Title: The Effectiveness of a Sibling Leadership Program for Adult Siblings of Individuals with Intellectual and Developmental Disabilities (IDD)

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Introduction: Siblings have longest-lasting familial relationship (Cicirelli, 1995). Siblings often fulfill non-normative roles from childhood; such roles range from caregiver, advocate, and therapist (Lee & Burke, in press). Some research indicates that siblings of individuals with IDD also need support with respect to their adjustment to disability, sibling relationship, future planning, and advocacy. For example, Meyer and Vadasy (1994) developed “sibshops” to help young siblings of individuals with IDD. However, there is a lack of intervention studies which support adult siblings of individuals with IDD. The purpose of this study was to develop and pilot-test the effectiveness of a leadership and support program for adult siblings of individuals with IDD.

Method: A total of 21 adult siblings participated in this intervention; on average, they were 36 years of age ranging from 21 to 67. The majority (71.4%) were female siblings; further, the participants were mostly highly educated (66.7%) and White (85.7%). We conducted a repeated measure ANOVA comparing pre-, post-, and follow-up data for siblings who participated in the sibling leadership program. The program was comprised of 15 hours of instruction and technical assistance to empower participants to advocate for their own brothers and sisters with IDD as well as other siblings. Using a repeated measure ANOVA, we tested the impact of the program on: participation in training activities (Burke et al., in press), empowerment (Koren et al., 1992), advocacy (Burke, Arnold, & Owen, 2015), motivation to impact change (Perry, 1996), and connectedness (Taylor et al., 2017).

Results: At post-intervention, participants demonstrated significantly greater empowerment, $F(2, 24) = 4.702, p = .01, ES = .46$ and greater connectedness with other siblings, $F(2, 24) = 2.728, p = .05, ES = .30$. There were no significant differences with respect to participation in training activities, advocacy, and motivation. Also, there were no significantly differences at the follow-up time point.

Discussion: This pilot study indicates that the sibling leadership and support program may be helpful for adult siblings of individuals with IDD; future research should include randomized control trials and larger samples to determine the effectiveness of sibling leadership programs. Further, sibling leadership and support programs may need to include additional technical assistance to maintain the effects.

References/Citations: