Regional Analysis of EHDI Outcomes in North Carolina

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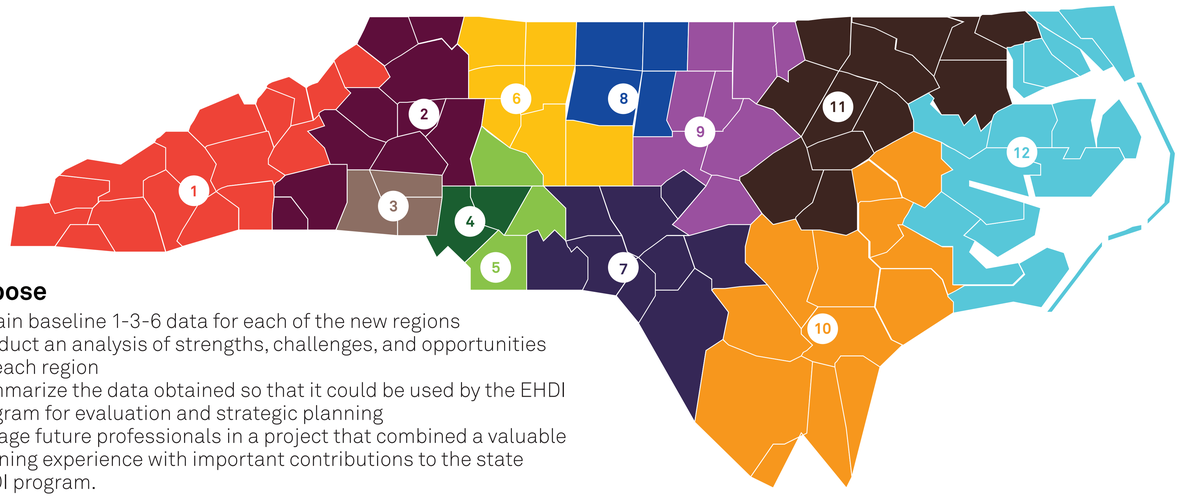
Introduction

Six UNC graduate students in audiology funded by the North Carolina LEND Program collaborated with staff from the North Carolina Division of Public Health to conduct a statewide analysis of EHDI-related outcomes for 12 newly created geographic regions, to determine strengths, challenges, and opportunities for EHDI program development and improvement. The EHDI program in North Carolina is located within the NC Department of Health and Human Services, Division of Public Health, and is administered by staff in the Genetics and Newborn Screening Unit who work closely with other agencies that serve children with special healthcare needs. In 2015, the EHDI program underwent major reorganization that increased the number of geographic regions from 6 to 12. Each region was assigned a single EHDI staff member responsible for monitoring screening, diagnosis, intervention, and related activities for children in their region. These changes are intended to improve continuity of care and greater familiarity with regional providers. The reorganization also resulted in three standing committees that focus on data application, enhanced education and training for professionals, and expansion of public awareness and family involvement.



Purpose

- Obtain baseline 1-3-6 data for each of the new regions
- Conduct an analysis of strengths, challenges, and opportunities for each region
- Summarize the data obtained so that it could be used by the EHDI program for evaluation and strategic planning
- Engage future professionals in a project that combined a valuable learning experience with important contributions to the state EHDI program.

Methods

In addition to quantitative data, the students examined demographic and geographic features that could impact the delivery of EHDI services. The first step was for the students to meet EHDI staff from each region. This opportunity was provided in October, 2015, when North Carolina held its first statewide EHDI Stakeholders Meeting which was hosted by NC LEND. Attendees were members of the EHDI staff and Advisory Committee including professionals, parents, and representatives of several agencies and programs that serve children with hearing loss in North Carolina. The 47 participants were assigned to rotating focus groups that worked to define strengths, challenges, and opportunities for program development and improvement. During the stakeholder meeting the LEND students met with EHDI staff to discuss regional characteristics, demographics, strengths, and needs. In the weeks that followed, the students examined regional 1-3-6 outcome data provided by the Division of Public Health. They also communicated with their EHDI representatives regarding perceived strengths, challenges, and opportunities within each region.

Combined 2012–2014 Values	Region 1	Region 2	Region 3	Region 4	Region 5	Region 6	Region 7	Region 8	Region 9	Region 10	Region 11	Region 12
Total Live Births (2012-2014)	12940	21967	12903	48823	13583	29388	35046	27138	66252	41424	25867	12940
Require ReScreen	384	559	427	1541	396	1106	569	397	1087	823	531	263
Require Diagnosis	146	135	120	414	99	298	178	121	326	305	157	45
Received Diagnosis By 3 Months ↑	32.2%	31.1%	28.3%	29.5%	29.3%	35.2%	16.9%	46.3%	33.7%	13.1%	20.4%	28.9%
Received Diagnosis After 3 Months ↓	19.2%	23%	29.2%	25.6%	26.3%	25.5%	28.7%	26.4%	26.1%	17.4%	22.3%	22%
Loss to Follow Up	38.4%	29.6%	40%	37.7%	39.4%	31.9%	48.9%	20.7%	31.3%	63.6%	51.6%	40%
*Other Loss	*10.2%	*16.3%	*2.4%	*7.2%	*5%	*7.4%	*5.5%	*6.6%	*8.9%	*5.9%	*5.7%	*8.9%
Require Early Intervention	44	42	27	86	29	77	51	68	112	50	35	9
Received Early Intervention By 6 Months ↑	63.6%	52.4%	51.9%	60.5%	62.1%	41.6%	49%	64.7%	54.5%	42%	28.6%	33.3%
Received Early Intervention After 6 Months ↓	15.9%	33.3%	33.3%	29.1%	17.2%	23.4%	25.5%	13.2%	25.9%	28%	45.7%	33.3%
Loss to Follow Up	6.8%	4.8%	3.7%	5.8%	17.2%	32.5%	19.6%	13.2%	16.1%	22%	14.3%	11.1%
*Other Loss	*13.7%	*9.5%	*11.1%	*4.6%	*3.5%	*2.5%	*5.9%	*8.9%	*3.5%	*8%	*11.4%	*22.3%
Hearing Aid Fitting By 6 Months	34.1%	33.3%	11.1%	24.4%	27.6%	24.7%	17.6%	29.4%	28.6%	30%	17.1%	11.1%
After 6 Months	27.3%	33.3%	25.9%	39.5%	27.6%	18.2%	31.4%	16.2%	28.6%	26%	37.1%	44.4%
Never Fit	38.6%	33.3%	63%	36%	44.8%	57.1%	51%	54.4%	42.9%	44%	45.7%	44.4%
Strengths	Local providers are expanding pediatric audiology services	EHDI consultants have the equipment needed to provide hearing screening	Several diagnostic sites	Birthing facilities provide their own rescreenings	Excellent cooperation of PCP and hospital staff in providing patient information to EHDI consultant	Strong rural Public Health Departments support EHDI Consultant with variety of family issues	Good working relationship with hospital staff, and others in system	Strong early intervention staff that can help family once 1-3-6 goals met	All birthing hospitals provide their own outpatient re-screenings	Good primary care provider and EHDI consultant relations and communication	Reliable referral pathways between primary care physicans and diagnostic sites	Accountability and reliability in communication, referrals, and follow up due to small numbers of primary care providers
Challenges	Lack of access to qualified service providers; families travel long distances for comprehensive care	Lack of access to qualified service providers; families travel long distances for comprehensive care	Lack of access to qualified service providers who accept Medicaid patients	Lack of access to qualified service providers who accept Medicaid patients	Home births refuse hearing screening	Lack of access to qualified service providers; families travel long distances for comprehensive care	Lack of access to qualified service providers; families travel long distances for comprehensive care	Red tape and lack of funding impedes generation of online EHDI training for providers	Multiple referrals to ENT for middle ear management results in delayed diagnosis and management of underlying sensorineural hearing loss	Lack of access to qualified service providers; families travel long distances for comprehensive care	Lack of access to qualified service providers; families travel long distances for comprehensive care	Lack of access to qualified service providers; families travel long distances for comprehensive care
Opportunities	Potential for cochlear implant services	Establish criteria for qualified providers of pediatric audiology services	Provider education (families attend 1< sites for diagnosis, hearing aid fitting, and ENT consultation	Provider area meeting (2 major health facilities in region)	Individual hospital NBHS liaisons	Strengthen EHDI consultant relationships with families and encourage use of public health resources to combat barriers to access 1-3-6 services	Outreach and use of technology for education and training (PCPs, midwives, system partners)	Online training for collaborating health partners	More consistency from health systems in diagnostic protocol and information provided to prepare for appointment	Expanding teleaudiology services	Education related to cultural competence and sensitivity	Include local health departments in the screening process and tracking babies potentially LTFU
Median Household Income [2014]	$38,654	$39,966	$43,339	$55,203	$49,942	$42,390	$38,534	$41,226	$50,568	$39,694	$38,419	$45,159
Medicaid Eligibles 0–5 Years [2014]	60–74%	60–74%	60–74%	35–60%	35–60%	60–74%	60–74%	60–74%	60–74%	60–74%	74–87%	60–74%

Results and Discussion

As anticipated, all 12 regions are doing well with the goal of screening by 1 month of age. There was considerable variability, however, in the goals associated with diagnosis and intervention. On average, 26.8% of regions statewide completed diagnosis by 3 months. The range among regions, from a high of 46.3% in Region 8 to a low of 13.1% in Region 10, shows substantial variability. While the statewide average for initiating early intervention by 6 months was 51.3%, only 24% had hearing aids fit by 6 months. Again we see significant variability among regions from a high of 34.1% with hearing aid fitting by 6 monthss in Region 1 to a low of 11.1% in Region 12. Also reported for each region are selected demographic characteristics including median household income and percent of children eligible for Medicaid between the ages 0–5. Further analyses are underway to explore the relationship of these variables to 1-3-6 and other EHDI-related outcomes.

A number of *Strengths* were common to nearly every region including expansion of EHDI-related services in some regions and an increase in the number of hospitals conducting their own outpatient re-screenings. Several regions reported good working relationships with hospitals and reliable referral pathways between the primary care physician and diagnostic sites. There were also a number of *Challenges* noted, some of which were common to several regions. Nine out of 12 regions reported families have difficulty accessing professional services, citing transportation as a key challenge. This problem is especially acute for families with children insured through the state Medicaid program. Other challenges were related to management of middle ear disease or missed screenings for babies born at home. It was gratifying to see a number of *Opportunities* with specific recommendations for program development and improvement. The findings reported here will be helpful to the EHDI Program in setting future EHDI-related goals and objectives.

Next Steps and Future Directions

This study has provided the first regional analysis since the statewide EHDI reorganization in 2015. The findings will be incorporated into EHDI goals and objectives with the aim of improving the quality and accessibility of services for children who are deaf or hard of hearing and their families.

The LEND-funded students involved with this project will soon be starting their fourth year externships, some in North Carolina and some in other states. Those remaining in North Carolina will present these findings to the EHDI Advisory Committee in July, 2016, and will participate in further analysis as time permits. A primary goal, to engage LEND-funded audiology students in a project aimed at combining a valuable learning experience with an important contribution to the state EHDI program, was clearly achieved.

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