

Missouri Department of Elementary and Secondary Education

Division of Special Education

Report on First Steps Children Identified through the Newborn
Hearing Screening Program

September 2005

Under the Newborn Hearing Screening law, Section 191.931 RSMo, the Missouri Department of Elementary and Secondary Education shall “monitor the delivery of early intervention services to those infants identified by the newborn hearing screening program and report annually to the department of health.”

This report is divided into five sections as follows:

1. Analysis of the number of children enrolled in First Steps and identified through the newborn hearing screening program during calendar year 2004.
2. Early intervention services provided to Newborn Hearing Screening children under an Individualized Family Services Plans (IFSP).¹
3. Amplification or other assistive technologies children are receiving under an IFSP to address hearing loss.
4. Children identified in 2003 and their progress within the First Steps program.
5. Children identified in 2002 and their progress within the First Steps program.

Personally identifiable information has been redacted pursuant to provisions of the Family Educational Rights and Privacy Act (FERPA), incorporated by reference in the Individuals with Disabilities Education Act (IDEA).

Children Identified by the Newborn Hearing Screening program and enrolled in the First Steps program

Based on the Department of Health and Senior Services’ (DHSS) three-year list of 471 children born in the years 2002-2004 and identified through the Newborn Hearing Screening (NHS), a total of 223 children (47.3%) were found in the First Steps database as of August 2005, meaning they had, at the very least, been referred for eligibility determination to First Steps at some point. This compares to 44.9% (135 of 301) in August 2004 and 31.0% (45 of 135) in August 2003.

<u>2004 Newborn Hearing Screening List</u>	
165 total children	
62 in First Steps Database	
49 found eligible	
	6 inactivated
	2 deceased
	1 completed IFSP prior to reaching maximum age
	1 moved out of state
	1 withdrawn by parent/guardian
	1 refused referral to Part B
	43 active IFSPs
	2 still in referral

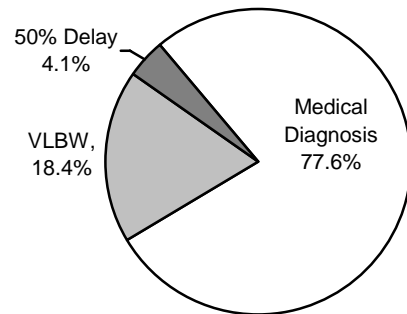
Of the 165 Hearing Screening children born in 2004, 62 were found in the First Steps database; 49 of those 62 were determined eligible for First Steps services based on one of Missouri’s First Steps program eligibility criteria (50% delay in one developmental domain, medical diagnosis, or very low birth weight) and received services through an Individualized

¹ Previous DSE Newborn Hearing Screening reports focused on services given to those born in the last calendar year listed for the report (e.g. the September 2004 report focused mainly on children born in calendar year 2003). Now that there is a larger number of NHS-related children in the First Steps program, this year’s report will focus on services provided to all NHS children found in the First Steps database instead of those born in one calendar year.

Family Service Plan (IFSP). Forty-three were listed as active in the system as of August 9, 2005.

Thirty-eight of the 49 eligible children (77.6%) were determined eligible based on Medical Diagnosis, nine (18.4%) based on Very Low Birth Weight, and two (4.1%) based on 50% delay in one developmental domain.

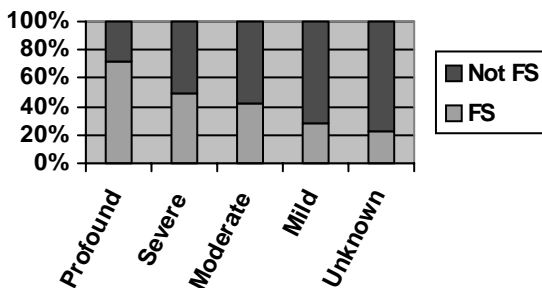
First Steps Eligibility



DHSS categorizes children based upon the degree of their hearing loss: profound, severe, moderate, mild, and unknown. Of the 165 children on the 2004 list, 15 of 21 children in the 'profound' category (71.4%), 7 of the 14 children in the 'severe' category (50.0%), 15 of 36 children in the 'moderate' category (41.7%), 21 of 76 children in the 'mild' category (27.6%), and 4 of the 18 children in the 'unknown' category (22.2%) had also been at least referred to First Steps for eligibility determination.

When all children on the 2002-2004 NHS list are considered, data trends appear to indicate that children with a greater potential need for assistance (those children in the 'profound' or 'severe' categories) are more likely to be referred to First Steps

Percentage of 2004 Children Referred to First Steps by Degree of Hearing Loss



than those children with a lesser need (those children in the 'moderate' and 'mild' categories). Forty-five of the 58 children in the 'profound' category (77.6%) have been referred to First Steps, while 25 of the 42 children in the 'severe' category (59.5%) have been referred. In comparison, only 66 of 120 children in the 'moderate' category (55.0%) and 66 of 195 children in the 'mild' category (33.8%) have been referred to First Steps.

Based on the 2004 data, 50 of 62 children served in First Steps were found to have a disease or diagnosis represented by an ICD9 code and description (there were 56 total diagnoses for these 50 children). Eighteen of the 62 children (29%) had a disease/diagnosis related to hearing loss. This list of different descriptions is as follows:

- Sensorineural Hearing Loss (specified and unspecified) – 9 children
- Hearing Loss (specified and unspecified) – 5
- Central Hearing Loss – 1
- Conductive Hearing Loss – 1

- Deaf Mutism, Oth. Classifiable – 1
- Neural Hearing Loss – 1

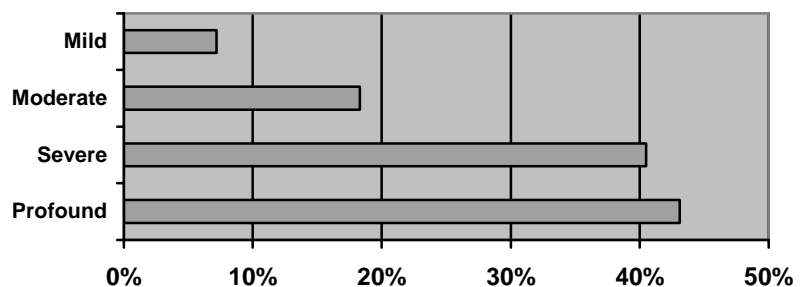
For the 223 First Steps children on the NHS list, 187 of them have at least one ICD9 code diagnosis (a total of 218 diagnoses, both hearing-related and not). The most common hearing-related diagnoses are as follows:

- Hearing Loss (specified and unspecified) – 48 children
- Sensorineural Hearing Loss (specified and unspecified) – 20
- Central Hearing Loss – 3
- Conductive Hearing Loss (specified and unspecified) – 3

Based on degree of hearing loss, 25 of 58 (43.1%) NHS children in First Steps with hearing loss described as 'profound' had a hearing-related ICD9 designation. Each step

down in degree of hearing loss saw a reduction in the percentage of overall children represented with such a designation. Seventeen of the 42 children with 'severe' loss (40.5%), 22 of 120 with 'moderate' loss (18.3%); and 14 of the 195 'mild' loss children (7.2%) had a hearing-related ICD9.

First Steps Children with Hearing-Related ICD9s, by Degree of Hearing Loss



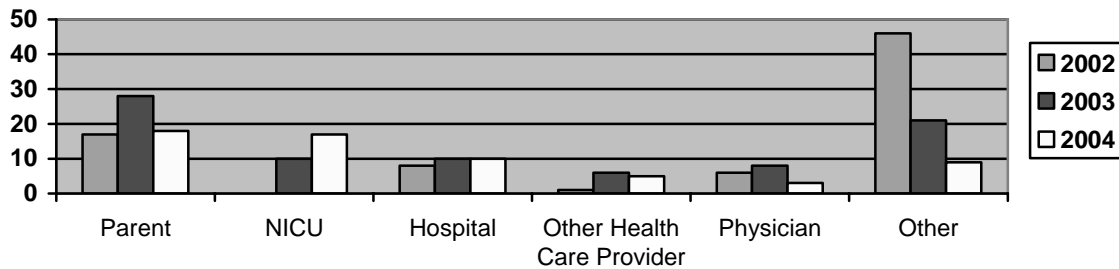
Other ICD9 designations that appeared three or more times among the 223 First Steps children from DHSS' comprehensive list include the following:

- Unspecified Delay in Development – 14 children
- Down's Syndrome – 10
- Cleft Palate (specified and unspecified) – 9
- Low Birth Weight Status, 500-999 Grams – 6
- Microcephalus – 5
- 25-26 completed weeks of gestation – 4
- Disorders Relating to Oth. Preterm Infants 750-999 Grams – 4
- Congenital Hydrocephalus – 3
- Disorders Relating to Extreme Immaturity of Infant – 3
- Disorders Relating to Oth. Preterm Infants – 3
- Low Birth Weight Status, 1000-1499 Grams – 3

Data indicates that the most common primary referral sources of children with hearing concerns in the First Steps system are “Parents”, “NICU”, and “Hospital (other than NICU)”.

From 2002 to 2004, the number of NICU referrals increased significantly (0 for 2002 children, to 10 for 2003, to 17 for 2004), while the number of referrals from sources other than the three primary referral sources above appear to have decreased.

Referral Sources for Hearing Screening Children Referred to First Steps Program



The full list of referral sources for children with hearing concerns during 2002-2004 is as follows:

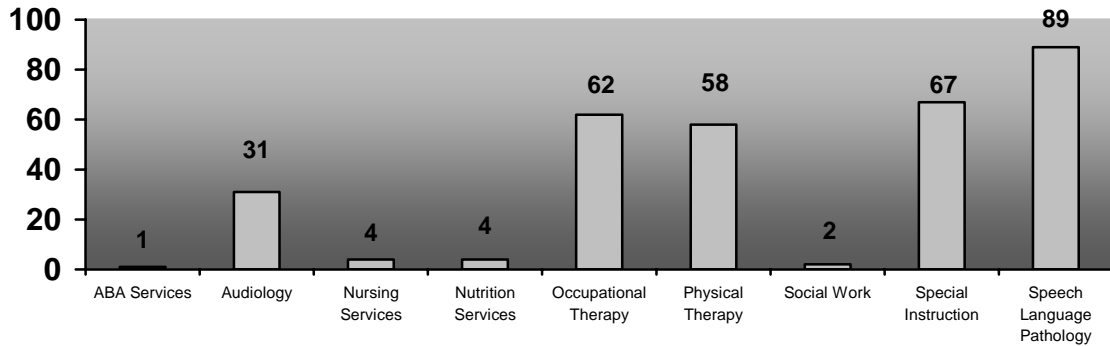
- Parents – 63 children
- Hospital (other than NICU) – 28
- Neonatal Intensive Care Unit (NICU) – 27
- Physician – 17
- Department of Mental Health (DMH) – 13
- Other Health Care Provider – 12
- Head Start/Early Head Start – 11
- Other LEA Program – 11
- Child care program/provider – 9
- Social Service Agency (including DFS) – 9
- Parents as Teachers – 6
- Missouri School for the Deaf (MSD) – 5
- Other Referral Source – 4
- Department of Health & Senior Services (DHSS) – 2

Early Intervention Services

IDEA and the Missouri State regulations require that Part C funds may only be used for early intervention services that an eligible child needs but is not currently entitled to under any other Federal, State, local or private source. Services and

assistive technology reported in this section reflects only those services paid for with Part C funds.

The most frequent services most provided for 143 Newborn Hearing Screening families and children with IFSPs Speech Language Pathology services (89 children), Special Instruction (67), Occupational Therapy (62), Physical Therapy (58), and Audiological services (31). The complete list of services is included in the chart below.



Services Received for all Newborn Hearing Screening List Children receiving services as of August 9, 2005.

As of August 9, 2005, 89 children were receiving Speech Language Pathology services (a total of 149 active authorizations) and 31 were receiving Audiology services (34 active authorizations). While all 34 active Audiology authorizations utilized a Special Purpose Center setting, the 149 SLP authorizations were provided in a variety of settings. The majority (103, or 69.1%) of the SLP authorizations took place in the Home (103, or 69.1%); 20 (13.4%) took place in a Special Purpose Center (20, or 13.4%), 20 (13.4%) took place in a Community Setting, and 6 (4.0%) took place in Other Family Locations.

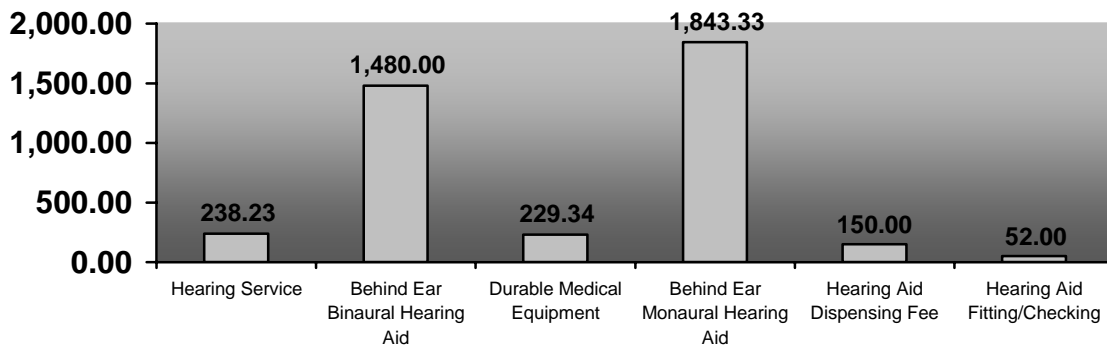
Amplification and Other Assistive Technologies

During the period of August 1, 2004, to July 31, 2005, 53 of the Newborn Hearing Screening children with First Steps IFSPs received some type of amplification device or other assistive technology through the First Steps system. A total of 301 authorizations for assistive technology for these children cost the system \$90,476.20, or an average of \$300.59 per authorization. Assistive technology ranged from Volume Control Covers (\$2) to a Phonak Microlink Personal FM System (\$2,894).

The 301 authorized assistive technology devices could be separated into 22 Healthcare Common Procedure Coding System (HCPCS) categories. The six hearing-related categories are presented below, in order of cost (highest to lowest):

- Hearing Service (V5299) – \$42,881.59
 - 180 authorizations, \$238.23 per authorization
- Behind Ear Binaural Hearing Aid (V5140) - \$17,760
 - 12 authorizations, \$1,480 per authorization
- Durable Medical Equipment, Miscellaneous (E1399) - \$13,990
 - 61 authorizations, \$229.34 per authorization
- Behind Ear Monaural Hearing Aid (V5060) - \$5,530
 - 3 authorizations, \$1,843.33 per authorization
- Hearing Aid Dispensing Fee (V5090) - \$150
 - 1 authorization
- Hearing Aid Fitting/Checking (V5011) - \$104
 - 2 authorizations, \$52 per authorization

The amount spent per authorization for hearing related assistive technology is shown in the following graph.



Amount per Authorization spent on Hearing-related Assistive Technology devices and procedures, August 2004 to August 2005

Follow-up on Children born in 2003 and Identified through the NHS Program

<u>2003 Newborn Hearing Screening List</u>	
154 total children	
83 in First Steps Database	
70 found eligible	
11 inactivated	
	6 moved out of state
	2 withdrawn by parent / guardian
	2 deceased
	1 moved to another SPOE
59 still active	
	55 active IFSP
	4 awaiting IFSP

Of the 154 children born in 2003 and identified by the Newborn Hearing Screening program, 83 were found in the First Steps database. Seventy of those 83 were found eligible and entered into the IFSP process, and 59 were listed as still active in the system as of August 9, 2005.

In comparison, DESE's August 2004 report showed 73 NHS children in the First Steps database (a 13.7% increase from 2004 to 2005), 62

determined eligible based on Missouri's eligibility criteria (12.9% increase), 58 determined eligible and still active in the First Steps system (1.7% increase).

Follow-up on Children born in 2002 and identified through the NHS Program

Of the 152 children born in 2002 and identified by the Newborn Hearing Screening program, 78 were found in the First Steps database as of August 9, 2005. Sixty-seven of those 78 were found eligible and entered into the IFSP process, and 41 were listed as still active in the First Steps system.

In comparison, DESE's August 2004 report indicated the following: 62 children served in the First Steps system (a 25.8% increase from 2004 to 2005) and 41 determined eligible and still active in the First Steps system (no change).

As the 2002 NHS children begin to age out of First Steps eligibility, a look at Part B-related exit reasons can begin to take place. Of the 26 First Steps-eligible children who have been inactivated from the system, 13 (50.0%) transitioned into Missouri's Early Childhood Special Education (ECSE) program, 2 (7.7%) were undergoing Part B eligibility determination, and 2 (7.7%) had been deemed Part B ineligible and exited the First Steps program without a Part B referral. The other nine were exited because of other reasons (moved out of state, withdrawn by parent/guardian, unable to locate, or moved to another SPOE).

<u>2002 Newborn Hearing Screening List</u>	
152 total children	
78 in First Steps Database	
67 found eligible	
26 inactivated	
	13 transitioned to Early Childhood Special Education (Part B)
	3 moved out of state
	3 withdrawn by parent / guardian
	2 unable to locate by Service Coordinator
	2 Part B eligibility determination in process
	2 Part B ineligible, exit without referral
	1 moved to another SPOE
41 still active	
	22 active IFSP
	1 still in referral
	18 awaiting IFSP -or- children with summer birthdays to be inactivated and moved on to Part B in September.

Conclusion

As more Newborn Hearing Screening children begin to appear in the First Steps program, more assessments of trends and data can be made. As would be assumed, there is a significant increase in First Steps participation between the first and second year for Newborn Hearing Screening children (meaning the percentage of 2002 NHS children found in the First Steps database increased

between 2003 and 2004; the percentage of 2003 NHS children increased between 2004 and 2005). For the 2002 NHS children, their third year saw a similar increase in First Steps participation.

<i>Percent of Newborn Hearing Screening Children found in First Steps database as of report date</i>			
	First Year	Second Year	Third Year
2002 children	31.0%	42.8%	51.3%
2003 children	46.8%	53.9%	
2004 children	37.6%		

As would also be expected, those children with severe and profound hearing loss are more likely to be found in the First Steps database and found eligible according to the First Steps eligibility criteria. Children on the Newborn Hearing Screening list are most likely to be referred to First Steps by either their parents, Hospitals, or Neonatal Intensive Care Units (NICU) and, if found eligible, receive speech language pathology and special instruction authorized on their Individualized Family Services Plan (IFSP).

One concern with this year's statistics is that only 37.6% of 2004 NHS children were found in the First Steps database, a lower first-year total than the 46.8% of 2003 children represented in the September 2004 report.

The Department of Health and Senior Services (DHSS) has received a grant to support implementation of Newborn Hearing Screening, both in terms of health care professionals' expertise in administering the screening and Early Intervention service providers' expertise in serving identified children. The Effective Practices section of the Division of Special Education is collaborating with DHSS to provide web-based, on-demand awareness training to First Steps service providers, coordinators, and System Points of Entry (SPOE) administrators. The purpose of this training is to increase the level of knowledge and skill used to serve identified children, and to improve the decision-making around which identified children meet Missouri's First Steps eligibility requirements. The First Steps system will support providers' participation in this training by authorizing it as creditable to the providers' ongoing credentialing requirements.

In future DSE reports to DHSS, the amount of data available for review will be significantly increased due to DESE's Summer 2005 initiation of a web-based Child Care Management (CCM) system for the First Steps program. Previously uncollected data related to outcomes, IFSP services, domain and demographic information, will be collected and analyzed over the course of the next 1-2 years.