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For the degree of: Doctor of Philosophy
Department: Interdisciplinary Health Sciences

Title: Factors Affecting Community Participation in Young Adults with Intellectual and Developmental Disabilities

Committee: Dr. Nickola Nelson, Chair
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Young adults with intellectual and developmental disabilities (IDD) participate less frequently in communities than other disabled and non-disabled peers (Verdonschot, de Witte, Reichrathe, Buntinx, & Crufs, 2009) even though they express a desire to participate (Kampert & Goreczny, 2007) and federal policy mandates community inclusion (Haertl, 2014). Participation in one’s community is linked to health and quality of life (World Health Organization, 2002). The broad goal of this three paper dissertation is to contribute to a deeper understanding of what facilitates and impedes community participation for young adults with IDD by (1) developing a new conceptual model, (2) evaluating a pilot intervention based on that model, and (3) investigating participation from the perspectives of adults with IDD.

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A review of literature about community participation reveals that existing models focus on the important interplay between the individual and his or her environment, but do not fully integrate the concept of activity as a bridge between the individual and environmental opportunities. Additionally, few models provide a process to guide intervention. The first paper in this dissertation offers a conceptual model that builds on existing models but incorporates activity and process to capture additional factors that may influence community participation.

The second paper reports a study that uses a pre- and post-intervention design to explore a pilot community intervention based on the conceptual model from paper one. In this study, four students in a post-secondary education program (all young adults with IDD; 2 males and 2 females) agreed to participate in weekly group intervention sessions. The Adolescent and Young Adult Activity Card Sort (Berg, McCollum, Cho & Jason, 2015) was used as the outcome measure. Students sorted pictures into piles before and after the four-week intervention to indicate activities in which they had participated within the past six months. The Wilcoxon Signed-Rank test showed no statistically significant differences in number of activities participated in pre and post intervention. When asked about barriers to activities they were interested in but had not participated in, students identified “never had the chance” and “difficulty with scheduling” most frequently.

The third paper provides results of individual semi-structured interviews about community participation experiences with the four students. Transcripts were analyzed using Cresswell’s (2013) phenomenological approach. This revealed nine themes that students described as influencing their participation experiences: physical safety, support, presence of an activity, logistical challenges, understanding context, family as community, identifying with previous communities, positive outcomes, and desired futures.

Results of the studies are consistent with prior research identifying activity as a key factor in community participation and the importance of support from family and others to encourage participation. Young adults with IDD showed interest in increasing community participation and were able to engage in interventions to help facilitate this, but recruitment and retention are challenges that need to be investigated further. The proposed conceptual model may help guide future research on interventions to increase meaningful community participation in young adults with IDD.