WHO, 2007).

The transactional relationships among the child with ASD, the family, and the demands of the community environment can serve as both facilitators of or barriers to family social participation and thus can enhance or inhibit mental health and well-being (Anaby et al., 2014; Piller et al., 2017). Our results are consistent with the three risk factors that Anaby et al. (2014) identified as limiting family social participation: (1) The child with ASD had difficulty understanding, meeting, and negotiating social expectations; (2) the community had expectations for child and parental behaviors and often lacked sensitivity to the families' circumstances; and (3) families had difficulty managing child behaviors and community expectations (Anaby et al., 2014). The families in this study recounted each of these risk factors as influencing their social participation.

This draws our attention to the potential long-term impact of the transactional relationships on social participation and mental health for families. Moreover, it further supports the argument that there is an increased need for community understanding and social sensitivity and inclusiveness toward people with ASD to facilitate increased social participation for this population and their families to improve mental health outcomes. Families in this study reported that they rarely experienced a sense of belonging, partly because of unsatisfying community interactions, outside of specific contexts, environments, or places and with specific core groups. This speaks to the importance of the context and environment and highlights the need to address the public's misinterpretation of child behaviors and family capacity caused by a broad general lack of knowledge and awareness of ASD. Although public policy and autism-specific organizations have increased awareness of the signs of autism, community education and public awareness programs are needed to increase understanding of and sensitivity to the social challenges faced not only by the person with autism but also by the family, to reduce stigma and increase family hardiness and resilience as protective factors for mental health (Gunty, 2021; Ooi et al., 2016; Weiss et al., 2013).

## Limitations and Future Research Directions

This study has several limitations. Although we used purposive sampling, we relied on the family's assurance of the child's diagnosis of ASD and did not require proof of diagnosis. In addition, our small sample consisted of families who were married and well educated, but, interestingly, even well-resourced families struggled with social participation in the community.

Although three families had children old enough to participate in the interview, we did not include these children because of our interest in the parental perspectives of family occupation. However, gaining



siblings' insight would provide a more potent family perspective of social participation. Moreover, we did not incorporate direct observations of the family's social participation or incorporate into the interview questions any explorations as to the family's perceptions of resilience or mental health.

Despite the magnitude of desire for family social participation in the community and the difficulty in achieving this, future research can build on this phenomenological study to investigate the perspectives of families with adult children with ASD and explore ways in which family social participation was supported in the community through the developmental stages of childhood. Research that explores relationships among constructs, such as grounded theory, can provide further understanding of facilitators, barriers, and decision making that could potentially reveal a theoretical model of maximizing social participation in the community for families raising a young child with ASD. Finally, intentional recruitment of under-resourced and nonmarried families would broaden our understanding of the social participation of families raising a young child with ASD. Intervention studies related to identifying social participation as having the potential to decrease the experience of isolation and stigma could contribute to the development and promotion of community understanding and result in more inclusive programs.

## Implications for Occupational Therapy Practice

The lived experience of social participation in the community by families raising a young child with ASD left us with a sense that, because of societal expectations, social participation is a difficult and evolving occupation for families; they desire and require additional supports to enable increased involvement and potentially see resulting improvements in both child and family mental health. Although family occupation is not a novel construct (DeGrace, 2004), and many researchers have investigated family occupation, clinical therapeutic efforts have focused largely on the child with ASD and manipulation of the environment to minimize their sensory, behavioral, and developmental differences (Case-Smith et al., 2015; Tanner et al., 2015). Through increased engagement in social participation within inclusive contexts (both environmental and social), families are able to both model and facilitate occupational engagement for their children with ASD in support of building and maintaining their current and future mental health and well-being. Researchers have suggested family training to support the social functioning and participation of family members with ASD (Tobin et al., 2014); yet, interestingly, only one family in our study reported having support from a professional to improve the family's social participation. The results of this study provide a glimpse into the resources that

families identified as helping them navigate the mismatch between society's social participation expectations and the abilities of children with ASD. They also reveal an opportunity to reduce barriers and promote meaningful family social participation by addressing characteristics of the child with ASD, the family, and the community that are rooted in capitalizing on and increasing supports. This is a potent opportunity for occupational therapy providers to build on their ability to reframe situations and maximize resource acquisition to maximize the development of social participation for young children with autism.

Our findings have the following implications for occupational therapy practice:

- Practitioners should seek to understand the meaning that social participation has for the family and its impact on mental health and well-being.
- Practitioners should seek to uncover the impact of "the struggle," including a mismatch between societal expectations, problem behaviors, and emotional regulation on the mental health and well-being of children with ASD and their families.
- Practitioners should aim to collaborate with families to enhance their understanding of social participation, including barriers to and facilitators of this participation in the context of their community and social environments.
- Practitioners can support families' desires for social participation through strategies for the prevention of problem behavior, the promotion of behavioral and emotional regulation, and the strengthening of supportive environments and persons.

## Conclusion

Occupational engagement is essential to development, enabling participation and promoting mental health and well-being across the lifespan (AOTA, 2020). This study examined the meaning ascribed to social participation experiences of families raising a young child with autism in their own words. Analysis of these families' experiences provided a better understanding of how they may affect the mental health and well-being of children and families. The results of this study provide a deeper understanding of the lived experience of community social participation, which, despite being marked by significant difficulties, demonstrates the strength of these families to persist and the positive impact of supports on improving community social participation.

## Acknowledgments

This research was conducted in partial fulfillment of Julie Smith's doctoral degree in rehabilitation sciences from the University of Oklahoma Health Sciences Center. The contents of this article were developed under a grant from the U.S. Department

of Education (H325K120310). However, the contents do not necessarily represent the policy of the U.S. Department of Education, and readers should not assume endorsement by the federal government. We are deeply thankful and appreciative of the families who generously shared their time and personal experiences as well as the tremendous support of the community surrounding the authors in bringing this article to submission. The findings were shared as a poster presentation at the American Occupational Therapy Association Annual Conference & Expo in April 2019 and the American Occupational Therapy Association Mental Health Specialty Conference in December 2022.

## References

- American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, 74(Suppl. 2), 7412410010. <https://doi.org/10.5014/ajot.2020.74S2001>
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.).
- 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, 908–917. <https://doi.org/10.1016/j.apmr.2014.01.005>
- Arakelyan, S., Maciver, D., Rush, R., O'Hare, A., & Forsyth, K. (2020). Community-based participation of children with and without disabilities. *Developmental Medicine and Child Neurology*, 62, 445–453. <https://doi.org/10.1111/dmcn.14402>
- Bagby, M. S., Dickie, V. A., & Baranek, G. T. (2012). How sensory experiences of children with and without autism affect family occupations. *American Journal of Occupational Therapy*, 66, 78–86. <https://doi.org/10.5014/ajot.2012.000604>
- Bramston, P., Bruggerman, K., & Pretty, G. (2002). Community perspectives and subjective quality of life. *International Journal of Disability, Development and Education*, 49(4), 385–397. <https://doi.org/10.1080/1034912022000028358>
- Case-Smith, J., Weaver, L. L., & Fristad, M. A. (2015). A systematic review of sensory processing interventions for children with autism spectrum disorders. *Autism*, 19, 133–148. <https://doi.org/10.1177/1362361313517762>
- Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). Sage.
- DaWalt, L. S., Usher, L. V., Greenberg, J. S., & Mailick, M. R. (2019). Friendships and social participation as markers of quality of life of adolescents and adults with fragile X syndrome and autism. *Autism*, 23, 383–393. <https://doi.org/10.1177/1362361317709202>
- DeGrace, B. W. (2004). The everyday occupation of families with children with autism. *American Journal of Occupational Therapy*, 58, 543–550. <https://doi.org/10.5014/ajot.58.5.543>
- Di Marino, E., Tremblay, S., Khetani, M., & Anaby, D. (2018). The effect of child, family and environmental factors on the participation of young children with disabilities. *Disability and Health Journal*, 11, 36–42. <https://doi.org/10.1016/j.dhjo.2017.05.005>
- Durdella, N. (2019). *Qualitative dissertation methodology: A guide for research design methods*. Sage.
- Edwards, B. M., Smart, E., King, G., Curran, C. J., & Kingsnorth, S. (2020). Performance and visual arts-based programs for children with disabilities: A scoping review focusing on psychosocial outcomes. *Disability Rehabilitation Journal*, 42, 574–585. <https://doi.org/10.1080/09638288.2018.1503734>
- Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, 31, 1011–1027. <https://doi.org/10.1111/j.1467-9566.2009.01174.x>
- Fletcher, P. C., Markoulakis, R., & Bryden, P. J. (2012). The costs of caring for a child with an autism spectrum disorder. *Issues in Comprehensive Pediatric Nursing*, 35, 45–69. <https://doi.org/10.3109/01460862.2012.645407>
- Germani, T., Zwaigenbaum, L., Magill-Evans, J., Hodgetts, S., & Ball, G. (2017). Stakeholders' perspectives on social participation in preschool children with autism spectrum disorder. *Developmental Neurorehabilitation*, 20, 475–482. <https://doi.org/10.1080/17518423.2016.1214188>
- Golos, A., Ben-Zur, H., & Chapani, S. I. (2022). Participation in preschool activities of children with autistic spectrum disorder and comparison to typically developing children. *Research in Developmental Disabilities*, 127, 104252. <https://doi.org/10.1016/j.ridd.2022.104252>
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, 15, 102–120. <https://doi.org/10.1111/1467-9566.ep11343802>
- Gray, D. E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health and Illness*, 16, 275–300. <https://doi.org/10.1111/1467-9566.ep11348729>
- Gunty, A. L. (2021). Rethinking resilience in families of children with autism spectrum disorders. *Couple and Family Psychology*, 10, 87–102. <https://doi.org/10.1037/cfp0000155>
- Halliwell, N., Podvey, M., Smith, J. D., Harris, K., Sylvester, L., & DeGrace, B. W. (2021). Experience of sleep for families of young adults with autism spectrum disorder. *American Journal of Occupational Therapy*, 75, 7505205120. <https://doi.org/10.5014/ajot.2021.043364>
- King, G., McPherson, A. C., Kingsnorth, S., Gorter, J. W., Avery, L., & Rudzik, A.; Ontario Independence Program Research Team. (2021). Opportunities, experiences, and outcomes of residential immersive life skills programs for youth with disabilities. *Disability Rehabilitation Journal*, 43, 2758–2768. <https://doi.org/10.1080/09638288.2020.1716864>
- Khetani, M., Graham, J. E., & Alvord, C. (2013). Community participation patterns among preschool-aged children who have received Part C early intervention services. *Child: Care, Health and Development*, 39, 490–499. <https://doi.org/10.1111/cch.12045>
- Kuhaneck, H. M., Burroughs, T., Wright, J., Lemarczyk, T., & Darragh, A. R. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. *Physical and Occupational Therapy in Pediatrics*, 30, 340–350. <https://doi.org/10.3109/01942638.2010.481662>
- Larson, E. (2006). Caregiving and autism: How does children's propensity for routinization influence participation in family activities? *OTJR: Occupation, Participation and Health*, 26, 69–79. <https://doi.org/10.1177/153944920602600205>
- Larson, E. (2010). Ever vigilant: Maternal support of participation in daily life for boys with autism. *Physical and Occupational Therapy in Pediatrics*, 30, 16–27. <https://doi.org/10.3109/01942630903297227>
- LaVesser, P., & Berg, C. (2011). Participation patterns in preschool children with an autism spectrum disorder. *OTJR: Occupation, Participation and Health*, 31, 33–39. <https://doi.org/10.3928/15394492-20100823-01>
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56, 640–649. <https://doi.org/10.5014/ajot.56.6.640>
- Lawlor, M. C. (2003). The significance of being occupied: The social construction of childhood occupations. *American Journal of*

- Occupational Therapy*, 57, 424–434. <https://doi.org/10.5014/ajot.57.4.424>
- Little, L. M., Ausderau, K., Sideris, J., & Baranek, G. T. (2015). Activity participation and sensory features among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 45, 2981–2990. <https://doi.org/10.1007/s10803-015-2460-3>
- Lussenhop, A., Mesiti, L. A., Cohn, E. S., Orsmond, G. I., Goss, J., Reich, C., . . . Lindgren-Streicher, A. (2016). Social participation of families with children with autism spectrum disorder in a science museum. *Museums and Social Issues*, 11, 122–137. <https://doi.org/10.1080/15596893.2016.1214806>
- Marsack, C. N., & Perry, T. E. (2018). Aging in place in every community: social exclusion experiences of parents of adult children with autism spectrum disorder. *Research on Aging*, 40, 535–557. <https://doi.org/10.1177/0164027517717044>
- Moore, T. G., McDonald, M., Carlon, L., & O'Rourke, K. (2015). Early childhood development and the social determinants of health inequities. *Health Promotion International*, 30(Suppl. 2), ii102–ii115. <https://doi.org/10.1093/heapro/dav031>
- Moustakas, C. (1994). *Phenomenological research methods*. Sage. <https://doi.org/10.4135/9781412995658>
- Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders*, 45, 2373–2381. <https://doi.org/10.1007/s10803-015-2403-z>
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heart ache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *Research in Autism Spectrum Disorders*, 3, 670–684. <https://doi.org/10.1016/j.rasd.2009.01.004>
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, 12, 745–762. <https://doi.org/10.2147/NDT.S100634>
- Piller, A., Fletcher, T., Pfeiffer, B., Dunlap, K., & Pickens, N. (2017). Reliability of the Participation and Sensory Environment Questionnaire: Teacher Version. *Journal of Autism and Developmental Disorders*, 47, 3541–3549. <https://doi.org/10.1007/s10803-017-3273-3>
- Piskur, B. (2013). Social participation: Redesign of education, research, and practice in occupational therapy. *Scandinavian Journal of Occupational Therapy*, 20, 2–8. <https://doi.org/10.3109/11038128.2012.744093>
- Prizant, B. M., Wetherby, A. M., Rubin, E., Laurent, A. C., & Rydell, P. J. (2006). *The SCERTS model: A comprehensive educational approach for children with autism spectrum disorders*. Brookes.
- Rosenberg, L., Bart, O., Ratzon, N. Z., & Jarus, T. (2013). Personal and environmental factors predict participation of children with and without mild developmental disabilities. *Journal of Child and Family Studies*, 22, 658–671. <https://doi.org/10.1007/s10826-012-9619-8>
- Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism*, 15, 373–389. <https://doi.org/10.1177/1362361310386505>
- Segal, R., Mandich, A., Polatajko, H., & Cook, J. V. (2002). Stigma and its management: a pilot study of parental perceptions of the experiences of children with developmental coordination disorder. *American Journal of Occupational Therapy*, 56, 422–428. <https://doi.org/10.5014/ajot.56.4.422>
- Tanner, K., Hand, B. N., O’Toole, G., & Lane, A. E. (2015). Effectiveness of interventions to improve social participation, play, leisure, and restricted and repetitive behaviors in people with autism spectrum disorder: A systematic review. *American Journal of Occupational Therapy*, 69, 6905180010. <https://doi.org/10.5014/ajot.2015.017806>
- Tobin, M. C., Drager, K. D., & Richardson, L. F. (2014). A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders*, 8, 214–229. <https://doi.org/10.1016/j.rasd.2013.12.002>
- Weiss, J. A., Robinson, S., Fung, S., Tint, A., Chalmers, P., & Lunskey, Y. (2013). Family hardiness, social support, and self-efficacy in mothers of individuals with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7, 1310–1317. <https://doi.org/10.1016/j.rasd.2013.07.016>
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18, 1075–1083. <https://doi.org/10.1177/1049732308320112>
- World Health Organization. (2007). *International classification of functioning, disability and health—Children and youth version (ICF-CY)*.
- Yee, T., Magill-Evans, J., Zwaigenbaum, L., Sacrey, L. A. R., Askari, S., & Anaby, D. (2017). Participation measures for preschool children with autism spectrum disorder: A scoping review. *Review Journal of Autism and Developmental Disorders*, 4(2), 132–141. <https://doi.org/10.1007/s40489-017-0102-8>

---

**Julie Smith, DSc, OTR/L**, is Early Intervention Lead, Oklahoma County, Family Health Services, Oklahoma State Department of Health, Oklahoma City, OK. At the time of the study, Smith was Doctoral Student, Rehabilitation Sciences Program, College of Allied Health, University of Oklahoma Health Sciences Center, Oklahoma City.

**Nicole Halliwell, DSc, OTR/L**, is Assistant Professor, Occupational Therapy Department, Marjorie K. Unterberg School of Nursing and Health Sciences, Monmouth University, West Long Branch, NJ. At the time of the study, Halliwell was Doctoral Student, Rehabilitation Sciences Program, College of Allied Health, University of Oklahoma Health Sciences Center, Oklahoma City; [n.halliwell.dsc.otr@gmail.com](mailto:n.halliwell.dsc.otr@gmail.com)

**Amy Laurent, PhD, OTR/L**, is Codirector, Autism Level UP!, North Kingstown, RI. At the time of the study, Laurent was Adjunct Faculty, Department of Psychology, University of Rhode Island, Kingston.

**Jessica Tsotsoros, PhD, OTR/L**, is Associate Professor and International Experience Coordinator, Department of Rehabilitation Sciences, College of Allied Health, University of Oklahoma Health Sciences Center, Tulsa.

**Katelyn Harris, OTR/L**, is Occupational Therapist, Intervention Center for Early Childhood, Irvine, CA.

**Beth DeGrace, PhD, OTR/L, FAOTA**, is Director of Kids Ministry, Crossings Community Church, Oklahoma City, OK. At the time of the study, DeGrace was Associate Professor, Department of Rehabilitation Sciences, College of Allied Health, University of Oklahoma Health Sciences Center, Oklahoma City.

## Appendix

### *Semistructured Interview Questions*

Tell me about your family's experiences of doing things in your community/outside your home. What kinds of things does your family do? Some people find it helpful to think about places where other people are present, like going to church, the park, restaurants, the library, the movies, sporting events, etc.

Probes:

- What are your family's experiences like when you \_\_\_\_\_? / How would you describe your family's experiences?
- When you think about your family's experience with/doing \_\_\_\_\_, how do you feel about it?
- How has your family's experience with/doing \_\_\_\_\_, and how you feel about it, changed over time?
- When you think about your family's experience with/doing \_\_\_\_\_, how would you describe your sense of belonging or connectedness to or acceptance by other people, the setting, etc.?