



Parents' Perceived Benefits and Barriers to Participation in Group-Based Activity Programs for Children with Disabilities

Margaret Winters, OTS; Areum Han, PhD, OTR/L

Department of Occupational Therapy | University of Alabama at Birmingham

Emily Wheat, Youth Program Manager | The Exceptional Foundation

Introduction

- About 17.8% of children aged 3 to 17 in the United States have developmental disabilities (Zablotsky et al., 2019).
- Participation in group-based activities provides opportunities for social interaction, growth, and development in children with disabilities (Huus et al., 2021).
- However, children with disabilities participate less frequently in community activities and experience greater restrictions compared to their peers without disabilities (Arakelyan et al., 2020).
- Understanding the key impacts, facilitators, and barriers that children with disabilities encounter in group-based activities is essential for promoting positive participation opportunities for this population.
- This phenomenological study explored the lived experiences of parents of children with disabilities regarding the perceived benefits and barriers to their children's participation in group-based activities.

Methods

- Parents were recruited from the Exceptional Foundation, a non-profit organization that provides activity programs for children and adults with disabilities.
- Potential participants were invited via a recruitment flyer distributed through the Exceptional Foundation Youth Newsletter.
- The participants were six mothers whose children had the following diagnoses: three with Autism Spectrum Disorder, two with Down Syndrome, and one with Tetrasomy 18p.
- Each participant took part in a 30- to 60-minute individual interview.
- The interview data were analyzed using interpretative phenomenological analysis (Smith et al., 2022) through the following steps:
 - Transcription of interviews
 - Repeated reading of individual interviews to understand each participant's experiences and perspectives
 - Exploratory noting by the researcher to identify patterns and connections within each interview
 - Construction of broader experiential statements for individual transcripts.
 - Identification of connections across those statements to consolidate broader themes across participants

Results



Figure 1. Common Themes

Theme 1: Enhanced Quality of Life. Participants generally regarded participation in group-based activities as enhancing the quality of life for both their child and themselves.

- **Subtheme 1a: Socialization and Community Engagement**
 - "I like her [the child] being with a group and being with everybody else, whether they have special needs or not. ... It's just so important to be around people and in group settings." (Participant 4)
- **Subtheme 1b: Independence and Personal Growth for the Child**
 - "I can't help but assume that having Exceptional Foundation and those relationships has built so much confidence and contentment in him [the child]. By nature, he is such a happy child, but I know Exceptional Foundation has given him the security and the confidence to remain a peaceful person because he loves it so much." (Participant 6)
- **Subtheme 1c: Positive Impacts for Parents**
 - "I mean it's a comfort to me. It's a relief to me. It makes me very happy, because you know, if you didn't have these opportunities then it takes a lot of the parent's time to figure out what to do, where to take them, how to set things up, it can be a lot." (Participant 4)

Theme 2: Barriers to Participation. Children with disabilities and their parents faced various barriers when becoming involved in group-based activities. Parents reported having to overcome these obstacles to ensure their child's involvement in the community.

- **Subtheme 2a: Personal Challenges for Children**
 - "For my child personally, a barrier is about her following directions. She is a boundary pusher with rules, which can make it hard, but I wish the general population could understand not to make an assumption based on ability." (Participant 5)
- **Subtheme 2b: Parental Concerns and Barriers**
 - "All of these kids are so different. And when you group them together or expect that they are at the same that they are all at this kind of same level mentally, and they are not sometimes. And I think that's a problem for me sometimes. I want to always presume competence and talk to him like the age he is. Just because he doesn't say much, doesn't mean he's not there and doesn't mean he doesn't understand." (Participant 3)

Theme 3: Supportive Factors and Community Needs. Participants identified common facilitators and community needs to enhance their child's participation in group-based activities.

- **Subtheme 3a: The Role of Supportive Communities and Programs**
 - "I am just grateful. I really am, for all the people that are out there that care and put their time and energy into making it [the community] better all of the time." (Participant 1)
- **Subtheme 3b: Future Opportunities and Awareness**
 - "Every one of us special needs kids' parents think about what happens later in the future especially when we are gone. That would be huge for the community to have that [a group living situation for their children]." (Participant 1)

Discussion

- All participants stated that having their child involved in group-based activity programs, whether within or outside the Exceptional Foundation, increased both their child's quality of life and their own.
- Parents and their children had to overcome initial barriers to community involvement, including a lack of resources and feelings of anxiety.
- All participants emphasized the need for the community to provide more safe and inclusive environments for their children, particularly as they transition into adulthood.
- These findings align with previous literature and contribute to existing research by offering a unique perspective based on the personal lived experiences of caregivers.
- The results of this study are limited by the small sample size and the participants' similar demographics, including gender and geographic location. These limitations prevent the generalization of findings to the broader population of parents of children with disabilities.

Conclusion

- Previous literature and the results of this study highlight the importance of group-based activity participation for children with disabilities.
- Given the significant restrictions this population faces, communities and health care professionals, including occupational therapy practitioners, can use these findings as a tool to advocate for community-based health promotion and to inform individualized interventions.

References

- 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(4), 445–453. <https://doi.org/10.1111/dmcn.14402>
- Huus, K., Morwane, R., Ramaahlo, M., Balton, S., Pettersson, E., Gimbler Berglund, I., & Dada, S. (2021). Voices of children with intellectual disabilities on participation in daily activities. *African journal of disability*, 10, 792. <https://doi.org/10.4102/ajod.v10i0.792>
- Smith, J., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: Theory, method, and research* (2nd ed.). SAGE Publications.
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. *Pediatrics*, 144(4), e20190811. <https://doi.org/10.1542/peds.2019-0811>

Acknowledgement & Contact information

Special thanks to: Emily Wheat, Areum Han, Megan Carpenter, and the amazing staff and participants at the Exceptional Foundation!

Contact information: Margaret Winters, OTS; wintersm@uab.edu