

Current Trends in Early Diagnosis and Intervention in North Carolina

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EHDI 2011

Overview

1. System of care for infants and toddlers with hearing loss in North Carolina (HL)
2. Review of early diagnosis and intervention
3. Key Findings from Survey of Infant and Toddler Services (SITS)
4. Study Limitations
5. Future Trends in North Carolina

Family-Centered Early Intervention

- “Children and families are inextricably intertwined” (Bailey et al, 1992)
- Individualized, Responsive, and empowering
- Addresses outcomes for the child *and* family

Efficacy of Early Intervention for Infants & Toddlers with Hearing Loss

- Average age of identification for children with severe to profound hearing loss was 12 to 14.5 months of age or later (Harrison & Roush, 1996; Meadow-Orlans et al, 1997).
- Infants who receive early diagnosis have better expressive language skills. (Apuzzo & Yoshinago-Itano, 1995; Calderon & Naidu, 1998; Yoshinago-Itano, Sedey, Coulter & Mehl, 1998)
- Age of intervention strongly predicts auditory skill performance and expressive language outcomes. (Calderon & Naidu, 1998; Pipp-Siegel, Sedey, Mayne & Yoshinago-Itano, 2002; Moeller, 2000)
- Parental involvement strongly contributes to favorable language outcomes. (Moeller, 2000)

EHDI Program Goals

- Screening of all newborns within the first 1 month of life
- Confirmation of hearing loss by no later than 3 months of age
- Receipt of intervention services by no later than 6 months of age
- Systematic data tracking, surveillance and integration
- Coordination of care with the newborn's medical home
- Culturally-competent support and inclusion of families throughout follow-up

NC's EHDI Program by the Numbers

- Authorized by NC General Assembly in **1999**
- Roughly **130,000 occurrent births** annually
- Over **98% of newborns** receive hearing screening each year
- An average of **205 babies** are diagnosed with hearing loss each year
- Around **170-180 infants are eligible** for early intervention services

NC Infant-Toddler Services

- Program originated shortly after passing of P.L. 99-457 in 1986
- Hybrid structure of state program affords more flexibility in services coordination
- 18 Child Developmental Services Agencies
- Office of Educational Services administer services for infant and toddlers with HL
- Three regional directors supervise services at local level (Wilson, 2006)

NC's Eligibility Criteria

“A child may be considered eligible either with a developmental delay or an established condition. ...*Specific conditions through which a child may be deemed eligible in [the latter] category include a unilateral or bilateral permanent hearing loss.*”

Stredler-Brown, Holstrum, & Ringwalt, 2008

Individualized Family Service Plan (IFSP)

- Identifies goals for family and child and is revised every 6 months
- Parents tend to influence the ‘goal selection process’ indirectly. (Minke & Scott, 1993)
- Caregivers who complete formal assessment tools or provide summaries of current levels take more active role in meeting. (Minke & Scott, 1993)
- Parental opinions not always given priority when there is disagreement. (Harrison, Dannhardt, & Roush, 1996)

Child Factors

Unilateral Hearing Loss

- Represents 22% of infants and toddlers with an identified hearing loss and 34% of all diagnosed children (CDC, 2007; Tharpe, 2008)
- Unilateral hearing loss contributes to delays in educational progress, with at least 22% to 35% of children failing one school grade (Bess & Tharpe, 1986; Bovo et al, 1988)
- Children with UHL have demonstrated poorer performance during sound localization tasks and speech recognition tasks of nonsense syllables in noisy environments (Bess, Tharpe, & Gibler, 1987)
- May not qualify for services after 2 years of age due to eligibility criteria for Part B preschool program (Brown, Holstrum, & Ringwalt, 2008)

Multiple Special Needs

- Approximately 38 to 42% of children who are deaf or hard of hearing have at least one additional special need [Gallaudet Research Institute (GRI), 2003; Picard, 2004].
- The most frequently identified conditions include, in order of decreasing prevalence: specific learning disability, intellectual disability, ADHD, and visual impairment (Roush, 2004; GRI, 2006).
- Infants born with at least 2 concomitant birth defects in addition to a hearing loss were more likely to receive a screening after 1 month of age or and diagnosis after 3 months (Chapman, Lynch, & Stampfel, July 2010)

Family Factors

Demographic Characteristics

- Infants from Black, non-Hispanic families in Virginia were more than 2x as likely to receive a hearing screening after the first month of life. (Chapman et al, July 2010)
- Recent evidence from other states suggests loss to follow-up care after screening or diagnosis is more likely for infants born to non-White caregivers (Liu et al, 2008)
- African-American families tend to have less positive experience of early intervention. (Hebbeler et al, 2007; Meadow-Orlans, 1997)

Level of Educational Attainment

(Kluwin & Corbett, 1998)

- Higher proportion of African-American and Hispanic/Latino parents of children with hearing loss who did not complete high school.
- Parents who did not finish high school were less likely to engage in their child's special education programs.

Social Support for Caregivers

- Joint reflection with other parents of hearing-impaired children has been acknowledged as a buffer against heightened maternal stress (Calderon & Greenberg, 1999)
- Parents view support from other parents of children who were deaf as critical to their coping in parenting a child with a cochlear implant. (Zaidman-Zait, 2007)
- Caregivers' level of perceived social support explained unique variance in parenting stress scores beyond the contribution of child factors. (Asberg et al, 2008)

Specific Aims

1. To describe the **types of infant and toddler services** that are most commonly received by families at intervention and caregivers perceptions on the early intervention process.
2. To identify the **median ages of diagnosis, hearing aid fitting and early intervention** for infants and toddlers who have received newborn hearing screening.

Specific Aims

3. To assess the extent to which specific child and family characteristics uniquely predict an **'on-time' versus later diagnosis** for infants and toddlers who received a newborn hearing screening.
4. To examine the extent to which specific child and family characteristics uniquely predict an **'on-time' versus later start to intervention** for infants and toddlers who received a newborn hearing screening.

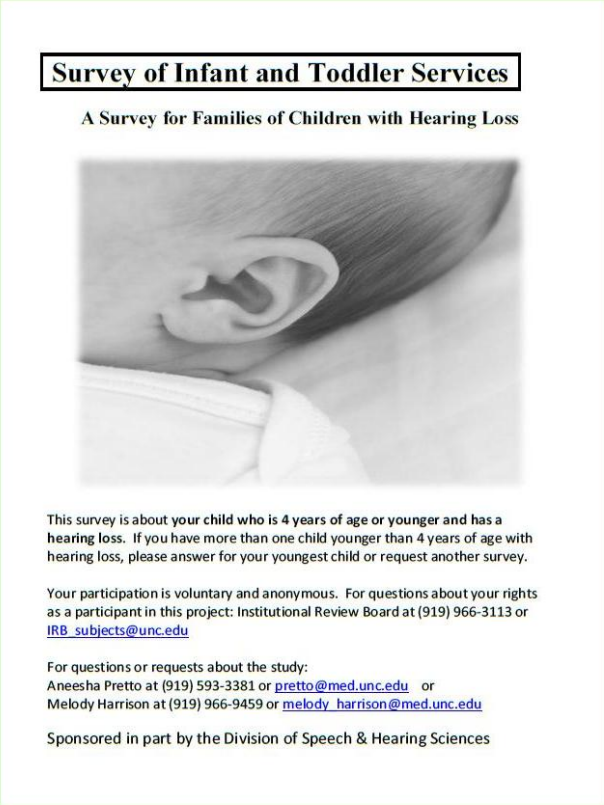
Survey of Infant & Toddler Services (SITS)

Target Population:

Infants and toddlers aged 9 to 39 months at the time of survey with a mailing address on file at BEGINNINGS, Inc.

455 Surveys Distributed


Response Rate: 24%
(n=100)



The flyer is titled "Survey of Infant and Toddler Services" in a bold, black, sans-serif font, enclosed in a thin black rectangular border. Below the title, the subtitle "A Survey for Families of Children with Hearing Loss" is written in a smaller, regular font. The central image is a close-up, black and white photograph of a baby's ear, showing the ear canal and the surrounding skin. Below the image, the text reads: "This survey is about your child who is 4 years of age or younger and has a hearing loss. If you have more than one child younger than 4 years of age with hearing loss, please answer for your youngest child or request another survey." The next paragraph states: "Your participation is voluntary and anonymous. For questions about your rights as a participant in this project: Institutional Review Board at (919) 966-3113 or IRB_subjects@unc.edu". The final paragraph provides contact information: "For questions or requests about the study: Aneasha Pretto at (919) 593-3381 or pretto@med.unc.edu or Melody Harrison at (919) 966-9459 or melody_harrison@med.unc.edu". At the bottom, it says "Sponsored in part by the Division of Speech & Hearing Sciences". The entire flyer is set against a light green background.

Survey of Infant and Toddler Services

A Survey for Families of Children with Hearing Loss



This survey is about your child who is 4 years of age or younger and has a hearing loss. If you have more than one child younger than 4 years of age with hearing loss, please answer for your youngest child or request another survey.

Your participation is voluntary and anonymous. For questions about your rights as a participant in this project: Institutional Review Board at (919) 966-3113 or IRB_subjects@unc.edu

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Sponsored in part by the Division of Speech & Hearing Sciences

Caregiver Characteristics

- Mothers represented 92% of respondents.
- Majority (82%) of caregivers were married.
- Highly educated families were well represented, at 58%.
- White/Caucasian parents represented exactly 3/4ths of sample.
- One-quarter of families resided in a rural area while 69% lived in a suburban area or a large or small city.

Child Characteristics

- Infants and toddlers were almost evenly represented by gender (Boys: 52%, Girls: 48%)
- Nearly one-third (30%) of caregivers reported at least one additional special need besides HL
- Nearly one-third (30%) of children had a unilateral HL, another 69% had a confirmed bilateral HL
- Over one-half (52%) were fitted with hearing aids, and another 13% had at least 1 cochlear implant

Specific Aim #1

Early Intervention Services

Parent Perceptions of Timeliness of Diagnosis & Follow-up

- Approximately 2/3rds of infants and toddlers (64%) received hearing aid amplification following diagnosis
- Over 32% of parents recalled that they did not receive hearing aids for their child until at least 2 months after diagnosis.
- More than one-third (34%) of caregivers reported a duration of at least three months between their child's diagnosis and the start of services
- Majority felt this wait was reasonable
- Sources of delay: 3rd-party payments and difficulty receiving reliable follow-up care.

Assessment & Planning of Intervention

- Over 90% felt included in the assessment process
- Around 1/4th of caregivers indicated that they did not complete any checklists or provide written report of their child's behavior for consideration during testing
- Over 90% of parents felt that they were allowed to make decisions at their own pace during the process and were perceived as equal partners when planning goals.
- Roughly 1/5th of parents *did not* feel or *were uncertain* if team members modified the IFSP as their child progressed

Components of Service

- Teachers of the deaf/hard of hearing served as primary provider. SLPs and Early Childhood Special Educators serving roughly 12 to 13% of families as primary provider.
- Most parents (64%) stated that their early intervention team included 2 to 4 different professionals although some families reported up to 8 separate professionals on their team.

Communication Mode

- More than one-half of parents (57%) indicated that they had adopted a spoken language approach for intervention with their child while just over 1/5th had decided to pursue a sign language approach, typically in combination with spoken language
- Majority (89%) of caregivers felt their provider was 'very skilled' in their chosen approach.

“What would you change about your infant and toddler services?”

“NOTHING”

I have no reason to change anything.

Really nothing. All of our expectations are met.

I AM VERY PLEASED WITH SERVICES.

I wouldn't change anything services are good

“Service Coordination”

The way my child is evaluated. Standardized tests not most preferred.

The process took too long.

INCREASE FREQUENCY OF VISITS

Assign service coordinator based on experience

“Scheduling”

**Time of day we met is close to dinner,
[my child] is tired.**

**Early evening sessions for families
who work.**

**SHOULD ARRIVE ON TIME, TEACHER IS OFTEN
LATE.**

“Parent Support”

**In depth teaching of normal speech
development**

**My city needs more parent support
groups.**

**I DO LIKE TO HEAR OF OTHER FAMILIES IN
SIMILAR SITUATIONS**

**More community based activities for kids that
sign**

“Provider Services”

Too much structure for age

Less songs during therapy, more traditional concepts

MORE FOCUS ON ASL

I would want the sessions to go a little faster

Trouble finding a qualified speech therapist

Specific Aim #2

Median Ages of Diagnosis, HA Fitting,
& Start of Intervention

Child Factors: Presence of Other Special Needs and Laterality of Hearing Loss

	Other Special Needs		Laterality of Hearing Loss	
	HL Only	HL & Other Special Needs	Unilateral	Bilateral
Age at Diagnosis	2.0 (55)	4.5 (18)	2.0 (25)	2.5 (48)
Age at HA Fitting	5.0 (36)	11.0 (13)	**	6.0 (46)
Age at Intervention	6.0 (48)	4.0 (19)	7.0 (19)	5.0 (48)

**Less than 5 cases

Family Factors: Racial/Ethnic Status & Level of Educational Attainment

	Racial/Ethnic Minority Status		Level of Educational Attainment		
	White	Non- White	High School	Some College/Tech. School	College Graduate
Age at Diagnosis	2.0 (53)	3.0 (17)	2.0 (15)	3.0 (16)	2.0 (40)
Age at HA Fitting	5.0 (33)	7.0 (14)	5.5 (12)	7.0 (9)	5.0 (25)
Age at Intervention	5.5 (48)	5.5 (16)	5.5 (12)	4.0 (16)	6.0 (36)

Specific Aim #3

'On-time' versus Later Diagnosis

Factors Influencing Later Diagnosis

- Children who did not pass their newborn hearing screening were less likely to have a later diagnosis
- Children whose caregiver reported the presence of other special needs were more likely to have a later diagnosis

Effective & Timely Follow-up

After failing the newborn hearing screening, the nurse was to schedule a follow-up appointment but did not. We thought it was fluid and took a few weeks to schedule. After the local audiologist confirmed a problem, she called [diagnostic clinic] to schedule a follow-up appointment. [The Diagnostic Clinic] never called so we followed through. This was all fine for us because we wouldn't have let it go. It was very easy for us to say to ourselves, "Well it's probably just fluid. I'm sure she can hear, but we'll make sure." Other families may just be dismissive without pressing ahead with appointments.

-Mother of a 38 month old girl with a severe to profound hearing loss.

Specific Aim #4

‘On-time’ versus Later Start to Intervention”

Factors Influencing Later Start to Intervention (> 6 months)

- Children who received a confirmation of hearing loss after 3 months of age were more likely to have a delayed start
- Children who had a unilateral hearing loss or a non-White caregiver were more likely to have a delayed start
- Children whose caregiver reported additional special needs were more likely to have an early start

Professional Barriers to Service

“The service provider seemed as though she didn’t want to do an IFSP – I got the impression that because he looked ‘normal’ she didn’t think there was a need for special services. She told me we could do one down the road if he seemed to need it – I had to push to have it done – he is profoundly deaf in one ear, moderate in the other – he needed it!”

-Mother of an 8 month old boy who was diagnosed at 3 months

Summary of Key Findings

- Positive experiences with early intervention
- Families are relatively tolerant of delays in receipt of amplification and intervention services
- Most families opt for a spoken language approach
- Children with multiple special needs have increased likelihood for delayed diagnosis but an earlier start to intervention
- Children with unilateral hearing loss or those born to non-White caregivers have an increased likelihood of delayed start to intervention.

Study Limitations

- Small sample size produces lower representation of the minority subgroups
- Self-administered Questionnaire requires moderate to high levels of English literacy
- Anonymity prevents multiple contacts with prospective respondents and cross-validation of responses
- Pilot data to further refine instrument

Future trends affecting EHDI services

- Universal referral form for audiologists
- Hearing Aid Insurance Legislation
- Infants and toddlers with hearing loss transferred to Department of Public Instruction
- Professional Outreach through the NC Consortium for D/HH Continuing Education

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