

Informing and Equipping Parents of People With Intellectual and Developmental Disabilities

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SUMMARY: Although many resources are available for people with intellectual and developmental disabilities (IDD), little is known about how likely these resources are utilized or how helpful they are perceived. The study surveyed 1,738 parents or caregivers of people with IDD about their familiarity and preference with IDD programs. Results revealed that parents and caregivers' familiarity with programs was limited and parents and caregivers desired to learn more information about IDD from official sources.

KEY FINDINGS:

- Most participants (59%) indicated that they were unfamiliar with available supports or programs for their family members with IDD.
- Participants were most likely to access resources through parent handbooks (84%) and printed (80%) or downloadable (79%) fact sheets.
- Participants were likely to seek help from local disability organizations (79%), disability employment providers (76%), friends (66%), people from the school system (62%), and relatives (61%).

IMPLICATIONS FOR MILITARY PROFESSIONALS:

Military professionals could:

- Provide support to dependents of Service members with IDD through a variety of avenues (e.g., pamphlets, home visits, online resources)
- Offer continual support to dependents of Service members who have IDD across their lifespan

IMPLICATIONS FOR PROGRAMS:

Programs could:

- Offer support groups for family members of individuals with IDD to promote healthy coping and family well-being
- Provide outreach services that increase awareness of available supports to military families with members who have IDD

IMPLICATIONS FOR POLICIES:

Policies could:

- Recommend that programs for military families provide information about available military and civilian resources for people with IDD
- Continue to support programs that assist military families with members who have IDD

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METHODS

- Participants were recruited through partnering organizations and school districts by various methods (e.g., fliers, emails) in Tennessee.
- The survey was completed in person or online, and measures included participants' familiarity with resources, preference of training topics, preference of resource types, and likelihood of accessing supporting networks (e.g., family members, friends).
- Data were analyzed to examine participants' utilization of resources based on the demographic factors (e.g., race/ethnicity, socioeconomic status).

PARTICIPANTS

- Participants included 1,738 parents or caregivers of people with IDD; the majority of participants (83%) identified as the mother of the person with IDD, 8% as the father, 4% as a grandparent, and 5% as other relatives or legal guardians.
- The majority of participants were White (80%); the race/ethnicity of the other 20% of the sample was unknown.
- Most participants (61%) were the parents or caregivers of individuals who were aged between 0-21 years, whereas the rest were the parents or caregivers of individuals who were aged between 22-78 years.
- The average age of participants was not reported.

LIMITATIONS

- The sample was solely recruited from Tennessee, so caution must be taken to apply the findings to other states.
- The resources, topics, and information dissemination pathways in the survey were based on existing programs; therefore, participants may have other needs that were not covered in the survey.
- The majority of the sample (83%) were mothers of individuals with IDD; therefore, caution should be taken to generalize the results to fathers or other caregivers.

AVENUES FOR FUTURE RESEARCH

Future research could:

- Replicate the study in other states to examine potential geographical differences in parents' utilization of IDD programs
- Inquire about parents' needs and preferences of not only existing IDD programs but also programs that do not currently exist, but parents would like to have
- Examine whether parents' utilization of IDD programs is influenced by their age

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