

# The Perceptions of Professionals Toward Siblings of Individuals With Intellectual and Developmental Disabilities

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**SUMMARY:** Little is known about how professionals view the inclusion of adult siblings in the care and service coordination of their brothers or sisters with intellectual or developmental disabilities (IDD). This study examined the existing perceptions of professionals about adult siblings of individuals with IDD as well as professionals' beliefs about the benefits and challenges of working with siblings of individuals with IDD. Results indicated that professionals viewed adult sibling involvement as beneficial overall and reported on systems in place to encourage sibling involvement.

#### **KEY FINDINGS:**

- Many professionals cited enjoyment in seeing their clients with IDD benefit from sibling involvement in their lives.
- Professionals reported that the greatest challenge is often gaining access to siblings, something that may not happen short of a crisis or until parents pass away.
- Some professionals reported that including siblings in the care of their patients was difficult due to feelings of resentment towards their sibling with IDD or already feeling overburdened with care of their sibling with IDD.

#### IMPLICATIONS FOR MILITARY PROFESSIONALS:

Military professionals could:

- Provide a questionnaire at intake for new clients that details any siblings, their level of involvement, and relationship quality with the sibling with IDD
- Collaborate with other professionals about ways in which to facilitate the inclusion of adult siblings in the care of individuals with IDD, including any military-specific challenges that may arise (i.e., siblings that live in another state)

#### **IMPLICATIONS FOR PROGRAMS:**

Programs could:

- Make information and materials available regarding how to involve adult siblings of individuals with IDD in their siblings' care electronically so the materials can be accessed by professionals who work with military families in civilian communities as well as on bases
- Offer workshops for professionals who work with individuals with IDD in military families that offer strategies to encourage involvement of adult siblings within a military context

#### **IMPLICATIONS FOR POLICIES:**

Policies could:

- Recommend integrating information about available resources for families with individuals with IDD into existing service delivery systems for military families
- Recommend professional education including information on military culture for professionals who work with individuals with IDD in military families

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## METHODS

- Participants were part of a larger study sample examining adult siblings of individuals with IDD. Participants for that study were recruited through email (e.g., emailed flyers) and through national support groups throughout the U.S.
- To be eligible, participants had to work with adults with IDD and their families, including siblings.
- Participants answered 22 demographic questions and 13 open-ended questions about their perceptions of working with adult siblings of individuals with IDD, how they encourage adult sibling involvement in care, and what was the greatest challenge in working with adult siblings.

### PARTICIPANTS

- Participants included 290 professionals who work with adults with IDD in a variety of settings, including as direct service providers, administrators, and supervisors.
- Professionals ranged in age from 20-71 years (M = 43.96, SD = 12.93, and the majority were female (86.9%).
- Most participants were White (88.6%), while 4.8% were Black, 3.8% were Latino, 2.1% were Asian, and 1% did not identify their ethnicity.
- Professionals responded from across the U.S., with 19.6% in the Midwest, 41.7% in the Northeast, 9% in the West, and 29.7% in the South and represented 45 of the 50 states as well as Washington DC.

## LIMITATIONS

- The use of a convenience sample means the results may not generalize to all professionals who work with adult siblings of individuals with IDD.
- The use of web-based recruitment methods may have missed a segment of professionals with limited or no internet access, limiting the ability to generalize findings.
- The researchers did not verify with participants if their interpretations of open-ended questions were correct, which could introduce bias into the findings.

### **AVENUES FOR FUTURE RESEARCH**

Future research could:

- Recruit a random sample in order to generalize findings to a wider portion of professionals
- Include a variety of types of recruitment methods (i.e., web-based, mailings, professional events) in order to ensure that portions of the population are not missed altogether
- Incorporate a way to collect contact information from participants willing to be contacted in the future to ensure the researchers' interpretations accurately reflect participants experiences

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