

Sanford Children's Hearing Loss Clinic

Start-up, Successes, & Challenges

Quinn Stein, MS, CGC

Amy Mroch, MS, CGC



What did our grant consist of?

- **Personnel:** Dollars for a genetic counselor to spend ~6 months/up to 20 hours a week building and coordinating Hearing Loss clinic
- **Travel:** Dollars for the clinic coordinator to visit the Hearing Loss Clinic at Boys Town in Omaha, Nebraska. The purpose of was to gain knowledge of operations and follow up in a successful Hearing Loss Clinic.
- **Other:** Dollars to invite Dr. William Kimberling to visit Sanford Children's Comprehensive Hearing Loss Clinic, for him to provide technical assistance, and for him to present at a Sanford School of Medicine Pediatric Grand Rounds (Usher Syndrome and Hearing Loss).





Background

- In 2001, South Dakota was awarded a CDC Cooperative Agreement to establish an Early Hearing, Detection and Intervention (EHDI) tracking program.
 - EHDI programs have been established across the nation
 - role is to support early identification of hearing loss through screening, audiologic and medical evaluation, & enrollment in early intervention.
 - According to South Dakota's EHDI program data, more than 96% of all infants have been screened in the state since 2006.
 - While it is encouraging that the rate of screening is high, the program is voluntary and lacks the structure to provide follow up for those identified with hearing loss. A program that is optional has no capacity for data collection or long-term follow up.
- Nowhere in the “region” was there an easily accessible hearing loss clinic
- We believed that by establishing a pediatric hearing loss clinic we could
 - provide in-depth evaluation of each child's hearing loss and its causes
 - communicate information to primary care physicians and educators
 - respond to the ongoing needs of families and children with hearing loss.

SANFORD
Children's

More Background

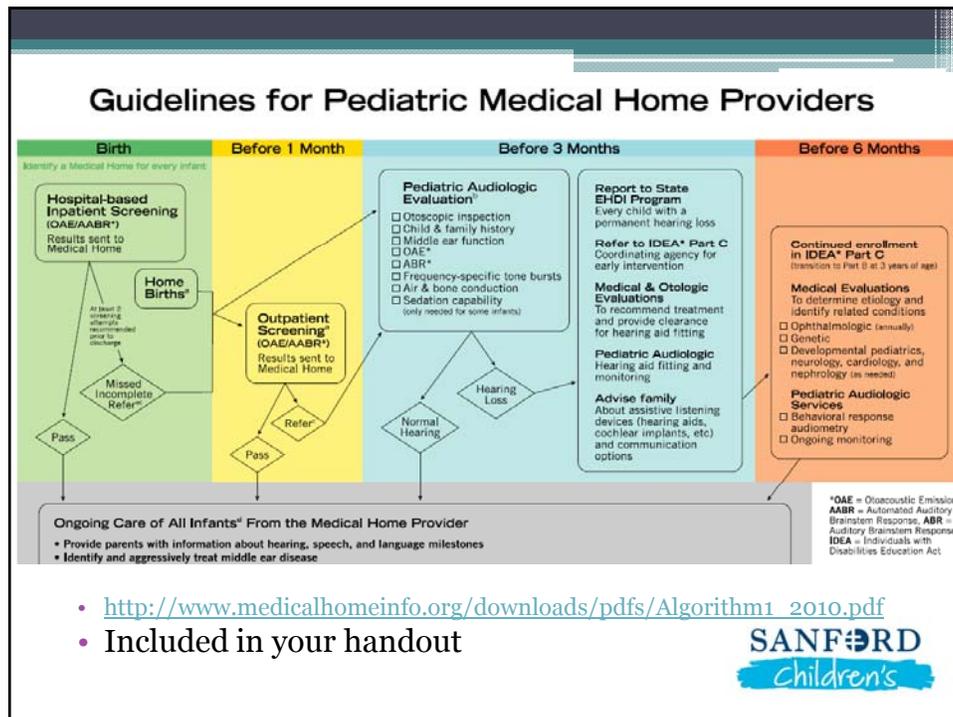
- The CDC, AAP, & the American Speech-Language-Hearing Association recommend infants with some degree of hearing loss begin receiving early intervention before 6 months of age.
- According to the AAP, at or before 3 months of age, every child with a permanent hearing loss should be identified and referred for medical and otology evaluations as well as for audiologic follow up. Medical evaluations also need to include ophthalmology and genetics.

SANFORD
Children's

Even More Background

- Genetic services for deafness are being sought more often since a specific diagnosis can often guide proper treatment. A study in the October 2009 *Journal of Genetic Counseling* documented that parents prefer that this genetic evaluation, including testing, occur either immediately at or a few months after the audiologic diagnosis of hearing loss.
- 50% of affected individuals have a genetic etiology
 - genetic counselors/medical geneticists are integral part of the evaluation.
- Currently, very few children with hearing loss are referred for genetic evaluation in South Dakota.
 - Those who are tend to be seen between 6-24 months of age
 - a medical plan has already been established.

SANFORD
Children's



Background Data

- In 2008, we (i.e. Genetics) received 2 referrals for hearing loss, both of which were identified through newborn hearing screening
- In 2009, we received two genetic referrals for hearing loss, one of which was identified through newborn hearing screening and one of which was an adult who also had vision loss.
- The incidence of hearing loss is believed to be 3 in 1,000 births.
 - SD has averaged 12,000 – 13,000 births per year for the past 3 years.
 - Empirically, this means that 35-40 children with hearing loss are born each year in South Dakota alone, and that the great majority of these children are not receiving a genetics evaluation

- Hypothesis: By including genetic evaluations and genetic counseling within a comprehensive hearing loss setting, we believe that we can both increase the number of children receiving a genetics evaluation and decrease the time from the identification of the hearing loss to genetics referral.
- Justification for genetic counselor: The unique skill set possessed by a genetic counselor (communicating complicated information to families, regular communication with physicians and allied providers, coordination of multiple appointment visits, written communication skills, and experience with rare conditions) make genetic counselors ideally trained as clinic coordinators, especially when *medical genetics* is one arm of a multidisciplinary clinic.



Proposal to Heartland

- establishment of Comprehensive Pediatric Hearing Loss Clinic
- target those children identified through South Dakota's EHD program who have failed their first screen without a follow-up screen and those children who have failed their first and second screen.
- A clinic could identify the potential genetic cause of the hearing loss, possible interventions and a medical plan to support children with hearing loss.
- Hearing aid evaluation & fitting or cochlear implant evaluation would be available.
- concept of this clinic is to provide a specialty medical home for children with hearing loss in our region.
- This clinic will improve coordination and communication between primary care providers, genetic specialist, multidisciplinary team members and the family.
- *Will also see children much older than 6 months*



Proposal to Heartland Genetics

- We will disseminate our experience through an oral presentation at the annual Heartland regional meeting. (Bismarck – Fall 2011)
- We will be willing to provide assistance to other entities looking at starting a similar clinic through site visits and hosting guests at Sanford Children's.



Coordinator = Genetic Counselor

The genetic counselor/coordinator shall

- work with the SD department of health to promote the clinic as a resource for those identified through the EHDI program
- work with the primary care physicians in establishing and communicating a medical plan
- provide genetic counseling to patients
- schedule monthly clinics
- arrange genetic testing when appropriate
- arrange ancillary appointments such as evaluations for developmental pediatrics, neurology, cardiology, and nephrology as needed
- collect baseline data regarding referrals and document diagnoses
- provide continuing education to clinicians, and
- partner with community/state/federal programs to help children and families adapt to the hearing loss



Personnel

- **Key**
 - Otolaryngologist (ENT)
 - Geneticist
 - Ophthalmologist
 - Audiologist
 - Speech Language Pathologist
 - Social Worker
 - Nurse
 - Genetic Counselor (also clinic coordinator)
 - *SD School for Deaf*
- **Adjunct**
 - Cardiology
 - Developmental pediatrics
 - Neurology
 - Nephrology
 - Infectious disease
 - Radiologist
 - Child Life



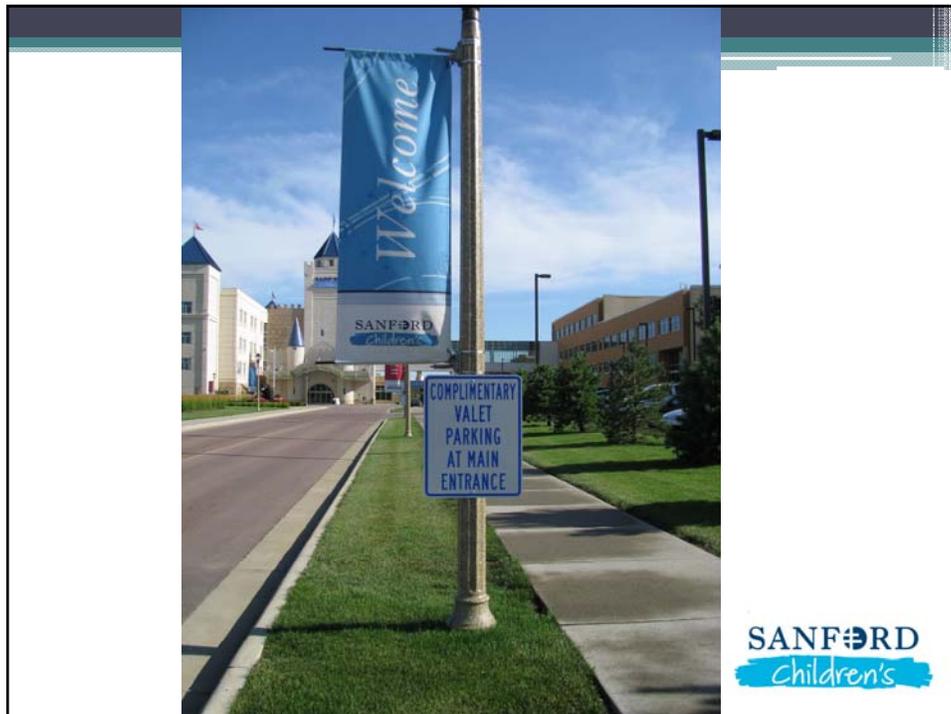
Sustainability

- The clinic bills for physician charges and any ancillary testing
 - (No one turned away from the clinic based on inability to pay)
- Upfront investment was the time needed to build relationships, identify patients and build a database for long term outcomes
- Some of the most important professional relationships and referral patterns have now been established, and more are being cultivated
- Sanford Children's Specialty Clinic will absorb the ongoing cost of the clinic coordination. This investment is minimal compared to the up-front time/costs needed to get the clinic off the ground.



Collaboration

- Dr. William Kimberling, expert on Usher syndrome & hearing loss.
 - March 16th/17th – gave pediatric grand rounds
 - which was awesome!
 - met with the hearing loss clinic team
- Sanford School of Medicine Center for Disabilities
- SD School for the Deaf
- South Dakota Department of Health



How many patients?

How often?

- This is how we wrote the proposal
 - A monthly clinic will be scheduled and 8-10 patients will be seen during each clinic.
 - However:
 - clinic space is a challenge
 - After observing noted that Boystown sees 2-4/clinic
 - referrals have amounted to 2-3 per clinic



Day to Day

- How is the clinic scheduled
- What happens during a “clinic day”



Types of Referrals seen so far

- Who have the patients been? (ages)
- Where have they come from? (places)
- What have been the diagnoses?
- When is the quickest patients can be seen?
 - Has the clinic resulted in earlier access for patients?



Suceses

- Getting started
 - February 2011
- Knowledgeable staff
- Long term Sustainability
 - Monthly clinics
- Partnership with School for the Deaf



Challenges

- Getting a website built
 - Done 8/4/11
 - <http://www.sanfordhealth.org/Stories/View/0826b6c3-e1eb-490a-b43e-f5052f2302ba>

- Getting referrals for patients <6 months
 - Attend yearly state Audiology conferences
 - Speak to AuD students
 - Volunteer to speak at other conferences
 - Legislation? (not likely)

