

Research Statement | Amy Pei-Lung Yu, MSW

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Intellectual and developmental disabilities (IDD) are lifelong conditions that impact the quality of life of both the individual with IDD and their families. In the U.S., approximately 72% of the 7.39 million individuals with IDD live at home with family members who provide most of the support to individuals with IDD. Family members often juggle many responsibilities while providing unpaid support, which is associated with high levels of physical and emotional caregiver stress. As such, there is an urgent need to invest in and expand training and support for family caregivers, especially those from racially and ethnically minoritized groups who often experience systemic barriers when seeking services for their relatives with IDD and social support for themselves. Using socio-ecological frameworks and intersectional approaches, my program of research focuses on 1) examining the health and wellbeing of individuals with IDD and their family caregivers, 2) investigating the contextual factors that may hinder or facilitate how family caregivers provide support to the individual with IDD across the lifespan, and 3) developing culturally relevant interventions that address health inequities, strengthen family-professional partnerships, and promote advocacy. Ultimately, I aim to inform practices and policies that improve the sustainability of family caregiving in underserved groups.

Research Trajectory. My research agenda is inspired by a decade of practice experience as a direct support professional (DSP), DSP supervisor, social worker, and researcher in the field of IDD. Specifically, my research activities focused on improving the quality of life (QoL) of adults with IDD and chronic illnesses. I spent many years co-developing Taiwan's first community-living person-centered service model that was grounded in a QoL framework (Schalock & Verdugo, 2022). To accomplish this, I wore many professional hats in a 24-hour residential center to test, adapt, and revise our previous service model, which allowed me to gain valuable experience working at the micro-level (e.g., providing direct support services), meso-level (e.g., offering training and support to families and staff) and macro-level (e.g., advocating for long-term support and care policies). From this work, I co-authored several publications both in English and Chinese in outlets such as *Journal of the Society for Social Work and Research*, *Research in Developmental Disabilities*, *Journal of Intellectual Disabilities*, *NTU Social Work Review*, and *Journal of Disability Research*. In addition, I collaborated on the translation and cultural adaptation of two internationally validated assessment scales, the Personal Outcomes Scale (POS) and San Martin Scale, with the POS being used across many community organizations in Taiwan. This is significant as the POS is one of the first assessment scales used in Taiwan that evaluates the QoL of adults with IDD instead of the individuals' deficits.

However, I faced immense challenges in model development as I struggled to retain staff that could continuously deliver quality support and services. In a meta-synthesis, I found that perceived unfairness and injustice in the organizational culture among staff contribute to this persistent high turnover (Yu, 2024), and that this in turn, impacts the quality of life of individuals with IDD. Despite this, I observed that families had to institutionalize their family member with IDD at an older age because caregivers could no longer provide care and support to their relatives at home. These experiences have profoundly transformed the way I think about support and service provision, in that there should be more focus on supporting family caregivers early on so that individuals with IDD would be able to receive sustainable and quality support while remaining at home.

Health Outcomes of Individuals with IDD and Family Caregivers. I matriculated into the Doctoral Program in Social Work at The University of Texas at Austin (UT Austin) to examine the health and wellbeing of individuals with IDD and their family caregivers from underserved groups and investigate the contextual factors that impact care/support provision to the individual with IDD. To understand the health effects of overweight and obesity among individuals with IDD from marginalized groups, I co-authored a publication in *Frontiers in Pediatrics* evaluating the associations between parenting strategies and BMI percentile among Latine/x children and youth with IDD (Magaña et al., 2023). We found that increased parental use of controlling dietary strategies was associated to a lower BMI percentile in Latine/x children with IDD, in contrast to literature on non-

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disabled children. This is significant as it underscores the need to employ disability- and culturally sensitive dietary approaches when managing weight among culturally diverse children with IDD.

Contextual Factors that Impact Care/Support Provision. To gain a deeper understanding of contextual factors that impact care/support provision, I co-created a conceptual model that describes the participatory process of co-developing a culturally tailored intervention with promotoras and Latina caregivers of children with IDD. It also includes engagement and retention strategies that were derived from the lived realities between promotoras and participants. This manuscript is currently in the revise and resubmit stage. Furthermore, to understand more about the dynamics of family caregiving, I conducted a scoping review of fathers, siblings, and grandparents as caregivers of family members with IDD. I found a glaring gap in the literature on culturally diverse fathers, siblings, and grandparents as caregivers of individuals with IDD and how caregivers work together to support their family member with IDD, particularly those who aged out of the school system. These findings spurred my dissertation's focus on exploring the dynamics of caregiving and support in immigrant families of adults with IDD and how they are shaped by their context, including cultural, social, political, developmental, societal, and environmental factors. Using the family system, life course, and socioecological perspectives, my dissertation investigates 1) the experiences of Chinese American family members who support an adult with IDD, 2) how family roles and interactions shape the support provided to the adult with IDD, 3) how the contextual and cultural factors shape the support provided to the adult with IDD, and their support needs moving forward.

Culturally Relevant Interventions. As part of a two-site project funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), I have been working closely with collaborators at the University of Illinois Chicago to develop, manualize, and test a health promotion intervention protocol and a culturally tailored curriculum that consists of ten individual sessions and three group sessions. To prepare our promotora (community health workers) for intervention delivery, I have developed and led intensive trainings focused on topics such as rapport-building, cultural humility, professionalism, and techniques for tailoring the intervention. At the same time, I have also been leading the UT Austin assessment team and co-managing both the quantitative and qualitative data. Upon completion of the pilot study, I tested the program and evaluation tools for their feasibility and acceptability alongside my colleagues, and revised the curriculum, trainings, and protocols for the current RCT. I now lead the research team in preparing for the pilot study manuscript. Our preliminary outcomes show promising results in promoting healthy lifestyles for Latine/x family members and their children with IDD. I have also published a first-authored manuscript evaluating the effect of a randomized waitlist-control trial of a culturally tailored parent education program in reducing depressive symptoms among Latina mothers of autistic children in *American Journal of Intellectual and Developmental Disabilities*. Findings suggest that a culturally tailored intervention led by peer mentors was effective at reducing symptoms of depression among participants both immediately after the intervention and four months post-intervention.

Future Directions. Based on potential significance of my dissertation and my promising research trajectory, I was awarded the UT Austin Continuing Fellowship to fund my dissertation. My dissertation will substantiate specific needs for future investigations in Chinese American immigrant families of adults with IDD. Findings will inform the development of family level culturally relevant interventions, guide clinicians in providing responsive support, and promote policies that are inclusive of the needs of immigrant families of adults with IDD. Furthermore, I plan to conduct and disseminate my research to the community by working alongside individuals with IDD, family caregivers, and professionals in developing research protocols, implementing programs, and improving service models, particularly in the areas of healthy aging and advocacy. Possible funding opportunities include the Disability and Rehabilitation Research Program under NIDILRR, the National Institutes of Health (NIH) R34, and other national, state or private organizations to support the pilot study of the interventions. I will also apply for the K series award from the NIH to gain further training.