

# Are Services and Supports Important in the Lives of Families of Children with Deafblindness?

Brief Report

May 16, 2011

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Making a Significant & Sustainable Difference in Quality of Life

Beach Center on Disability

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In the fall and winter of 2009, researchers from the Beach Center on Disability distributed a survey to families of children with deafblindness in 16 states across the nation. The purpose of this study was to learn if families felt that services (e.g., education, related services, health services) and supports (e.g., from friends, extended family, from other parents of children with disabilities) they received in the year prior to completing the survey were adequate in meeting their child and family needs.

There is very little data on the service and support needs of families who have children with deafblindness. Service providers, administrators of services, and policy makers need to understand families' specific needs in order to improve the service system. In this study, we asked these questions:

- ✓ Are families' perceptions of services and supports related to family quality of life? (We provide more information on family quality of life in this report.)
- ✓ Does family satisfaction with their partnerships with professionals make a difference in how supports and services impact family quality of life for families of children with deafblindness?
- ✓ Is the relationship between service and support adequacy and FQOL dependent on the age of the family member with deafblindness?

In this report, we share the answers to these questions and tell you what we think they mean for education professionals and for families of children with deafblindness. We will also share how these findings have been and will be disseminated.

If you participated in this study, we want to thank you for the time you took to provide your input. We assure you that we are working to make sure that your voice is heard.

We hope you find the information in this report helpful and encourage you to contact us with any questions you may have.

Sincerely,

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## **Deafblind Family Study: Definition of Key Variables**

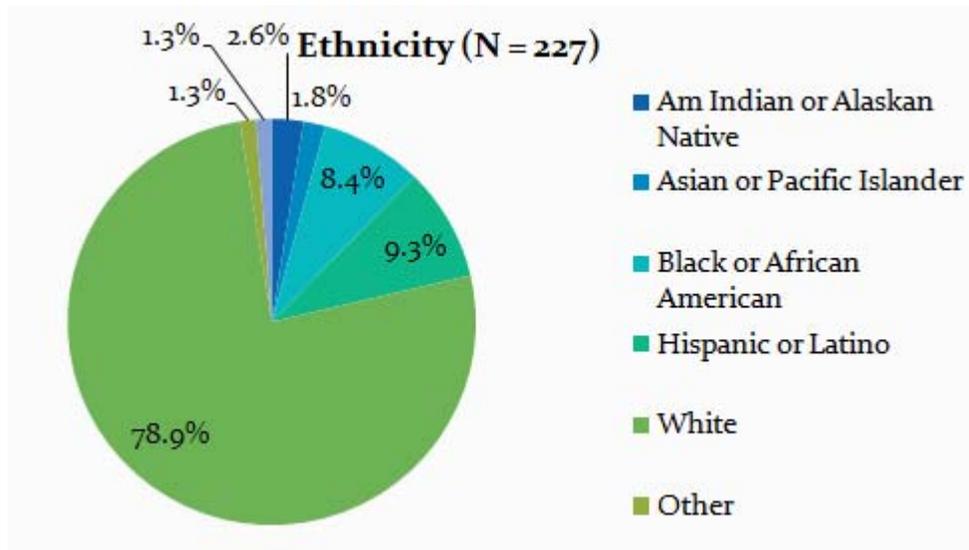
- ✓ *Service and Support Adequacy* refers to families' perceptions of how adequate services and supports were (during the 12 months prior to completing the survey) in meeting child and family needs across the following broad areas:
  - a. Health Services (e.g., well-child checks, nutrition services, nursing services)
  - b. Education Services (e.g., special education, early intervention services, hearing services)
  - c. Related Services (e.g., occupational therapy, physical therapy, intervener services)
  - d. Information Services (e.g., state deafblind projects, parent/family organizations, state department of education)
  - e. Friend and Family Support (e.g., friends, extended family members, parents of children with disabilities)
  - f. Child Care Services (e.g., full- or part-time child care in home or day care, respite services)
  - g. Service Coordination (e.g., case management and/or care coordination, medical home)
  
- ✓ *Family quality of life*, or FQOL, is a positive measure of families' overall satisfaction with the following broad areas of family life:
  - a. Family interaction
  - b. Emotional well-being
  - c. Physical/material well-being
  - d. Parenting
  
- ✓ *Family-professional partnerships* are based on trust, respect, communication, professional competence, respect, commitment, equality, and advocacy. The Beach Center Family Professional Partnership Scale measures families' satisfaction with their child or family's main service provider.
  
- ✓ *Age of family member with deafblindness* was determined by the family member with deafblindness' date of birth.

<b>Purpose</b>	To determine if service adequacy is related to family quality of life
<b>Participants</b>	227 parents of children certified as deafblind between the ages of birth and 22
<b>Sampling Procedures</b>	Recruited through State Deafblind Technical Assistance Projects
<b>Research Questions</b>	<ul style="list-style-type: none"> <li>• Controlling for marital status and family income, is service and support adequacy related to FQOL?</li> <li>• Controlling for marital status and family income, do satisfaction with family-professional partnerships moderate the relationship between service and support adequacy and FQOL?</li> <li>• Controlling for marital status and family income, does age of the family member with deafblindness moderate the relationship between service and support adequacy and FQOL?</li> </ul>
<b>Measures</b>	<ul style="list-style-type: none"> <li>• Beach Center Service and Support Adequacy Scale—Deafblind</li> <li>• Beach Center Family Professional Partnership Scale</li> <li>• Beach Center Family Quality of Life Scale</li> <li>• Demographic Measure</li> </ul>
<b>Analyses</b>	<ul style="list-style-type: none"> <li>• Reliability and exploratory factor analyses of FQOL and Partnership measures</li> <li>• Reliability analysis of SAS-DB</li> <li>• Univariate Analysis of Variance</li> <li>• Hierarchical multiple regression analysis</li> <li>• Hierarchical multiple regression moderator analysis</li> </ul>

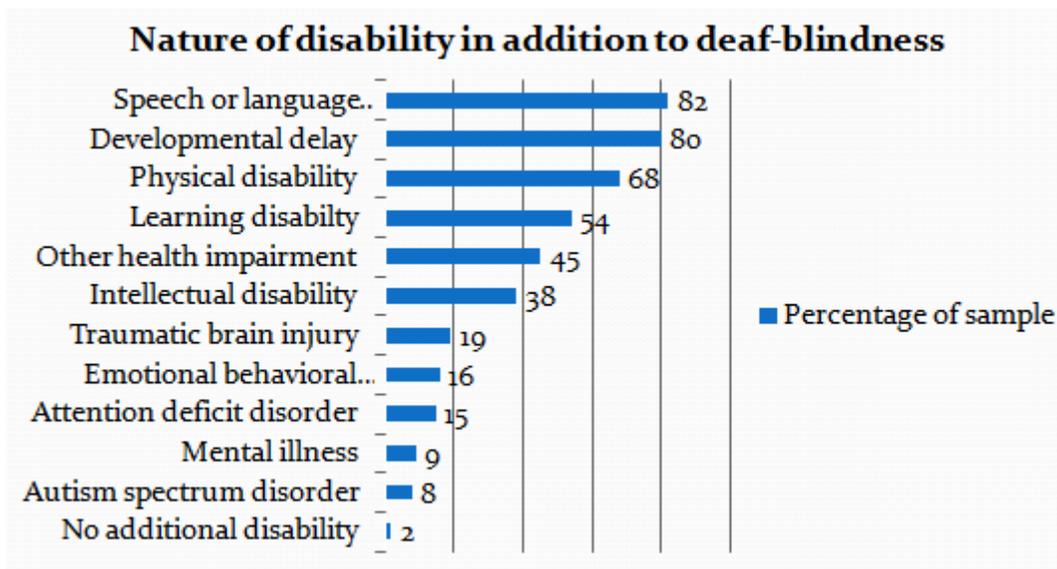
## Key Findings

### Participants

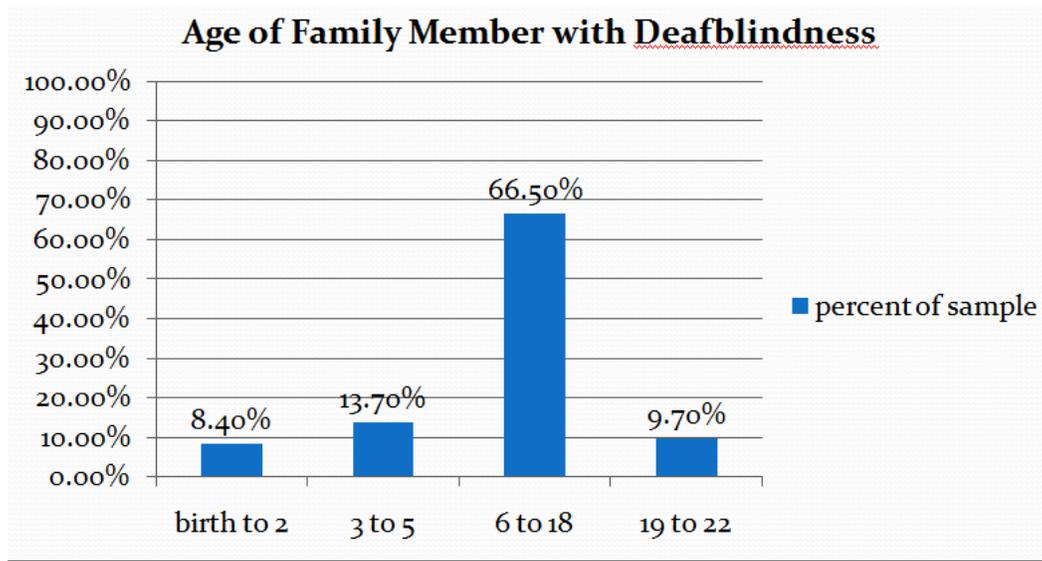
- Two-hundred twenty-seven families from 16 states across the US returned the survey. The response rate was approximately 11%.
- *Ethnic distribution:*



- *Disability characteristics:* Many of the children in our sample have multiple disabilities (disabilities in addition to deafblindness).

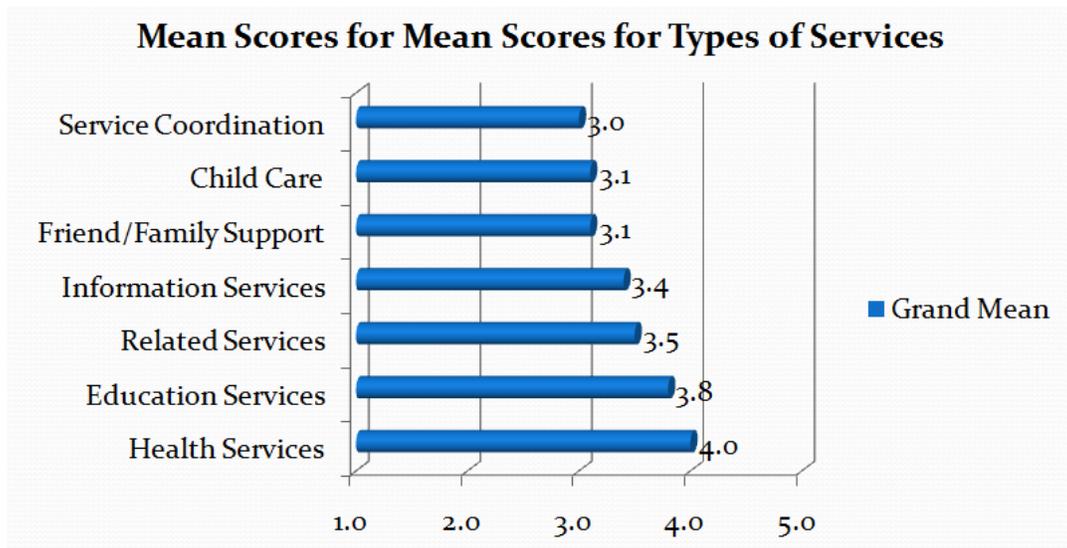


- *Age of family member with deafblindness:*

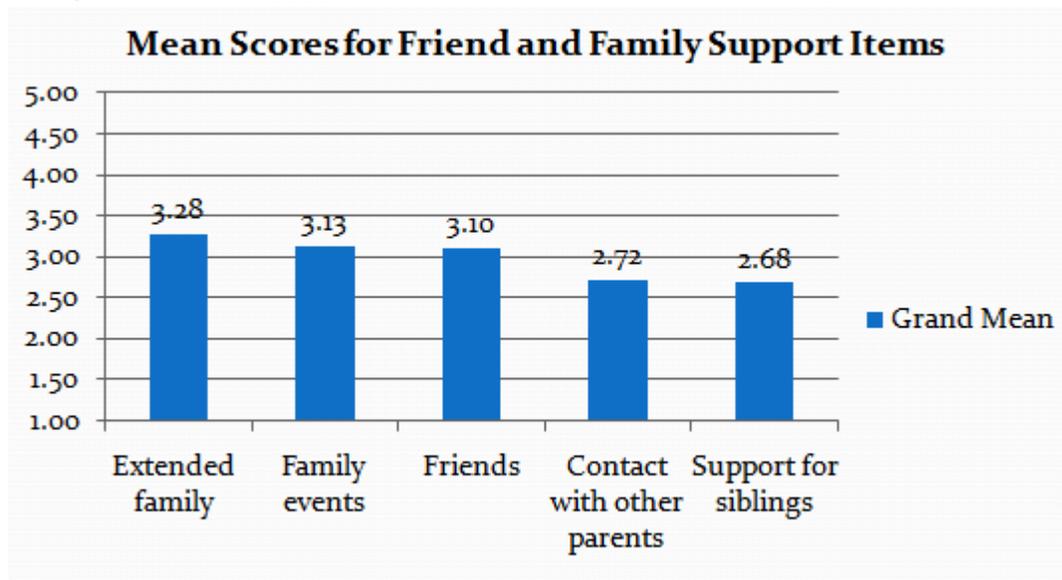


Service and support adequacy and FQOL

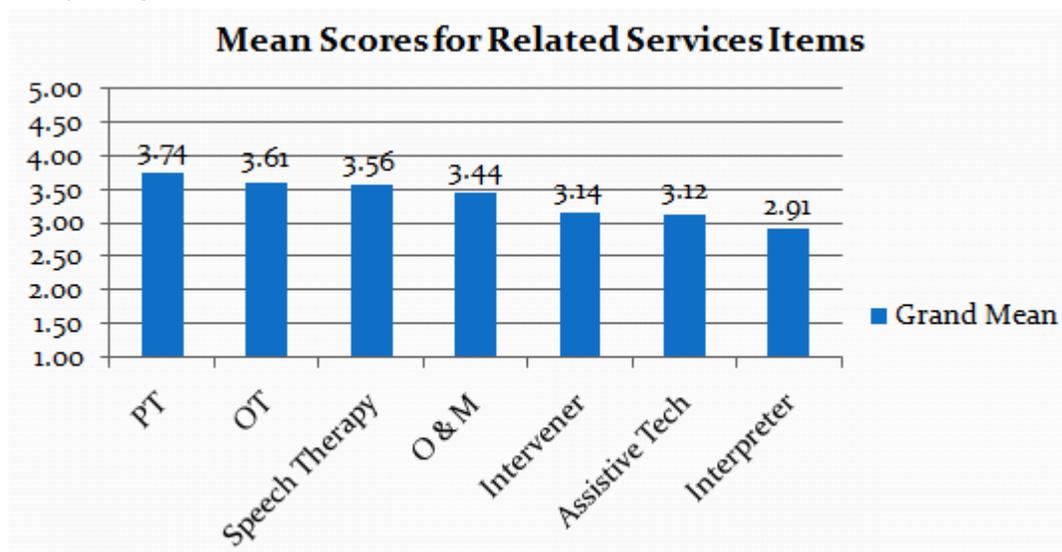
- **Services and supports do matter in the lives of families who have a child with deafblindness.** Families who thought their supports and services were more adequate tended to have higher family quality of life.
- Overall, families were most satisfied with health services and least satisfied with service coordination services. (Scores were on a scale from 1-services did not meet child and family needs at all to 5-services completely met child and family needs.)



- Both friend and family support and related services significantly predicted FQOL.
  - Families were most satisfied with extended family and least satisfied with support for siblings.



- Families were most satisfied with physical therapy services and least satisfied with Interpreting services.



Service adequacy, family-professional partnerships, and FQOL

- Satisfaction with family-professional partnerships was significantly related to FQOL.
- The relationship between service adequacy and FQOL was greater or less, depending on families' satisfaction with partnerships.

### Service and support adequacy, age of the child, and FQOL

- Age was not significantly related to FQOL.
- Although not statistically significant, there is trend of decreasing satisfaction with services as the family member with deafblindness ages.

### **Implications for Education Professionals**

- ***Friend/Family Support, Related Services, and FQOL:*** For families of children with deafblindness, friend/family support and related services are particularly important for family quality of life.
  - Teachers and other service providers who partner with families of children with deafblindness should provide information and opportunities to extend families' social networks. Even though this is not typically a focus of services in the education field, the findings of this study suggest that adequate friend and family support is necessary in the lives of families who have a child with deafblindness. Since we know that family and child outcomes are correlated, providing this support to the family will, in turn, benefit the child.
  - Related service providers need to understand the critical role they play in the lives of families who have a member with deafblindness. Administrators need to pay particular attention to family needs in this area so that they can allocate the appropriate quality and quantity of these services.
- ***Family-Professional Partnerships, Service and Support Adequacy, and FQOL:*** Parent-professional partnerships can buffer the negative effects of perceived inadequate services on FQOL. Service providers who work with families of children with deafblindness need continual professional development in evidence based partnership practices. Preservice education and related services programs must also incorporate training in family-professional partnerships.
- ***Age of Family Member with Deafblindness, Service and Support Adequacy, and FQOL:*** The aim of services in the US is to prepare learners with disabilities to be: self-sufficient economically, live independently, etc., etc. Families' dissatisfaction in this study and data in the area of transition for learners with disabilities in general (i.e., 30% of learners with disabilities graduate high school as opposed to 70% of learners without disabilities) are discouraging—as children age, families are less satisfied with services. The relationship between parents' perceptions of service adequacy and FQOL are dependent on the age of the child. Systems level reform is needed to address families' increasing dissatisfaction with services as their child with deafblindness ages.

## Implications for Families

- *Seek out support from families and friends.* Additional research is needed to understand more clearly families' preferences for support; however, one factor is apparent from this study: support from extended family, friends, other parents of children with deafblindness or a similar disability, and support for siblings is important for family quality of life. Thus, an implication of this study for families is the importance of building informal support networks. Some suggestions for accomplishing this include joining community organizations, accessing resources through your state Parent Training and Information Center (PTI), or becoming more active with networking opportunities through your State Deaf-Blind Technical Assistance Project. Many of these projects host annual family meetings where families can meet other families who have children with deafblindness. To find out more information about your state's Deaf-Blind Technical Assistance Project, visit the National Consortium on Deaf-Blindness website: <http://www.nationaldb.org/>
- *Work toward building a partnership with the service providers that work with your child and family.* Family-professional partnership refers to "...a relationship in which families (not just parents) and professionals agree to defer to each other's judgments and expertise, as appropriate for the purpose of securing benefits for students, other family members, and professionals" (Turnbull, Turnbull, Erwin, & Soodak, 2006). For more information about partnerships, including tips, real stories, tools, and publications, visit the Beach Center on Disability website: <http://www.beachcenter.org/families/partnerships/default.aspx>
- *Advocate for services and supports throughout the school career of your family member with deafblindness.* The results of this study show that families are less satisfied with services as their child ages. One way that this trend of decreasing satisfaction can be addressed is if parents become advocates for their family's goals and vision for their child. For more information on legal advocacy and disability visit the National Disability Rights Network: Protection and Advocacy for Individuals with Disabilities: <http://www.napas.org/>. For a resources related specifically to severe disabilities, visit the TASH website: <http://tash.org/advocacy-issues/>.

## Dissemination of Deafblind Family Study Findings

### Publications:

Kyzar, K., Summers, J.A., & Cote, M. (2010). Families' perceptions of disability-related supports and services: Report of a national survey of families who have children with deafblindness. *CHARGE Accounts*, 20(4), 8-10.

Kyzar, K.B. & Turnbull, A.P., and Summers, J.A. (2011). *Perceptions of families who have children with moderate and severe disabilities about disability-related services and supports: A research synthesis*. Manuscript submitted for publication.

Kyzar, K., Summers, J.A., & Turnbull, A.P. (2011). *The relationship of perceptions of service and support adequacy to family quality of life for families of children with deafblindness*. Manuscript in preparation. University of Kansas.

### Presentations:

Kyzar, K., & Summers, J.A. (2011, November). *Perceptions of disability-related services and supports: Focus on deafblindness*. Poster presentation at the Division of Early Childhood 27th Annual International Conference on Young Children with Special Needs and Their Families, National Harbor, MD.

Kyzar, K. & Stuckey, D. (2011, April). *Deafblindness and family support: Issues and Family supports and services for families of children who are deaf-blind: Impact on family quality of life*. Paper to be presented at the Council for Exceptional Children International Convention, National Harbor, MD.

Kyzar, K., Summers, J.A., Cote, M. (2010). *Impact on families of services for students who are deaf-blind: A national survey*. Paper presented at the OSEP Project Directors Conference, Washington, DC.