

Factors that Affect Families' Decision-Making about Late-Life Transitions for Individuals with Intellectual Disabilities

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Parents of individuals with intellectual disabilities (ID) historically have not had to plan for the end of life care for their sons and daughters with ID due to their brief life spans. As quality of life has increased longevity, the need for families to make plans for transitions in care from the parents to other carers has emerged. To date, research has shown that families make few plans other than adding their son or daughter's name to a waitlist for housing in anticipation of changes that will occur as parents age. A qualitative research method, ethnography, was used to gather information from families as they think about transitions in late-life care for their family members with ID. Themes families discussed included parents' unwillingness to burden their other children, siblings' lack of knowledge about the care needs of their siblings with ID, and siblings' distrust and poor understanding of ever-changing service delivery systems. Additional themes revolved around mothers' historical roles as carers for their sons and daughters with ID and their reluctance to shift to a family structure that includes more shared responsibilities among family members. In addition, periodic ideological differences between parents, siblings, and service delivery systems in terms of a supposed dichotomy between autonomy and safety for the individual with ID interrupted conversations about transitions in care responsibilities.