My View On Services

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Reasons for the Survey

• Funders
• Data instead of anecdotal
• Use for programming going forward
• Reduce Lost to Follow-up
Thank You

• City: ___________       Zip code: ________      Year child was born: ______

• Was your child born in Illinois (please circle):     Yes       No

• Did your child pass newborn hearing screening: Yes      No

• At what age was your child identified with a hearing loss?
  • Years: ___________      Months: _____________________

• Diagnostic Results: Unilateral (one ear) Bilateral (two ears)

• Has your child been identified as having Auditory Neuropathy/Dys-synchrony: Yes        No

• Degree of Hearing Loss:
  Right Ear: Mild    Moderate   Moderate-Severe Severe   Profound
  Left Ear:  Mild    Moderate   Moderate-Severe Severe   Profound

• Are you a:      mother     father     grandparent      guardian      other: __________

• Is your child now or previously enrolled in intervention services (early intervention through the state or private)? Yes     No
• Did it begin by 6 months of age (please circle)? Yes No

• Does/Did you child have an IFSP (Individual Family Service Plan) through your local Child and Family Connections (Illinois Early Intervention) office?
  Yes No

• Did your child receive services privately (through a private school or provider)? Yes No

• At the time of this survey, what is the primary language used at home? English Spanish Polish Sign Language Other ________

• At the time of this survey, what is the primary communication mode used in your home with your child with hearing loss:
  Oral/Speech ASL Signed English Cued Speech

• Please circle any of the evaluations that your child has received to date: vision genetics speech and language occupational evaluation/therapy physical evaluation/therapy developmental evaluation/therapy other: _________________________

• Who first explained to you the different ways to communicate with your child?
  Developmental Therapist Developmental Therapist/Hearing Service Coordinator another parent audiologist ENT Other Early Intervention provider Other: _________________________
What challenges did you experience related to getting your child’s hearing test completed after leaving the hospital (check all that apply)?

_____ My baby was not screened at the hospital
_____ Unsure of where to go after our baby failed the screening
_____ Screening test results were not shared with us
_____ Delay in appointment availability
_____ ABR test only available under sedation
_____ Missed appointments due to: ________________________________
_____ Transportation problems
_____ Unable to afford the test
_____ Our baby had other medical/health problems
_____ Our baby had middle ear fluid
_____ We live far from the testing clinic
_____ Repeated testing was needed
_____ Other, please specify: _____________________________________
When you first found out that your child had a hearing loss, many concerns arose in the following weeks. Place an X next to the top 3 concerns you experienced.

_____ Your child’s medical needs
_____ Your family’s finances
_____ Your child’s success in school
_____ Your child’s ability to make friends
_____ Your child’s ability to communicate with the family
_____ Who would pay for your child’s hearing aids
_____ Where your child would get speech and language therapy
_____ Other, please specify: ____________________________
Which Professionals Work With You
Pediatrician, Developmental Therapist/Hearing, Deaf Mentor, Cochlear Implant Team Member

• Do you and your child receive services from...
• Were you offered this service?
• How much did working with this provider reduce your level of stress?
• How much did working with this provider improve your ability to communicate with your child?
• How much did working with this provider increase your comfort level with hearing loss?
What Do Services Provide You With?

How important is this for you now? How much are you getting of this? Are you satisfied with this?

- Information about available services
- Information about how to communicate with my child who is deaf/has hearing loss
- Knowledge about how deaf children grow up
- Professionals help me to make my needs known and to fight for things necessary
- Coordination of all of the services, and professionals involved with my child and family
- Support to make decisions about my child who is deaf/with hearing loss and my family
- Confidence building in parenting a child who is deaf/with hearing loss
- Contact with other parents of deaf children/with hearing loss (parent-to-parent support)
To What Extent are Professional Services... And how important is this for you?

• Trusting you as the expert.
• Taking into account your family’s culture and lifestyle when working out support plans.
• Providing an optimistic view of the future.
What Has Been the Result of Services/Support?

Overall, how much have professional services made a difference for:

• Your child
• Yourself
• Other parent/guardian
• Child’s Siblings
• Extended Family (Grandparents, aunts/uncles, etc.)
Has this difference been positive for:

- Your child
- Yourself
- Other parent/guardian
- Child’s Siblings
- Extended Family (Grandparents, aunts/uncles, etc.)
Number of Parents Surveyed: 39

Location: Statewide Illinois

Time Period: March 1 – July 31, 2010
Second Round: January 1 – July 31, 2011

Parent Pool: CHOICES for Parents, Developmental Therapists/Hearing in Chicago, Guide By Your Side, Institute for Parents of Children who are Deaf or Hard of Hearing

Through EHDI Supplemental funding, parent received a gift card, return postage paid
Primary Language Used at Home:
English: 31
Spanish: 6
Urdu: 1
Hindi: 1
Year Child Was Born

- 2007 (13)
- 2008 (7)
- 2009 (4)
- 2004 (4)
- 2005 (4)
- 2006 (6)
- 1975 (1)
Challenges experienced related to getting hearing test completed after leaving the hospital

Other: Doctor said that everything was OK, Doctor said to watch the infant's development, 2 out of country births so infant was not screened
Age Child’s Hearing Loss was Identified

- 0 - 3 months (15)
- 1 - 2 years (11)
- Over 2 years (5)
- 7 - 11 months (3)
- 4 - 6 months (3)
- Unmarked (2)
When parents first found out that their child had hearing loss, the following concerns arose:

- Child's medical needs (18)
- Child's success in school (27)
- Child's ability to make friends (11)
- Child's ability to communicate with family (29)
- Where child will get speech/language therapy (21)
- Who will pay for hearing aids (5)
- Familys finances (6)
- Other (5)*
Number of parents who were offered to work with a Deaf Mentor: 9

Number of parents who work with a Deaf Mentor: 5

Number of parents who declined a Deaf Mentor: 4

Unanswered: 4 (of 39)
Primary Communication Mode Used with Child with Hearing Loss*

- Oral/Speech (34)
- ASL (8)
- Signed English (6)
- Cued Speech (1)

* Some parents chose more than one mode
How important is the following to you?
Not Important, Somewhat Important, Important or Very Important?

• Information about how to communicate with my child?
  • Important: 2
  • Very Important: 37

• Support to make decisions about my child and family?
  • Somewhat Important: 1
  • Important: 8
  • Very Important: 30

• Contact with other parents (parent-to-parent support)?
  • Somewhat Important: 4
  • Important: 12
  • Very Important: 23
Professional Services

• 10 parents felt that professionals were not trusting them as the expert on their own child.

• 4 parents felt that professionals did not provide an optimistic view of the future for their child.
Next Steps

• Analyze more data
• Separate English and Spanish results
• On-line surveys
• What do you want to know?