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Conference Abstract

Consumer-directed support: Impact of hiring practices on adults with ID/DD and families

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Abstract

Aim: Consumer-directed long-term care services have grown dramatically over the past decade, both in the US and internationally. Flexibility in hiring, including the ability to hire family and friends, is a key determinant of interest in consumer direction. This study examined the differential experiences and outcomes for people with intellectual and developmental disabilities (ID/DD) and their families receiving consumer-directed services based on the type of personal support worker (PSW) hired (family, friends, agency staff, non-agency staff).

Method: The data includes responses from written surveys sent to families in the Illinois Adult Home Based Support Services Program (a Medicaid waiver program) along with interviews conducted with adults with ID/DD in the program. The measures filled out by 446 families using the Family Satisfaction with Consumer Directed Supports survey (and consumer interview) were used for analysis of satisfaction with the PSW, self-efficacy in hiring and managing the PSW, and the self-determination and community participation of the adults with ID/DD.

Results: PSWs were most likely to be family members followed by agency staff, friends, and non-agency staff. There were no significant differences between groups on demographics of the person with ID/DD or of the primary caregiver, with the exception of caregiver gender and household income. Families who had lower income were less likely to hire agency staff. Ancova analyses controlling for these two factors indicated significant differences between different types of PSWs regarding the family caregiver's satisfaction with their PSW and their self-efficacy in hiring and managing their PSWs. Participants who hired a family member reported higher levels of satisfaction, followed by friends and staff. However, family caregivers felt the highest amount of self-efficacy when they hired non-agency staff followed by friends, family, and agency staff. There were no significant differences in the self-determination and community participation of the adult with disabilities.

Conclusions: These findings suggest that families within a consumer directed program are most satisfied when they hire family and friends as PSWs. However, when they hire non-agency staff they feel better able to manage the PSWs. Also, the extent to which families hire other family members as PSWs is influenced in part by economic considerations. Furthermore, there is little evidence that hiring family members restricts the self-determination and community participation of adults with ID/DD.

Keywords

aging, intellectual disability, consumer-directed, person-directed, community care, social care

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