

To Plan or Not to Plan: The Development of a Therapeutic Intervention to Assist Families of Individuals with Cognitive Disabilities in Late-Life Planning

Sara H. Qualls, Heidi S. Layton, Ashley A. Williams, Kimberly E. Hiroto, and Shannon Foster

No services are available to help caregivers of persons with cognitive disabilities (CD) cope with age-related changes that reduce functioning. Recent medical advances have increased life expectancy for persons with CD to their 60s and 70s. Subsequently, this cohort is unprepared for late-life care and unaware of the transition(s) in care that will likely occur. Research suggests that families are not planning or preparing well for these transitions. Indeed, less than 1/3 of families have a legal succession plan in place and fewer have made the kinds of personal plans that ensure continuity of care, relationships, and life supports (Heller & Factor, 1991). The present intervention is designed to provide counseling, consultation, education, cognitive screens, and referral services with the final goal of making and distributing a letter of intent. All persons with a CD and their families or staff members are welcome participants. Additional goals include parental communication with all involved parties about one's wishes for their adult son or daughter with a CD. This process will be completed by focusing on the carer's wishes for their adult child and how those wishes can best be served after a transition in care has occurred. Overall, this intervention is designed to assist parents and care staff in creating a personal legacy for their loved one with a CD.