Title: Who Helps? Characteristics and Correlates of Informal Supporters to Adults with Intellectual and Development Disabilities

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Introduction: With diminishing funding for state agencies and long waiting lists for services, it is estimated that only 1 in 4 adults with intellectual and developmental disabilities (IDD) receive formal, or paid, supports (Braddock et al., 2015; Larson et al., 2015). Instead, individuals and families are turning to informal, or natural (i.e., unpaid) supports. While much discussed, informal supports have been the focus of little research. This study addressed the following 3 questions: (1) Who is providing informal supports to adults with disabilities and does the number of supporters differ across the life areas of recreation, employment, and housing?; (2) Who are nonfamily informal supporters and are they connected to family supporters?; and (3) Which characteristics of the adult with IDD, parents, or siblings relate to the number of informal supporters in each life area?

Method: Participants included 657 adult siblings of individuals with disabilities who responded to a national, web-based survey. Sibling respondents were predominantly female, White, and well-educated. Although average ages were in the mid-30s, respondent ages ranged from 18 through 75 years. Participants resided across 42 states. Individuals with disabilities (i.e., the brothers and sisters of participants) were primarily male, and ranged in age from 20 through 74 years. The most common disabilities included developmental disability; learning disability; speech language impairment; autism; intellectual disability; physical disability; Down syndrome; and mental health disability.

Using McNemar tests, we compared overall percentages of any support across the three areas and of percentages of each individual supporter (e.g., sibling respondent, parents) from Recreation vs. Employment vs. Housing. We also compared within each individual area to determine whether supporters were more often sibling respondents than parents, other siblings, or non-family members. Using repeated measures ANOVAs, similar analyses were performed to compare the total numbers of supporters across the three areas. Write-in responses describing non-family informal supporters were coded using constant comparative analysis and emergent coding. Furthermore, we examined the correlates of the number of informal supporters in the areas of Employment, Housing, and Recreation first separately and then through multiple regression analyses. We examined characteristics of the sibling, parents, and individual with disabilities as potential correlates.

Results: Overall, 97.9% of adults with IDD received some level of informal support; 28.5% received support in only two life areas and 59.1% in all three areas. Comparing across areas, higher percentages received support in Recreation and Housing, as opposed to Employment. Similarly, the total numbers of supporters also significantly differed across areas, with the total numbers of Recreation supporters greater than total supporters in either Housing or Employment.

Across the areas of Recreation, Employment, and Housing, 9 identical categories emerged from coding of nonfamily supporter write-in responses. These categories included: (1) Professional supporters; (2) Friends; (3) Staff; (4) Agencies; (5) Caregivers; (6) Church; (7) Coaches; (8) School; and (9) Acquaintance-Other. Although the survey explicitly asked participants to list only unpaid non-family supporters, many respondents listed (potentially) paid supporters. Additionally, non-family informal supporters most often occurred in the presence of family supporters.

Across all three domains, significant correlates related to the mother’s age, mother’s health, and parents’ ability to parent their offspring with disabilities. In every case, fewer informal supporters were present if mothers were older, if parents were in poorer health, or parents were currently less able to care for their offspring with disabilities. As these various age-related variables correlated together, we entered the most highly correlated variable, parents’ current ability to care for the offspring with disabilities, into regression analyses. Parent caregiving ability related to the number of informal supporters with respect to the recreation and employment domains.

Discussion: Taken together, these findings tell us much about informal supporters and, indirectly, about the lives of adults with IDD. In terms of informal supports, most individuals do have such supports, but these supporters are most often family
members; particularly parents. When we examined who constituted the nonfamily members providing informal supports, many of these supporters were paid or potentially paid people. Although we specifically asked respondents to list only unpaid, nonfamily supporters (we even underlined the word “unpaid”), over 50% of nonfamily informal supporters were (possibly) paid. These findings cast doubt on any straightforward distinction between formal and informal supporters. The roles of informal and formal supporters may, in fact, be more fluid than previously thought.

These findings also highlight the ways in which levels of informal support drastically change over time, particularly in terms of aging families. Without exception, individuals with older, less-healthy, or deceased parents had fewer informal supporters. This finding implies that as parents age and/or decline in health, they are unable to assume the role of informal supporter. This finding may also suggest that parents, mothers in particular, may assume the role of brokers of their offspring’s other informal supports, coordinating and managing other supporters. Thus, when parents are older or deceased, individuals seem to have fewer informal supporters.

References/Citations: