

Family Needs Assessment

Summary Report

National Center on Deaf-Blindness

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Table of Contents

Part I: Background	3
How old is your child?	3
At what age did you know that your child was deaf-blind?	3
At what age was your child when you were referred to a state deaf-blind project?.....	3
Who referred you to your state deaf-blind project?.....	4
Part II: Child and Family Needs and Strengths	5
What are the current top 3 needs you have for your child?	5
What do you most need information about?.....	5
What are your greatest strengths as a family in addressing the needs of your child? What are you most successful at?	6
Part III: Experiences with Agencies and Service Providers	8
What agencies has your child received services from? How was your experience?.....	8
What service providers—both public and private—have worked with or are currently working with your child?.....	10
Part IV. Experiences and Interactions with Other Families	12
How many times per month, on average, do you have an opportunity to communicate with another family member of a person who is deaf-blind (in person or by phone or via distance technology)?	12
How do you like to communicate with other families?	12
Is there a group for parents of children who are deaf-blind in your state? If so, are you a member of that group? Are you presently involved in advocacy at the state or national level to improve services for children who are deaf-blind?	12
Part V. Supports for Families.....	14
What helps you make decisions about your child's education, health, and developmental needs? .	14
What supports have been most helpful from other families?	14
What supports from your state deaf-blind project have been most helpful?	15
How do you like to receive information?	15
Do you have additional comments you would like to share?	16

Part I: Background

In 2017, NCDB, with input from state deaf-blind projects, the National Family Association for Deaf-Blind (NFADB), and the CHARGE Syndrome Foundation, conducted a national survey to collect information about the needs of families of children with deaf-blindness. The results can be used by NCDB, state deaf-blind projects, and family and community organizations to better serve families of children who are deaf-blind.

Families were recruited by a variety of agencies/organizations, including:

- NCDB
- State Deaf-Blind Projects
- NFADB
- Charge Syndrome Foundation

Online and print versions of the survey were available in both English and Spanish.

A total of 184 individuals responded to one or more questions. This section provides a summary of their answers to background questions about their child including age, age at diagnosis, and when and by whom they were referred to their state deaf-blind project.

How old is your child?

184 individuals responded. Age ranged from less than one to sixty-one years of age (average 12 years, 3 months). The majority (91%) were aged birth to 21.

Age	Number
Birth to 2	9
Preschool (3 to 5)	38
Elementary School (6 to 11)	54
Middle/High School (12 to 17)	42
Young Adult (18 to 21)	25
22 to 30	10
Over 30	7

At what age did you know that your child was deaf-blind?

182 individuals responded. A significant majority of their children were diagnosed before age three (74%).

At what age was your child when you were referred to a state deaf-blind project?

132 individuals responded. Age of referral varied significantly, but typically occurred sometime after an initial diagnosis. For example, while 74% were diagnosed before age three, only 38% had been referred by age three.

Age at Time of Referral	Number
At birth	54
Before age 1	34
1 to 2 years old	47
3 to 5 years old	29
6 to 10 years old	15
Older than 10	2
Not sure	1

Who referred you to your state deaf-blind project?

63 individuals responded. They recalled a wide range of people and programs that provided referrals. Part C personnel were the most common, followed by school personnel.

1. Part C provider (22%)
2. School personnel (19%)
3. State deaf-blind project contacted me (13%)
4. Hospital/medical professional (11%)
5. Another parent or friend (10%)
6. I sought them out (self-referral) (8%)
7. Social worker or other program or agency (6%)
8. Don't remember (11%)

Part II: Child and Family Needs and Strengths

Part II focuses on the needs of children and the needs and strengths of their families.

What are the current top 3 needs you have for your child?

180 individuals responded. They identified 485 critical needs. The 485 need statements were sorted into 33 specific categories, with the 10 most frequent being:

1. Communication system
2. Qualified knowledgeable personnel at local level
3. Social engagement
4. Health
5. Independent living and functional living skills
6. Supports in the home and community
7. Parent training
8. Technology use
9. Transition
10. Vision supports

What do you most need information about?

154 individuals responded. They identified many information needs, including (in order of frequency):

1. Assistive technology
2. Communication methods and instruction
3. Advocacy skills to support child in school and community
4. Impact of vision and hearing loss
5. Helping child build social skills and friendships
6. Building a network of support for child
7. Transition to adult life
8. Supporting child with complex medical needs
9. Interveners in school

10. Dealing with challenging behaviors
11. What child's life will be like in adulthood
12. Dealing with IEPs and assessments
13. Movement
14. Employment
15. Sibling support
16. Transition from early intervention to school

What are your greatest strengths as a family in addressing the needs of your child? What are you most successful at?

Self-identified family strengths from the 124 individuals who responded to this question fell into three broad categories: 1) Family Characteristics and Dynamics (reported by 123 respondents); 2) Skills and Abilities (102 respondents); and 3) Development of External Supports (reported by 12 respondents).

Family Characteristics and Dynamics

- Family is a strong team
- Adaptability, determination, and patience
- Love, humor, and faith
- Knowing and understanding our child
- Being consistent
- Allowing child freedom to explore
- Focusing on strengths and maintaining high expectations
- Including child in all family activities
- Celebrating successes

Skills and Abilities

- Taking care of educational and medical needs
- Ability to advocate for our child
- Ability to find resources
- Ability to communicate with our child
- Ability to teach specific skills (applies to parents who are also experienced educators)

- Ability (financial) to provide support

Development of External Supports

- Connections with other families
- Having external supports

Part III: Experiences with Agencies and Service Providers

This section summarizes responses regarding experiences with the various agencies and service providers that provide services for their children.

What agencies has your child received services from? How was your experience?

166 individuals responded. Almost all reported working with school districts and/or a department of education (93%). Of these, approximately 70% reported having had positive experiences.

Considerably fewer (58%) reported on their interactions with Part C agencies. Of these, approximately 75% reported that their experiences were positive. Fewer respondents reported having had interactions with state developmental disabilities and/or vocational rehabilitation programs. Less than half (40%), reported that these experiences were positive.

Frequency and satisfaction of experiences with state and local programs

Service/Program	Our child has received services from this agency	Positive Experience	Negative Experience	Neutral
School District	154	106 (69%)	26 (17%)	22 (14%)
Part C (Infant and Toddler Services)	97	73 (75%)	7 (7%)	17 (18%)
Developmental Disabilities	84	35 (42%)	15 (18%)	34 (40%)
Vocational Rehabilitation	48	18 (38%)	9 (19%)	21 (43%)

Other programs included the medical system, public health agencies, state parent training and information centers (PTIs), Helen Keller National Center Regional Representatives, and an open-ended “other” category.

Most families reported interactions with the medical system (78%). Of these, almost 80% of reported positive experiences. Far fewer reported interactions with their public health system (36%). Fewer than half reported positive experiences (47%).

Fewer still (28%) reported receiving services from a Hellen Keller Regional Representative or their state PTI (23%). While only about half of the individuals reported positive experiences with these programs, few reported negative experiences.

Frequency and satisfaction of experiences with the medical system and other programs

Service/Program	Our child has received services from this agency	Positive Experience	Negative Experience	Neutral
Medical System	130	102 (78%)	8 (6%)	20 (16%)
Public Health	60	28 (47%)	10 (17%)	22 (36%)
Helen Keller Regional Representative	46	24 (52%)	5 (11%)	17 (37%)
Parent Center	38	16 (42%)	6 (16%)	16 (42%)
Other	43	41 (95%)	1 (2%)	1 (2%)

43 respondents mentioned additional local, state, and national agencies and programs from which they had received satisfactory services, including:

- Deaf-blind specific agencies and organizations
- Blindness/visual impairment agencies and organizations
- Other agencies and organizations

Deaf-Blindness

State Deaf-Blind Projects

CHARGE Syndrome Foundation

Deaf-Blind Association

Deaf-Blind Services

Blindness/Visual Impairment

Children’s center for visually impaired

Junior Blind of America

Low vision clinic

National Federation of the Blind

Commission for Blind

Idaho School of Blind

Lighthouse

Anchor Center

Other

Parks & Recreation

Boise state FUSE project (adaptive equipment)

Easter Seals Rehabilitation Center

Family to Family Health Information Center

What service providers—both public and private—have worked with or are currently working with your child?

162 individuals responded to this question about education, medical, and social service providers. The question asked about both public and private service providers. They are combined here to demonstrate the range of service providers who work with, or have worked with, their child.

At least three quarters of respondents indicated that their child had worked with or was working with a speech language pathologist, special education teacher, occupational therapist, physical therapist, or teacher of the visually impaired. More than half reported working with early intervention teachers, regular education teachers, teachers of the deaf or hard of hearing, school nurses, orientation and mobility instructors, paraeducators, and school administrators. Only about one in four reported working with an intervener, teacher of the deaf-blind or an interpreter.

Educational personnel who have or currently work with child

Education Personnel	Frequency
Speech Language Pathologist	150
Special Education Teacher	143
Occupational Therapist	141
Physical Therapist	138
Teacher of the Visually Impaired	126
Early Intervention Teacher	120
Regular Education Teacher	106
Teacher of the Deaf or Hard of Hearing	105
School Nurse	104
Administrator (School or District)	96
Orientation & Mobility Instructor	94
Paraeducator	84
Intervener	46
Teacher of the Deaf-Blind	37
Interpreter	33

Medical or social service personnel who have or currently work with child

Medical/Social Service Personnel	Frequency
Ophthalmologist	150
Audiologist	148
Pediatrician	145
Physician	141
Optometrist	110
Social Worker	68
Public Health Nurse	31
Other	43

Part IV. Experiences and Interactions with Other Families

Part IV focuses on experiences and interactions with family groups and other families. Family members were asked about the frequency with which they interacted with other families, their preferred means of communication, and their participation in state/local family groups as well as state and national advocacy activities.

How many times per month, on average, do you have an opportunity to communicate with another family member of a person who is deaf-blind (in person or by phone or via distance technology)?

A total of 149 individuals responded to the question regarding frequency of interactions with other families.

- 74 (49.7%) reported they never communicate with other families
- 53 (35.6%) reported communicating 1 to 2 times per month
- 5 (3.4%) reported communicating 3 to 5 times per month
- 17 (11.4%) reported communicating more than 5 times per month

How do you like to communicate with other families?

A total of 152 individuals responded to the question about their preferred means of interacting with other families. Respondents could select more than one answer.

- 112 (73.7%) identified in-person interactions as a preferred means of communication
- 90 (59.2%) identified interacting within private Facebook groups as a preferred means of communication
- 69 (45.4%) identified talking on the phone as a preferred means of communication
- 69 (45.4%) identified texting as a preferred means of communication (very few preferred email). 25% identified some form of online communication (e.g., Skype, FaceTime, Google Chat, etc.) as a preferred means of communication
- Several respondents were not interested in communicating with other families

Is there a group for parents of children who are deaf-blind in your state? If so, are you a member of that group? Are you presently involved in advocacy at the state or national level to improve services for children who are deaf-blind?

A total of 132 individuals responded to the open-ended question about their participation in state parent groups and state and national advocacy efforts.

- 69 (52.3%) indicated there was a parent group in their state

- 40 (30.3%) of the 69 indicated they were active in the group
- 28 (21.2%) indicated that there wasn't a parent group in their state
- 46 (34.8%) did not know or did not respond
- 13 (9.8%) indicated that they were active in state and/or national advocacy efforts

Part V. Supports for Families

Part V focuses on family supports at local, state, and national levels. Family members were asked a series of questions related to who they relied on for decision-making advice, supports they found most helpful, support they received from state deaf-blind projects, and on how they like to receive information.

What helps you make decisions about your child's education, health, and developmental needs?

A total of 156 individuals responded to this question. They were asked to rank the following resources from most to least helpful: my own expertise and knowledge of my child; state deaf-blind project; reading and self-study; watching online videos; attending trainings/workshops; expert advice (e.g., Part C providers, teachers, physicians); advice from a parent of a child who is deaf-blind; information from a local or national parent group; other.

Responses were grouped into three categories: themselves, experts, and members of other families. Overall, parents relied most on their own knowledge about their child and knowledge gained through self-study. The numbers in parentheses reflect the combined rankings for all respondents.

1. Themselves
 - Their own knowledge of their child **(1)**
 - Reading and self-study **(3)**
 - Watching online videos **(8)**
2. Experts
 - Service providers (e.g., Part C providers, teachers, physicians) **(2)**
 - State deaf-blind project personnel **(5)**
 - Trainings and workshops **(4)**
3. Other Families
 - Parent of a child who is deaf-blind **(6)**
 - Local or national parent group **(7)**

What supports have been most helpful from other families?

Respondents were asked to identify who provided the most support to their family and the nature of that support. A total of 112 individuals responded to these open-ended questions. The numbers in parentheses indicate the number of respondents identifying that source of support.

1. Other families **(41)**
2. State deaf-blind project **(37)**
3. CHARGE Syndrome Foundation **(27)**
4. NFADB **(10)**
5. HKNC **(3)**
6. Usher Syndrome Foundation **(2)**
7. Have not received supports **(9)**
8. Other **(22)**

Respondents identified the specific types of supports that were most helpful, regardless of source. These are listed below in order of frequency, with connections to other families being identified most often.

1. Connections to other families
2. Conferences and parent weekends
3. Facebook groups
4. Resources/information used in home, community, school
5. One-on-one assistance, technical assistance, and training related to child's education
6. Support in obtaining services in school and the community

What supports from your state deaf-blind project have been most helpful?

A total of 102 individuals responded to the question about the most helpful supports from state deaf-blind projects. These are listed below in order of frequency.

1. Parent workshops/weekends (45%)
2. One-on-one support (26%)
3. Access to resources and information (25%)
4. Technical assistance to school teams (23%)

How do you like to receive information?

A total of 155 individuals responded to the question regarding how they best like to receive information. Respondents were asked to rank from most to least favorite the ways in which they like to receive information. Responses are presented in overall order of preference based on these rankings. The numbers in parentheses refer to the number of individuals who ranked the item as the most desirable method.

1. In-person training **(60)**
2. Website **(37)**
3. Online training **(12)**
4. Online self-study (with support) **(7)**
5. Family stories (examples from families) **(17)**
6. Mentoring from another family member **(3)**
7. Online self-study (without support) **(3)**
8. Social media **(7)**

Do you have additional comments you would like to share?

Forty individuals provided additional comments. These have been summarized into six categories and are listed below in order of frequency:

1. Need more support groups for parents to connect and share thoughts, experiences, and feelings **(13)**
2. Need help navigating state programs and agencies, especially adult/community services and programs **(6)**
3. Need qualified personnel in our state—interveners and teachers **(4)**
4. Need more support from national organizations and projects **(4)**
5. Resources need to be easier to find **(5)**
6. Thank you for your supports/activities **(8)**