**Paper Title:** Exploring the Experiences of Social Isolation and Loneliness for Adults with Intellectual Disabilities and Extensive Support Needs

**Authors:** Marisa H. Fisher1, Elizabeth Liffley1, & Zach Rosetti

**Introduction:** Due to a lifetime of professional care (e.g., 1:1 assistance), adaptive challenges (e.g., non-speaking, safety concerns), and social exclusion (e.g., limited access to integrated education, employment, and activities), adults with intellectual disabilities and extensive support needs (ID-ESN; i.e., moderate to profound limitations in intellectual functioning and adaptive behavior, intensive daily support needs) may be at high risk for social isolation and loneliness (Gilmore & Cuskelly, 2014). Despite this, nearly all extant research on social isolation and loneliness has systematically excluded individuals with ID-ESN (Petroutsou et al., 2018). Such exclusion from research participation occurs because of misguided assumptions that individuals with ID-ESN cannot provide insight into their own experiences (Kooijmans et al., 2022) and because of the cognitive and social demands embedded in nearly all self-report instruments (Shogren et al., 2021). The current study evaluated the feasibility of three data collection procedures to improve and support participation of adults with ID-ESN in research about their experiences and perceptions of social isolation and loneliness.

**Method:** Four adults with ID-ESN (2 male/2 female) participated in the current study. Data were collected in urban, suburban, and rural settings. Participants were shadowed for an average of 7 hours across an average of 4 different activities each (e.g., day program, community events, work, home) to capture participant-initiated interactions, responses, body language, and facial expressions (e.g., affect). Following shadowing, participants completed one week of daily diaries at the end of each day to answer questions about their activities, who they were with, and how they felt across 4 periods of the day. Participants were provided a variety of support methods (e.g., verbally via Zoom, independently on iPad, parents as scribes, and using picture cards) to complete the diaries. Finally, semi-structured interviews were completed with each participant about their daily activities, perceptions and experiences of social isolation and loneliness, and their desired social lives. Interviews lasted about 30 minutes each and used information gained from the shadowing and daily diaries to yield more detailed and in-depth information. Participants responded verbally and by pointing to picture cards (e.g., about their activities, emotions), as appropriate.

**Results:** Participants were able to complete all data collection procedures and triangulation across datasets yielded valuable insight regarding participants’ social experiences. Participants understood the concept of loneliness (“I just don't like being lonely...makes me feel, you know, left out or something. And it’s hard”). Participants conceptualized feelings of loneliness as missing close friends, family members, and former teachers they no longer see regularly. An analysis of the daily schedules and daily diaries indicated that the participants had different experiences with social isolation and loneliness based on the social opportunities they were afforded. One participant was involved in few community-based activities during the week, and she reported (using picture cards) that she sometimes felt lonely at her community activities (e.g., a sports league) or when interacting or accompanied by with only a caregiver. Alternatively, the three other participants were busy with various activities throughout each day and most evenings. During shadowing, we observed various activities and differentiated preferred versus less preferred activities based on participant interactions, affect, and behaviors. One participant was shadowed at his day program during which he did not initiate or respond to others, and either sat at a table alone or played video games alone (i.e., appeared socially isolated). When shadowed at a disability-specific sports activity, however, he was observed initiating and responding to others, while laughing and joking around (i.e., appeared socially connected).

**Conclusion:** This study demonstrated feasibility of multiple data collection methods used for triangulation with adults with ID-ESN. Findings included clearly distinguishable social experiences that may be related to social isolation and loneliness across four adults with ID-ESN, demonstrating our ability to describe their experiences and use those findings to qualitatively characterize experiences of social isolation and loneliness for adults with ID-ESN. Recognizing the importance of reducing and preventing social isolation and loneliness experiences for adults with ID-ESN, we present the importance of identifying patterns across experiences and using innovative data collection approaches to better understand facilitators and barriers of social connection and belonging to improve outcomes for adults with ID-ESN.

**References:**

Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(3), 192–199. https://doi.org/10.1111/jppi.12089

Kooijmans, R., Mercera, G., Langdon, P. E., & Moonen, X. (2022). The adaptation of self-report measures to the needs of people with intellectual disabilities: A systematic review. *Clinical Psychology: Science and Practice*, *29*(3), 250–271. https://doi.org/10.1037/cps0000058

Petroutsou, A., Hassiotis, A., & Afia, A. (2018). Loneliness in people with intellectual and developmental disorders across the lifespan: A systematic review of prevalence and interventions. *Journal of Applied Research in Intellectual Disabilities*, *31*(5), 643–658. https://doi.org/10.1111/jar.12432

Shogren, K. A., Bonardi, A., Cobranchi, C., Krahn, G., Murray, A., Robinson, A., Havercamp, S. M., & The Nisonger RRTC on Health and Function. (2021). State of the field: The need for self-report measures of health and quality of life for people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 286–295. https://doi.org/10.1111/jppi.12386