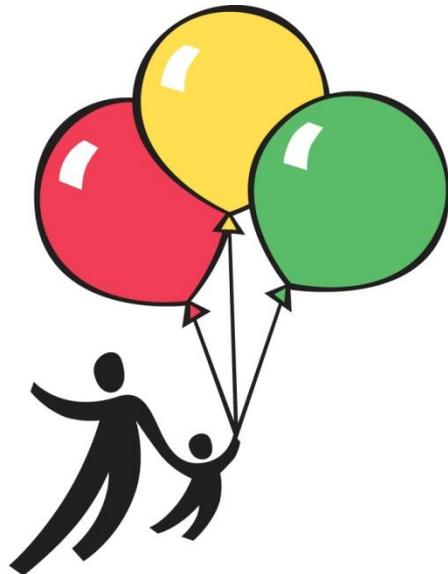


My View On Services



CHOICES
for Parents



**Illinois Early Hearing Detection
and Intervention Program**

Karen Aguilar, Coalition Director

Ginger Mullin, Illinois EHDl Coordinator

Reasons for the Survey

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

Thank You

Young, A.M., Gascon-Ramos, M., Campbell, M., and Bamford, J. (2009) The Design and Validation of a Parent-Report Questionnaire for Assessing the Characteristics and Quality of Early Intervention Over Time J. Deaf Stud. Deaf Educ. 14(4): 422-435.

- 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:

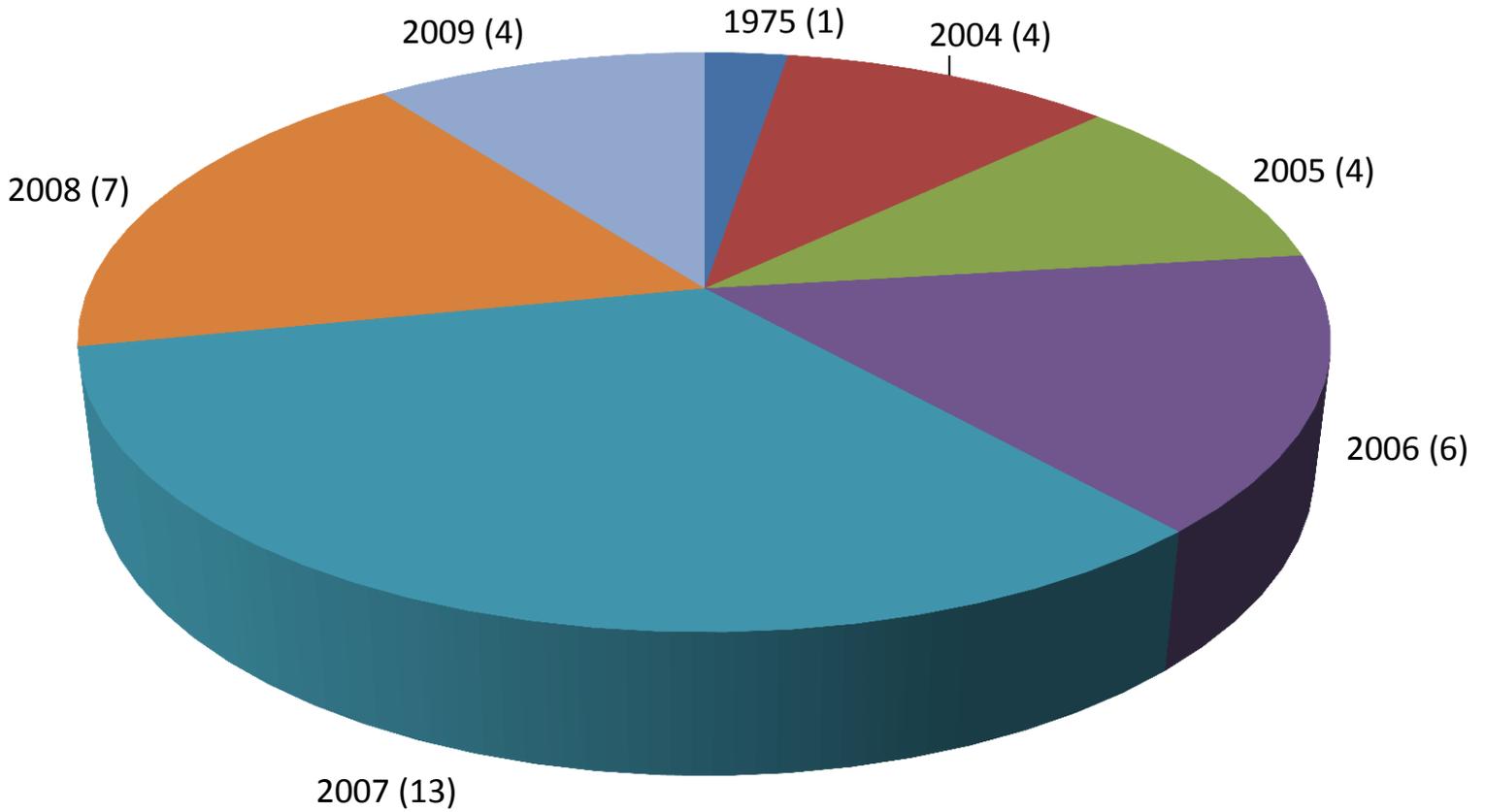
English: 31

Spanish: 6

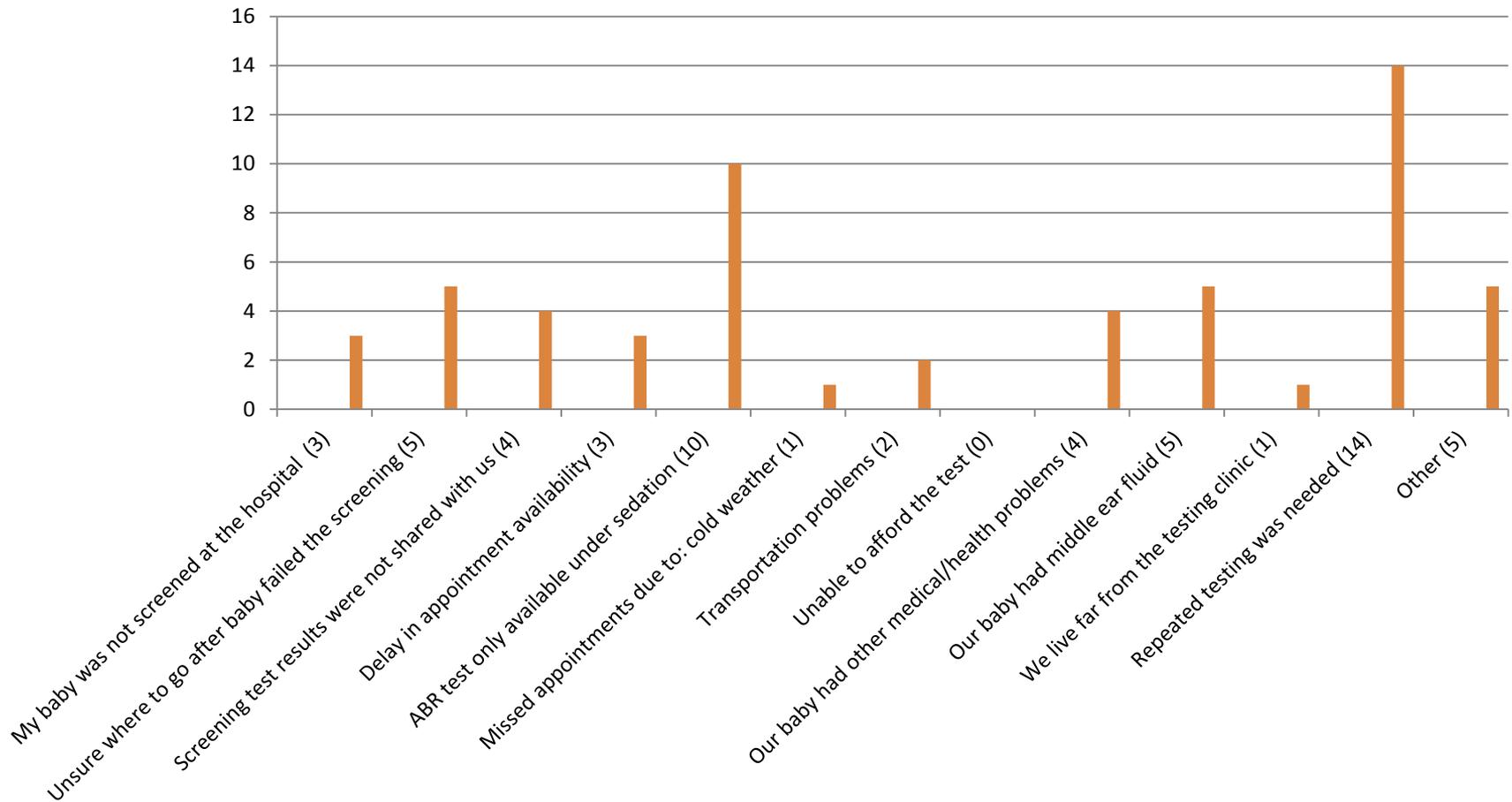
Urdu: 1

Hindi: 1

Year Child Was Born

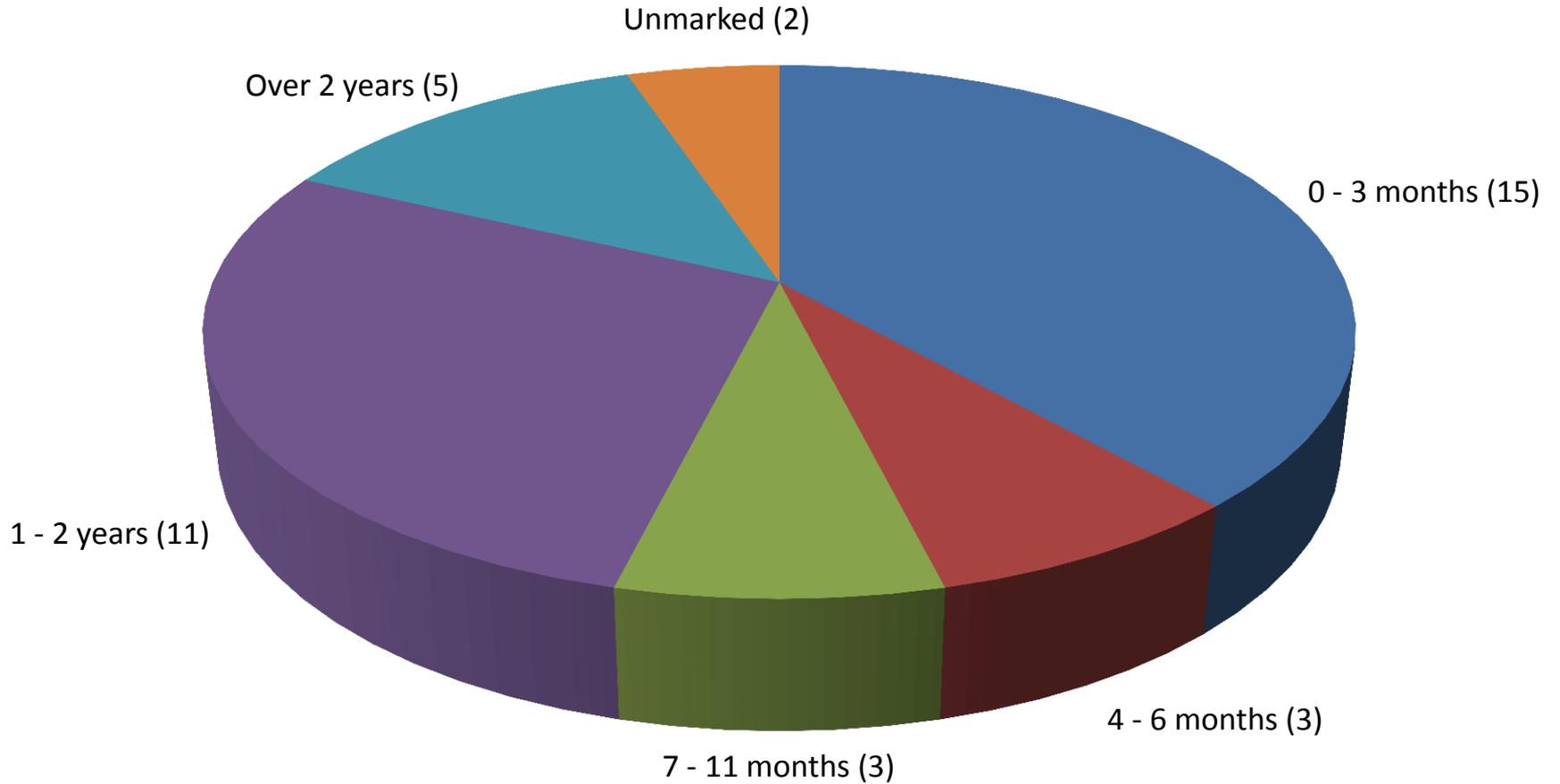


Challenges experienced related to getting hearing test completed after leaving the hospital

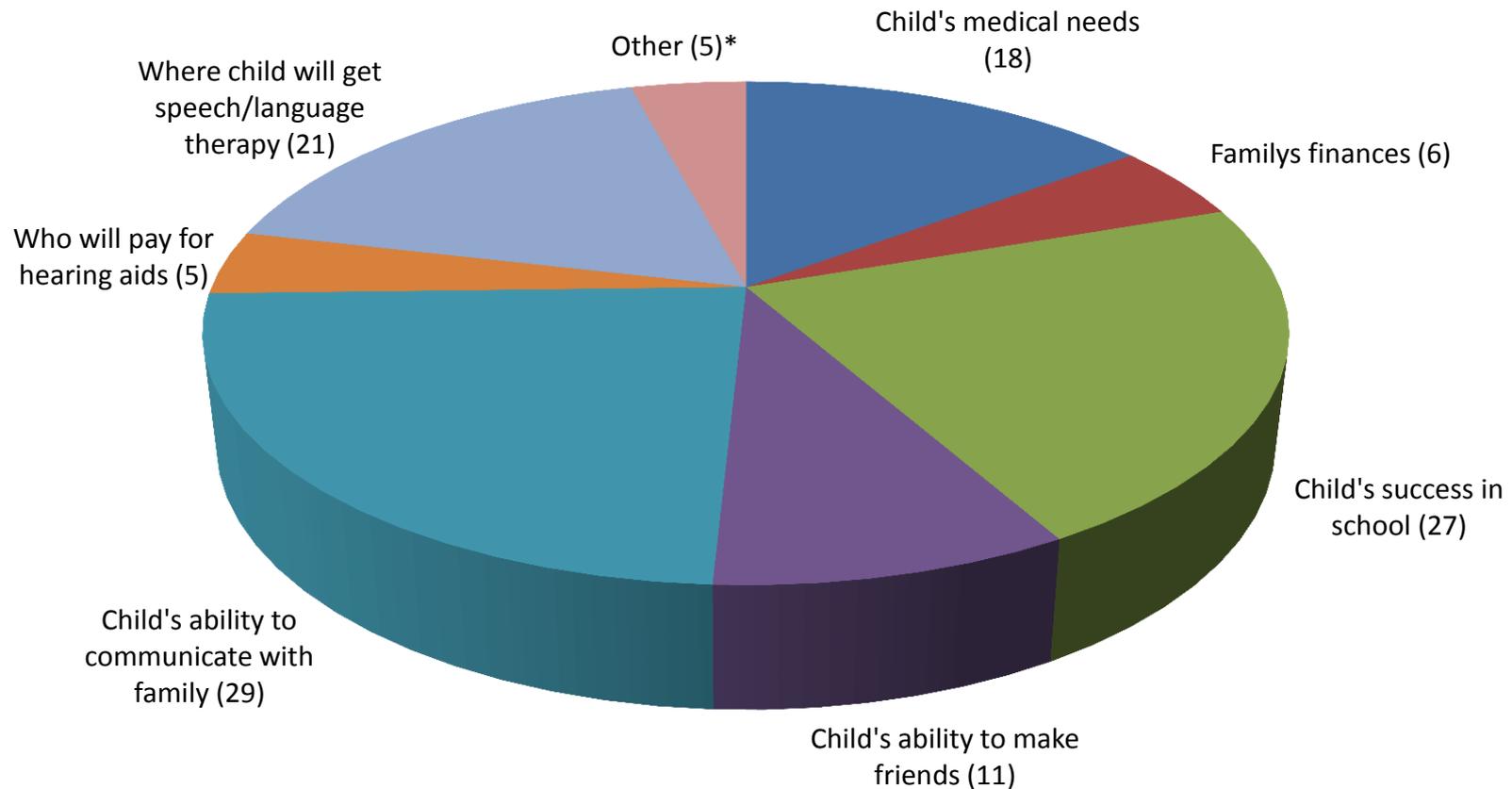


Other: Doctor said that everything was OK, Doctor said to watch the infant's development, 2 out of country births so infant was not screened

Age Child's Hearing Loss was Identified



When parents first found out that their child had hearing loss, the following concerns arose:



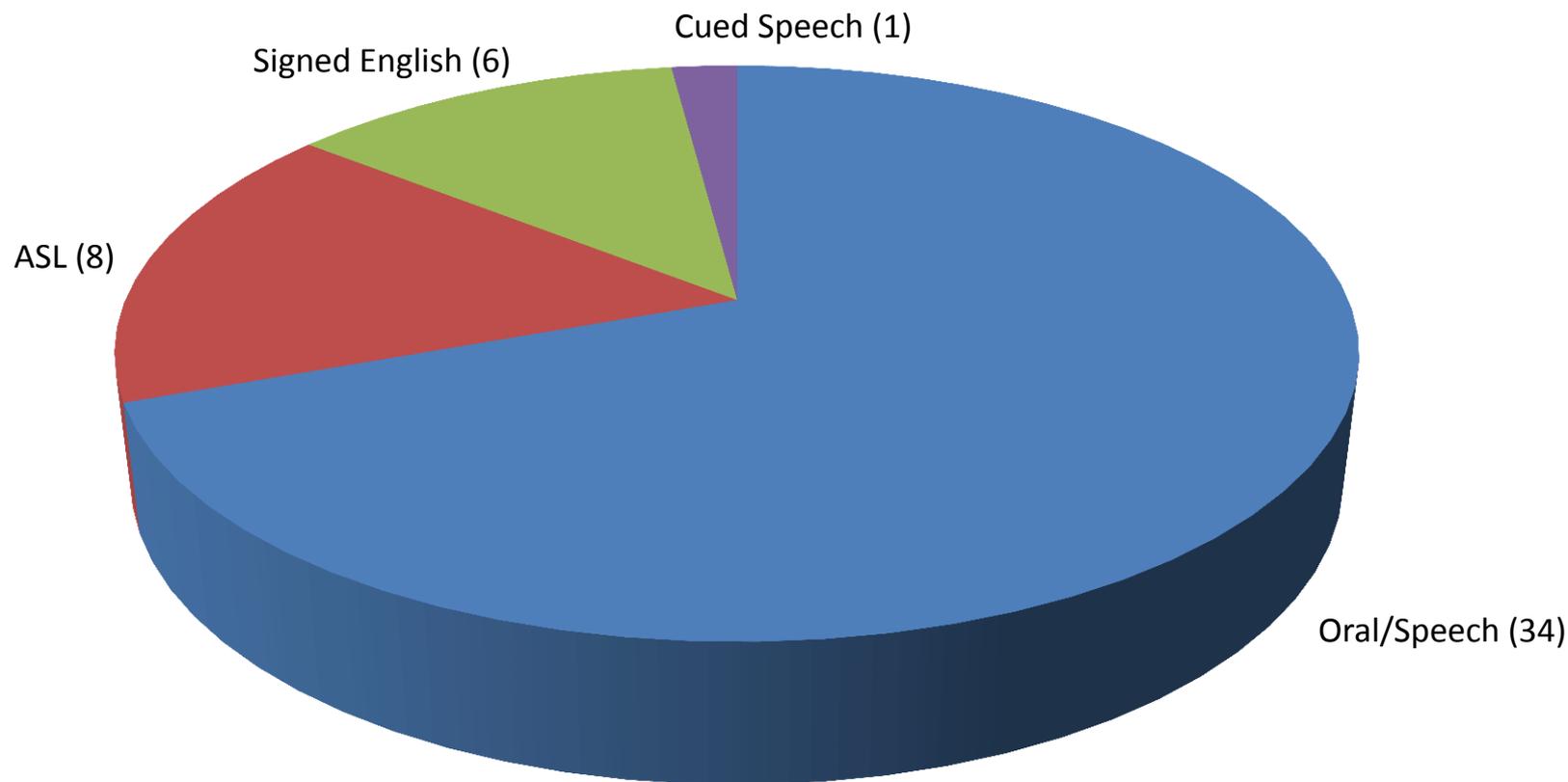
Number of parents who were offered
to work with a Deaf Mentor: 9

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*



* 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?