

Putting Research to Work for Military Families



Focus:
Civilian

Services and Supports, Partnership, and Family Quality of Life: Focus on Deaf-Blindness

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SUMMARY: Services (e.g., educational, social, health programs) and social supports are very important for the well-being of families of youth with disabilities. Caregivers of youth with deaf-blindness (i.e., severe auditory and visual impairments) reported their families' quality of available services and supports, of life, and of the partnership with youth's primary provider. Relationships, especially high-quality relationships with primary providers, can greatly improve the well-being of families with youth with deaf-blindness.

KEY FINDINGS:

- Having more social support and greater satisfaction with a youth's primary provider (e.g., teacher, healthcare provider, childcare provider) were related to higher family quality of life.
- Married caregivers reported higher family quality of life than unmarried caregivers.
- Only at high levels of primary provider satisfaction did caregivers who had high satisfaction with educational services also report high family quality of life.

IMPLICATIONS FOR MILITARY PROFESSIONALS:

Military professionals could:

- Attend trainings about how to build positive partnerships with families with youth with developmental disabilities, including youth with deaf-blindness
- Facilitate digital support groups, for military families with youth with deaf-blindness

IMPLICATIONS FOR PROGRAMS:

Programs could:

- Provide each youth with deaf-blindness in military families with a designated, highly-trained provider that assists the youth in communication, learning, and personal care during school
- Offer classes to educate military families with youth with deaf-blindness and other disabilities about education laws regarding disabilities and how to advocate for their children

IMPLICATIONS FOR POLICIES:

Policies could:

- Encourage the training of professionals working with military families with youth with deaf-blindness about how to work with these youth and build strong partnerships with their families
- Promote the development of childcare programs with specialized, trained staff for military youth with disabilities, including youth with deaf-blindness

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METHODS

- Primary caregivers of youth, age birth to 21 years with deaf-blindness, were recruited through each state's deaf-blind census; 16 states distributed surveys with an 11% response rate.
- Caregivers completed surveys regarding family quality of life, quality of available supports and services, and quality of partnership with the youth's primary professional provider.
- The relationships between family quality of supports and services, quality of life, and quality of primary provider partnership were examined.

PARTICIPANTS

- Participants included 277 caregivers of youth with deaf-blindness in the following age ranges: 0-2 years (8%), 3-8 years (32%), 9-14 years (29%), 15-18 years (19%), and 19-22 years (10%).
- Caregivers were primarily female (90%) and parents (94%) of a youth with deaf-blindness; they identified as White (79%), Latino (9%), Black (8%), and Asian American or Native American (3%).
- The majority of youth had co-occurring language or speech disorders (82%), developmental delays (80%), and physical disabilities (68%).

LIMITATIONS

- Caregivers were primarily White mothers of youth with deaf-blindness, and results may not generalize to other caregivers of youth with deaf-blindness or with other disabilities.
- Respondents may differ from non-respondent caregivers in several ways (e.g., stress level).
- The type of school youth attended (e.g., public, private, specialized) was not assessed and may have influenced results, especially results related to educational services.

AVENUES FOR FUTURE RESEARCH

Future research could:

- Examine the effects of the quality of the provider partnership on specific domains of family quality of life (e.g., emotional well-being, physical well-being, family interactions)
- Investigate the characteristics of high-quality provider partnerships and how they may differ between educational, informational, and other types of providers
- Explore the association between provider training and caregiver rating of partnership quality

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