

The Transition into Aging with a Cognitive Disability:  
Preparing Families for Late-Life Caregiving  
University of Colorado at Colorado Springs  
Layton, H.S., Foster, S.M., Qualls, S.H.

When adults with cognitive disabilities (CD) leave the school system between the ages of 18 and 21, they have no societal structures to assist them in “launching” into adulthood, navigating the transitions of adulthood, or facing old age. Families whose children without CD embark on this transition rely extensively upon colleges and work settings to socialize their children into adulthood, but families of persons with a disability have no societal structures providing comparable support. Families may turn to the service delivery system but it is neither designed nor funded to provide comprehensive support for adult development; any more than it was designed to do so for child development, a period when the schools play an enormous socializing role. Only a bare bones, grossly inadequate service system is funded to support persons with CD after they leave the school-centered service delivery system. In adulthood, no societal structure promotes continued development through the aging process, leaving the entire task of prompting, organizing, and supporting adult development to the family.

Families face this transition essentially alone, without social guidance from society at large, without social structures to support the launching phase of family development, and typically without access to the service system due to extraordinary underfunding. Parents typically maintain responsibility for all aspects of their adult child’s development: social, cognitive, physical, occupational, health, etc. Obviously, parents have no training to take on this massive role. Perhaps more shocking to those who have not lived the experience, families have no resources to guide them through this transition.

We propose to develop and field test a four part intervention program designed to address this dramatic need by (a) giving families information about the functional abilities of their loved one, (b) providing guidance about how to apply that information in everyday life to maximize independence, (c) counseling as needed to assist the family in accomplishing developmental tasks, and (d) providing information about resources to support their efforts. Specifically, we propose to provide: (a) a cognitive profile of strengths and deficits in the person with CD (and in parents with age-related cognitive decline, if needed); (b) recommendations to family carers about how to maximize independence using strengths, based on the cognitive profile; (c) counseling with the family carer to guide the implementation of recommendations along with preparation for future family caregiving; and (d) a resource list of service partners. In other words, we propose to build into the ongoing service system at The Resource Exchange (our local CCB) a program of assessment and interventions that helps families deal with the immediate age-related declines in the midlife adult with a CD, while developing and initiating plans for the future.