

# Putting Research to Work for Military Families



Focus:  
Civilian

## The Roles of Adult Siblings in the Lives of People with Severe Intellectual and Developmental Disabilities

Hall, S. A., & Rossetti, Z. (2017). The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.12421

**SUMMARY:** Individuals with intellectual and developmental disabilities often have significant support needs that may be filled by their siblings. To understand this relationship, this study sought to investigate the types of roles an individual assumes when they have a sibling with either severe intellectual and developmental disabilities or extensive to pervasive support needs. Findings from this study indicated that these individuals may assume at least four out of seven different roles in their lifetime, such as friend and legal representative.

### KEY FINDINGS:

- Participants identified having assumed seven distinct roles: caregiver (65%), friend (65%), advocate (62%), legal representative (54%), sibling (52%), leisure planner (34%), and informal service coordinator (19%).
- Almost half (48.1%) of the participants assumed at least four or more of the seven roles.
- Roles assumed by participants changed over time. Most notably, participants indicated an increase in sibling responsibilities as they transitioned into adulthood due to assuming roles (e.g., legal representative) that their aging parents could no longer fulfill.

### IMPLICATIONS FOR MILITARY PROFESSIONALS:

Military professionals could:

- Attend trainings on intellectual and developmental disabilities to enhance their ability to provide support to Service members who have a sibling with intellectual and developmental disabilities
- Facilitate support groups for Service members who have a sibling with intellectual and developmental disabilities

### IMPLICATIONS FOR PROGRAMS:

Programs could:

- Disseminate information on advocacy and legal representation to Service members with a sibling with intellectual and developmental disabilities
- Provide classes on ways to maintain effective communication for Service members with a sibling with intellectual and developmental disabilities

### IMPLICATIONS FOR POLICIES:

Policies could:

- Promote the development of inclusive leisure activities for Service members and their sibling with intellectual and developmental disabilities
- Recommend professional education including information on military culture for civilian professionals who work with Service members caring for a sibling with intellectual and developmental disabilities

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## METHODS

- Data were collected via an online survey; the survey was only offered electronically (no paper copies were distributed).
- Participants were recruited through partnerships with sibling organizations and organizations supporting individuals with intellectual and developmental disabilities and their families.
- To analyze the data, each researcher individually read the first 24 survey results and identified initial themes. Researchers then compared their themes and refined them into codes. These codes were then used to analyze the remaining surveys.

## PARTICIPANTS

- The study sample included 79 participants with an average age of 40 years. Of this sample, 74.7% of the participants were female, and 74.7% of the participants were older than their sibling.
- Participants in the study had at least one sibling with either severe intellectual and developmental disabilities or extensive to pervasive support needs.
- The most commonly reported disabilities among the siblings were intellectual disability (55.7%), autism spectrum disorder (29.1%), down syndrome (20.3%), and cerebral palsy (16.5%).

## LIMITATIONS

- Data for this study were only collected through electronic means, this limited the study from reaching participants who did not have access to a computer or internet.
- Descriptions of disabilities were assessed by participants' reports instead of official diagnosis which limits the study as participants reports may be inaccurate.
- Findings reflect the experiences of participants who were also part of support groups for families of individuals with disabilities at the time of survey completion; hence, findings of the the study may not generalize to all individuals who do not attend such groups.

## AVENUES FOR FUTURE RESEARCH

Future research could:

- Study the impact caregiving an adult sibling with disabilities has on caregivers' health
- Include participants with siblings who have intellectual and developmental disabilities that were not involved in support groups
- Investigate the relationship between roles and specific types of intellectual and developmental disabilities

## ASSESSING RESEARCH THAT WORKS



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