**Symposium Title**: Understanding social, vocational, and service experiences of adults with IDD: Application of socioecological framework

**Chair**: Brianne Tomaszewski[[1]](#footnote-1) and Leann Smith DaWalt[[2]](#footnote-2)

**Discussant**: Bonnie Kraemer[[3]](#footnote-3)

**Overview**: Research on autistic adults and adults with intellectual and/or developmental disabilities (IDD) often focuses solely on the individual with the disability. However, there are multiple levels of influence on an individual's quality of life and wellbeing. This panel applies a socioecological framework to highlight the importance of an individual and their surrounding contexts, including an individual's microsystem (community), mesosystem(relationships among communities), exosystems (indirect environments), and macrosystems (cultural values and norms, such as available infrastructure). Libster and colleagues and DaWalt and colleagues highlight the social networks and caregiver support impacts on mental health (microsystems and mesosystems) in autistic adults. Loeb and colleagues highlight individual support needs and services (microsystems, mesosystems), services landscape (exosystems), and infrastructure/policy (macrosystems) when examining services and housing preferences in adults with IDD. Finally, Marx and colleagues highlight the use of GPS and GIS data (microsystems, mesosystems, exosystems) and their impact on the quality of life for adults with IDD. Together, this panel highlights innovative methodology to increase our understanding of the complexity of adult lives on IDD and its influences on mental health, quality of life, and service needs.

**Paper 1 of 4**

**Paper Title**: Dimensions of social support and quality of life among autistic adults

**Authors**: Natalie Libster[[4]](#footnote-4), Leann Smith DaWalt2 , Julie Lounds Taylor4

**Introduction**: Social support among autistic adults is associated with increased psychological wellbeing (e.g., Charleton et al., 2023). However, to tailor efficient and effective mental health interventions for autistic populations, it is important to understand *how* their social relationships are associated with their psychological health. According to the convoy model of social relations (Kahn & Antonucci, 1980), the structural characteristics, functions (i.e., types of support), and quality of one's social network are associated with wellbeing (Fuller et al., 2020). Findings from the general population have found that adults who have larger and more diverse social networks, more positive social relationships, more frequent contact with their social supports, and higher degrees of instrumental and emotional support from their social networks experience improved mental health outcomes (Ali et al., 2018; Hefner & Eisenberg, 2009; Merz & Huxhold, 2010; Perkins et al., 2012). However, the convoy model has not been used to examine dimensions of social support among autistic adults. To better inform mental health interventions for autistic populations, the current study aimed to identify associations between the structure, function, and quality of autistic adults' social relationships and their psychological quality of life.

**Method**: Autistic adults (N=146) between 18-36 years old (M=25.83) participated in the current study. Participants completed an online interview during which they were asked to list and describe up to 10 people in their social network who were close or important to them; they were then asked to rate their satisfaction with their social network. Participants also completed the World Health Organization Quality of Life Scale (WHOQoL-BREF; 1998) using an online survey platform. A linear regression analysis was implemented to determine associations between psychological quality of life (PQOL) and the following social network (SN) variables: 1) Number of people in SN; 2) Number of diverse relationships in SN; 3) Number of people adult hung out with over the past week; 4) Number of people adult chatted with online or on the phone over the past week; 5) Number of people adult talked to about a problem over the past week; 6) Number of people who helped adult over the past week; and 7) Satisfaction with SN. Age, sex, and IQ were included as covariates.

**Results**: Compared to adults who were dissatisfied with their social networks, those who were neutral (*b*=3.51, *p*=.04), satisfied (*b*=5.73, *p*<.001), and very satisfied (*b*=6.53, *p*<.001) with their networks had significantly higher PQOL. Meanwhile, adults who talked to more people in their networks about a problem reported significantly lower PQOL (*b*=-0.27, *p*=.04). The number of people adults talked to about a problem was significantly correlated with the number of personal stressors they experienced over the past year (*r*=0.38, *p*<.001) as measured on the Life Events Questionnaire (LEQ; Accurso et al., 2015). A post-hoc moderation analysis revealed a significant interaction between the number of personal stressors adults experienced and the number of people they talked to about a problem on PQOL (*b*=0.08, *p*=.03). Personal stressors had a more negative effect on PQOL among adults who talked to fewer people about their problems (*b*=-0.50, *p*=.001) compared to adults who talked to more people about their problems (*b*=-0.11, *p*=.34).

**Discussion**: Contrary to findings in the general population (e.g., Ali et al., 2018), the current study found that the structural and functional characteristics of autistic adults' social networks were not associated with psychological wellbeing. However, receiving support about a problem seemed to protect adults from the negative mental health outcomes associated with personal stressors. Adults who were more satisfied with their social networks also experienced heightened psychological quality of life, as has been demonstrated in the general population (Merz & Huxhold, 2010). Therefore, rather than solely focusing on increasing the quantity of autistic adults' social networks and the frequency of their social contacts, it is equally important for future interventions to facilitate the development of supportive relationships that meet their individual needs.

**References**

Accurso, E. C., Garland, A. F., Haine-Schlagel, R., Brookman-Frazee, L., & Baker-Ericzén, M. J. (2015). *Life Events Questionnaire (LEQ)* [Database record]. APA PsycTests.

Ali, T., Nilsson, C. J., Weuve, J., Rajan, K. B., & De Leon, C. F. M. (2018). Effects of social network diversity on mortality, cognition and physical function in the elderly: a longitudinal analysis of the Chicago Health and Aging Project (CHAP). *J Epidemiol Community Health*, *72*(11), 990-996.

Charlton, R. A., McQuaid, G. A., & Wallace, G. L. (2023). Social support and links to quality of life among middle-aged and older autistic adults. *Autism, 27*(1), 92-104.

Fuller, H. R., Ajrouch, K. J., & Antonucci, T. C. (2020). The convoy model and later‐life family relationships. *Journal of Family Theory & Review*, *12*(2), 126-146.

Hefner, J., & Eisenberg, D. (2009). Social support and mental health among college students. *American Journal of Orthopsychiatry*, *79*(4), 491-499.

Kahn R. L., & Antonucci T. C. (1980). Convoys over the life course: Attachment, roles, and social support. In Baltes P. B., Brim O. (Eds.), *Life-Span Development and Behavior* (Vol. 3, pp. 254–283). New York: Academic Press.

Merz, E. M., & Huxhold, O. (2010). Wellbeing depends on social relationship characteristics: Comparing different types and providers of support to older adults. *Ageing & Society*, *30*(5), 843-857.

Perkins, M. M., Ball, M. M., Kemp, C. L., & Hollingsworth, C. (2013). Social relations and resident health in assisted living: An application of the convoy model. *The Gerontologist*, *53*(3), 495-507.

The WHOQOL Group (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*(3), 551-558.

**Paper 2 of 4**

**Paper Title**: Sources of support for activities of daily living for autistic adults

**Authors**: Leann Smith DaWalt2 ,Marsha Mailick2, Julie Lounds Taylor4

**Introduction**: Increasing attention is being given to understanding life course outcomes for autistic adults. Less is known, however, about the contextual factors that support daily wellbeing. The present study examined the sources of support for autistic adults in completing activities of daily living and tested if the amount of support differed for those who did and did not co-reside with their parents. We also explored if those with unmet needs in activities of daily living had different mental and physical health outcomes than those who had adequate supports.

**Method**: Autistic adults (N=148) were drawn from an ongoing longitudinal study of autistic adults. Participants were 64.2% male with an average age of 26.10 years (SD=4.75); 95% had average or above average intellectual functioning. Participants completed the Waisman Activities of Daily Living (WADL; Maenner et al., 2013) indicating their level of independence in key domains including household tasks (e.g., washing dishes, laundry), personal care (e.g., grooming, dressing), food preparation (e.g., preparing simple foods, preparing complete meal), and instrumental (e.g., errands, daily finances). For each task that adults did not perform independently, they reported who helped them with those tasks. The non-mutually exclusive sources of help included mother, father, sibling, other relative, neighbor/friend, informal paid support, disability service, general service, other, and not receiving help from anyone. We classified those who did not perform at least one task independently and did not receive help for that task as having an unmet ADL need. Autistic adults also completed the World Health Organization Quality of Life Scale (WHOQoL-BREF; 1998), the Beck Depression Inventory – II (BDI-II; Beck et al., 1996), and a self-rated health measure on a 4-point scale (poor health to excellent health). We compared autistic adults who lived with their parents (n=91) to those who did not live with their parents (n=57) on the amount of support received from each type of supporter. We also compared the QOL, mental health, and physical health outcomes for those who reported having at least one unmet ADL need (n=39) to those whose ADL needs were fully met (n=109).

**Results**: Results indicated that few autistic adults in this sample were fully independent in ADL (14.2%). Level of independence varied, however, by the type of daily living activity. Almost all of the autistic adults were fully independent with personal care (95.9%) and the majority were fully independent in food preparation (58.8%). Household tasks and instrumental ADLs were less likely to be completed independently (31.1% and 27.7% of sample completing fully independent, respectively). Notably, over a quarter of adults had at least one unmet ADL need (26.4%) with the vast majority of those unmet needs being in the area of household tasks.

For the whole sample, parents were the most common source of support for completing ADLs when help was needed, with mothers supporting 2.34 and fathers supporting 1.51 of the 16 ADL items queried, on average. Support was notably lower from the other support categories (e.g., <.50 ADL items being supported). Compared to those who did not live with their parents, autistic adults who were co-residing reported receiving more ADL support from mothers (3.03 vs 1.23, p<.001), fathers (2.12 vs .53, p<.001), and siblings (.74 vs .18, p<.001) and less support from neighbors/friends (.09 vs .33, p<.05). There were no statistically significant differences between the two groups in terms of receipt of support from other relatives, informal paid supports, disability services, general services, or not receiving help from anyone. Those who had unmet ADL needs reported significantly poorer QOL (p<.01), greater depressive symptoms (p<.05), and poorer physical health (p<.001) than those whose ADL needs were met.

**Discussion**: Findings highlight parents as significant sources of support for autistic adults without intellectual disability, particularly in the areas of completing household tasks. Those without support for completing ADLs may be particularly vulnerable for poorer mental and physical health, suggesting important areas for future research into causal mechanism and avenues for intervention.

**References**

Beck, A. T., Steer, R. A., & Brown, G. (1996). *Beck Depression Inventory–II (BDI-II)* [Database record]. APA PsycTests. <https://doi.org/10.1037/t00742-000>

Maenner MJ, Smith LE, Hong J, Makuch R, Greenberg JS, Mailick MR. (2013) Evaluation of an activities of daily living scale for adolescents and adults with developmental disabilities. *Disability and Health Journal, 6*(1),8-17.

The WHOQOL Group (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*(3), 551-558.

**Paper 3 of 4**

**Paper Title**: The impact of living situation and support needs on service use and housing preferences for adults with IDD

**Authors**: Hayden Loeb1,Shannon C. LaPoint[[5]](#footnote-5), Elena Lamarche1, Alison Marx1, Brianne Tomaszewski1

**Introduction**: The evolving support needs of individuals with intellectual and/or developmental disabilities (IDD) are not met with appropriate services in adulthood (Shattuck et al., 2011; Heller, 2017). Service utilization may be impacted by living situations and support needs (Stancliffe et al., 2010; Tichá et al., 2013). Adults with IDD living with family members are less likely to access preventative healthcare services compared to other housing situations(Tichá et al., 2013). Most individuals with IDD and high support needs have difficulty expressing their choices in housing and service use. (Stancliffe et al., 2010). The purpose of the present study was to examine further how support needs impact service use and housing preferences for this population. The following research questions were addressed: 1) Does living situation impact service use and housing preferences? 2) Do support needs impact service use and housing preferences?

**Method**: Data were gathered using a mixed methods approach that included survey and interview data. The survey included 82 caregivers of individuals with IDD, and a subset of adults with I/DD (n = 13) completed a semi-structured interview. Adults with I/DD ranged in age from 18-54 years (M = 29.00, SD = 7.43). Caregivers provided information about their loved one's support needs, services received, and preferred future housing. Adults with IDD answered questions about their living situation and preferred future housing. Interview responses were analyzed using Braun & Clarke's (2006) inductive thematic analysis framework. Group differences for adults with IDD living with (67%) and without (33%) family members were examined via independent two-sample t-tests. Logistic regressions were performed to examine the impact of support needs on service receipt and housing preferences.

**Results**: Adults with IDD not co-residing with relatives were significantly more likely to use services (*t*(53) = 2.16, *p* = .036, *d* = .50) compared to those living with relatives, specifically employment, community living, and community transition services. Mean support needs scores were calculated for each adult with I/DD, then categorized into low (30.5%), moderate (32.9%), and high (36.6%). There were no significant differences in living situation across the three groups. Individuals with low support needs were more likely to have no unpaid supervision, OR= 13.3, *p* = .04, or several hours a week, OR = 21.7, *p* =.01 compared to individuals with high support needs receiving 24 hours of unpaid support. Individuals with high support needs are more likely to receive the services via the Innovations Waiver than individuals with other support needs, OR=3.6, *p* = 03. Finally, independence (*"Well, I would like to live independently, in an apartment with roommates"*) and access to services *("I would like to live in an apartment for adults with disabilities in a public transportation area*") were two interview themes related to housing preferences of adults with I/DD.

**Discussion**: Results show that adults with IDD living without their relatives reported increased use of non-residential services compared to those living with their relatives. Adults' living situation was independent of support needs and impacted housing preferences; during interviews, many adults with IDD who lived with family members expressed a desire to live on their own. This underscores the importance of exploring non-familial housing options for adults with IDD to facilitate both community participation and self-determination in adulthood. Support needs impacted service use but not housing preferences. Adults with IDD emphasized that accessible services are essential when considering future housing, consistent with previous research (Friedman, 2019). There is an impetus to increase access to not only residential services but also all services relevant to adulthood for individuals with IDD in order to optimize opportunities for self-determined living.

**References**

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Friedman, C. (2019). There’s no place like home: A national study of how people with intellectual and/or developmental disabilities and their families choose where to live. Washington, D.C., and Towson, MD: The Arc of the United States and CQL The Council on Quality and Leadership.

Heller, T. (2017). Service and Support Needs of Adults Aging with Intellectual/Developmental Disabilities. In *Testimony to the US Senate committee on aging, working and aging with disabilities: from school to retirement.*

Shattuck, P., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-High School Service Use Among Young Adults with an Autism Spectrum Disorder. *Arch Pediatr Adolesc Med., 165*(2), 141-146. doi:10.1001/archpediatrics.2010.279

Stancliffe, R., Lakin, K., Larson, S., Engler, J., Taub, S., & Fortune, J. (2010). Choice of living arrangements. *Journal of Intellectual Disability Research, 55*(8), 746-762. https://doi.org/10.1111/j.1365-2788.2010.01336

Tichá, R., Hewitt, A., Nord, D., & Larson, S. (2013). System and Individual Outcomes and Their Predictors in Services and Support for People with IDD. *Intellectual and Developmental Disabilities, 51*(5), 298-315. https://doi.org/10.1352/1934-9556-51.5.298

**Paper 4 of 4**

**Paper Title**: Using GIS and GPS, service needs, and daily living skills to understand quality of life

**Authors**: Alison Marx1, Dara Chan[[6]](#footnote-6), Hayden Loeb1, Brianne Tomaszewski1

**Introduction**: Disability support services, services providing health, social care, and advocacy for people with intellectual and/or developmental disabilities (IDD) are crucial to promoting health and wellbeing (Lakhani et al., 2019). Disability support services often promote community involvement of people with IDD through programs that aim to improve community participation (Chenoweth et al., 2011). However, in North Carolina, 54% of stakeholder respondents reported a lack of adequate support services across the state(Technical Assistance Collaborative, 2021). The use of subjective (surveys) and objective( Global Position System [GPS] and Geographic Information System[GIS]) data may provide in-depth information to identify individual and environmental barriers and supports for community participation for adults with IDD in North Carolina.

**Method**: 36 adults with IDD ages 19-48 participated in the study (Mean age= 25.8 years SD= 7.29). Adults with IDD completed surveys on demographic information, quality of life using the World Health Organization Quality of Life and Disabilities Module, and daily living skills using the Waisman Activities of Daily Living Scale. GPS data, daily social diaries, and a semi-structured interview were utilized. Information was collected through GPS device tracking and diaries regarding the participants' total number of unique locations visited, types of activities, and time spent away from home. Activity space was also analyzed using GIS mapping data to examine the relationship of accessibility to actual resource use and community participation outcomes with adults with ID/DD. Linear mixed models were conducted to examine how daily living skills, services received, unmet service needs, occupation, living circumstances, number of unique locations, and activity spaces were related to overall quality of life and domains of quality of life.

**Results**: Receiving vocational rehabilitation services in adulthood was associated with higher overall quality of life, B= 17.54, SE = 7.35, *p* = .02, physical quality of life, B = 27.45, SE= 6.95, *p* < .001, psychological quality of life, B = 25.9, SE = 11.52, *p* =.04. Needing mental health services in adulthood was associated with poorer overall quality of life, B= =15.9, SE=7.43, *p* = .04, psychological quality of life, B= - 21.6, SE= 9.86, *p* = .04, and social quality of life, B= -21.8, SE = 10.0, *p* = .04. Needing transportation services in adulthood was associated with lower environmental quality of life, B = -24.75, SE = 10.4, *p* = .03. A fewer number of unique locations an adult visited was associated with higher quality of life disabilities, B= -2.35, SE= .87, *p* = .02, and higher psychological quality of life, B = -2.28, SE= 0.88, *p* = .02. Daily living skills were associated with higher overall quality of life, B = 1.06, SE = -.41, *p* = .02. Activity spaces were not associated with any variables.

**Discussion**: The correlation between receiving vocational rehabilitation (VR) services and higher overall, physical, and psychological quality of life suggests that employment services are vital to the wellbeing of adults with IDD. Employment of individuals with IDD has demonstrated positive effects on self-esteem, self-confidence, and independence levels (Almalky, 2020). Individuals with IDD have at least the same prevalence of mental health disorders as the general population and are possibly more susceptible to some mental health disorders (Ailey, 2003). However, there is a noted lack of providers, services, or capacity to serve people with IDD with mental health concerns (Lamar, 2020). Our findings indicate that this unmet need negatively impacts an individual's overall, psychological, and social quality of life. Transportation services are also identified as an important need for adults with IDD. These findings support the idea that there is a critical need for improvement of services for individuals with IDD to ensure a high quality of life. Additionally, the association between fewer unique locations visited and higher disability and psychological quality of life could indicate the positive impact of routine on the wellbeing of adults with IDD. Limitations of our research include a small sample size, a small representation of rural communities, and an inability to control other life factors, such as health conditions during the research study, which could have impacted their movement in the community.

**References**

Ailey, S. (2003). Beyond the disability: recognizing mental health issues among persons with intellectual and developmental disabilities. *Nursing Clinics, 38*(2), 313-329. https://doi.org/10.1016/S0029-6465(02)00048-8

Almalky, H. (2020). Employment outcomes for individuals with intellectual and developmental disabilities: A literature review. *Children and Youth Services Review, 109,* 105052. https://doi.org/10.1016/j.childyouth.2019.104656

Chenoweth, L., Clements, N. (2011). Participation Opportunities for Adults With Intellectual Disabilities Provided by Disability Services in One Australian State. *Journal of Policy and Practice in Intellectual Disabilities, 8*(3), 172-182. https://doi.org/10.1111/j.1741-1130.2011.00307.x

Lakhani, A., Parekh, S., Gudes, O., Grimbeek, P.M., Harre, P., Stocker, J.K., & Kendall, E. (2019). Disability support services in Queensland, Australia: Identifying service gaps through spatial analysis. *Applied Geography, 110*, 102045.

Lamar, R. R. (2020). National needs assessment: Mental health services for people with intellectual and developmental disabilities. *Mental Health and Developmental Disabilities National Training Center*. https://mhddcenter.org/wp-content/uploads/2020/04/MHDD-National-Needs-Assessment-2020.pdf

Technical Assistance Collaborative, & Human Services Research Institute (2021). *An assessment of the North Carolina Department of Health And Human Services' system of services and supports for individuals with disabilities*. https://www.ncdhhs.gov/media/12607/download?attachment

1. TEACCH Autism Program, University of North Carolina at Chapel Hill [↑](#footnote-ref-1)
2. Waisman Center, University of Wisconsin-Madison [↑](#footnote-ref-2)
3. San Diego State University [↑](#footnote-ref-3)
4. Vanderbilt University Medical Center [↑](#footnote-ref-4)
5. University of Florida [↑](#footnote-ref-5)
6. Division of Clinical Rehabilitation and Mental Health Counseling, Department of Health Sciences, University of North Carolina at Chapel Hill [↑](#footnote-ref-6)