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ISD OUTREACH:

building connections

to empower indiana families with young deaf and hard of hearing children

By Cindy Lawrence

At the time of this printing, the Indiana First Steps and Early Hearing Detection and Intervention programs are undergoing system changes due to budget constraints. The Outreach Department at the Indiana School for the Deaf (ISD) is proposing changes that may result in a more seamless service delivery. To learn more about these changes, visit www.deaf-kids.org.

In Indiana, families with newly identified deaf and hard of hearing children may have varying experiences in discovering the support systems available to them. Indiana has a Part C early intervention (EI) program, known as First Steps, that serves all children at risk or identified with a disability. This program, however, is not yet seamless in taking families from the newborn screening and identification stages through the EI and service delivery stages. ISD's Outreach Department, mandated by Indiana Code 20-22-2 to serve as a statewide resource providing outreach services and consultation to public schools serving deaf and hard of hearing children, has taken a multifaceted approach to helping create a more fluid experience for families in need of EI services.

Collaboration Efforts

A critical factor in ISD Outreach's ability to provide this support to families of newly identified deaf or hard of hearing children has been a strong relationship with other state agencies. When the Universal Newborn Hearing Screening (UNHS) mandate passed in 1999, it was crucial that First Steps, ISD Outreach, and the Indiana State Department of Health (ISDH) work together in the implementation of a statewide Early Hearing Detection and Intervention (EHDI) program. ISDH oversees early hearing detection programs in the state. First Steps had the funding for an appropriate intervention, but lacked the comprehensive specialized services that ISD Outreach had. All three agencies, working in tandem, have been able to make progress towards developing a more unified statewide system of EI service delivery.

SKI-HI training photos courtesy of Cindy Lawrence



Left: Indiana professionals participate in SKI-HI training.

ISD Outreach EI staff began planting seeds of collaboration long before formal systems of the EHDI program were implemented. Examples include:

- ISD audiologists and speech-language pathologists had been, and continue to be, involved with their state professional organizations. They also provide in-service training workshops to other EI agencies and centers serving deaf and hard of hearing children, and attend state and national conferences.
- The ISD Outreach director, EI coordinators, and other Outreach staff participated in various First Steps committees and initiatives.
 - The director was involved in the task force that brought the UNHS legislation to Indiana and then partnered with the Department of Health in initial efforts to implement the program.
 - Outreach coordinators and staff participated in the formation of committees and workgroups that then created protocols and materials for professionals and parents with participation from varying perspectives at all stages.

As an example of a successful collaborative effort, the inclusion of all perspectives and an effort to achieve consensus resulted in the creation of a balanced and comprehensive *Family*

Resource Guide that helps guide parents through their journey and identify resources available.

Building Capacity Statewide and in Rural Indiana

ISD Outreach has led several efforts to grow the state's capacity to provide services for newly identified and young deaf and hard of hearing children in the state, and the families and professionals working with them.

In 2001, the ISDH received a federal grant that included funds for regional outreach audiologists, which ISD Outreach administered through an agreement with the ISDH. Seven audiologists were hired to provide part-time regional supports to their local hospitals in the implementation of the UNHS program. They also provided technical support to the ISDH during development of the EHDI program. Today, these regional audiologists report to the ISDH. They continue to provide support, technical assistance, and resources for birthing hospital staff and other audiologists. The networking between ISD Outreach and these audiologists continues to benefit families statewide by ensuring a connection between ISD Outreach staff and audiologists in every part of the state.

The same 2001 grant also funded a Family Conference, coordinated by ISD Outreach. As the result of a keynote

presentation by Leeanne Seaver, executive director of Hands & Voices, at the 2003 Family Conference, two co-chairs agreed to start up an Indiana chapter of Hands & Voices. This chapter now runs the Family Conference.

ISD Outreach used a second grant awarded in 2004 by the ISDH to launch the Training for Early Language Development (TELD) project. The TELD project is based on the curriculum created by the SKI-HI Institute at the Utah State University to design state-of-the-art family-centered programming for infants and young children with hearing loss. Parent advisors (PAs) visit families at home to provide activities that support early language development as outlined in the SKI-HI curriculum. The grant funded the following:

- The costs for SKI-HI trainers to come to Indiana and provide six full days of training twice in the first two years of the grant; up to 25 professionals were trained each time.
- The costs of ordering several copies of the two-volume set of curriculum materials, which are passed among PAs and returned to ISD Outreach whenever PAs leave the program.

ISD Outreach knew the grant funds were finite. They successfully aimed to “grow” their own trainers within the state who were qualified to provide training for the PAs. They used ISD’s budget to send a trainer to “Train the Trainer” sessions in Utah. By the time the grant funds ran out, before the third training session was scheduled, one of the EI coordinators at ISD Outreach had become a SKI-HI trainer. This coordinator, the only deaf SKI-HI trainer, has since been joined by another ISD Outreach staff member as an eligible SKI-HI trainer in the state of Indiana. This capacity allows ISD Outreach to add to the four cohorts of PAs already trained as additional potential PAs are identified in every part of the state, well after the grant money has run out. Having eligible SKI-HI trainers on staff at ISD Outreach also allows them to keep up with high turnover in the EI field and the part-time nature of PA work, and the trainers provide ongoing professional development to the current PAs.

Not all participants who attended the PA training sessions went on to become PAs or EI providers for First Steps for various reasons, including the complex process of applying for and becoming an official PA (PAs are supervised and paid for by First Steps). However, many are professionals working with families in various capacities and, therefore, support the approach and goal of empowering parents with comprehensive information. ISD Outreach has been tailoring their approach in recruiting potential PAs and determining who would be most



likely to follow through with delivering the curriculum. In doing so, it was found that existing teachers of the deaf and current EI providers working with deaf and hard of hearing children are the best candidates.

The two SKI-HI trainers provide another important service. First Steps in Indiana is divided into regional System Point of Entry (SPOE) clusters, where service coordinators provide intakes and develop and update Individual Family Service Plans (IFSP) for families. The two SKI-HI trainers provide several forms of support to each of the seven SPOE’s in the state:

- Direct training in the needs of deaf and hard of hearing infants and children and their families
- A training packet that includes general information about EI for deaf and hard of hearing children and the critical need to provide accessible language.
- Information about the role of SKI-HI PAs for families (this is crucial since the system doesn’t have service definitions that are disability specific), specifically that PAs empower parents to provide language-rich environments through interaction with other children and adults who provide accessible language.

The TELD project has had a significant impact on increasing the availability and the quality of services throughout Indiana, both in terms of direct services to families and the education of the professionals who work with them. The effect has been especially profound in parts of rural Indiana, where it can be difficult to find professionals who are experienced in working with young deaf or hard of hearing children.

Empowering Parents Through Collaboration Between the Deaf Community and Families

The TELD project gradually built capacity throughout Indiana for PAs and, more importantly, built awareness statewide of the specific needs for families with deaf and hard of hearing children. The SKI-HI program provides unbiased comprehensive information about all areas of language and communication and, most importantly, about how children develop and acquire skills within their natural environment. A survey conducted in 2008 confirmed that parents were very satisfied with their PA and the SKI-HI program and felt more confident about parenting their child. However, parents still benefit from a team of supports as illustrated in the Family Support diagram developed by Hands & Voices and the National Center for Hearing Assessment and Management. As ISD Outreach continues to increase its capacity to provide comprehensive services for families, they seek to find support in

all areas, including parent-to-parent support, information, adults who are deaf or hard of hearing and existing communities, and support provided by professionals.

In 2009, ISD Outreach began a pilot Deaf Role Model (DRM) Program in response to the need they saw to provide a Deaf adult role model to families in the comfort and natural setting of their homes. What began with a few families and one DRM has grown to a current caseload of 25 families served by nine DRMs. The DRMs are ISD staff and community members that want to share their life experiences and assure parents that their deaf children can grow to become successful adults, too. The feedback has been very positive:

“When Lethia came to my home, I saw that there was hope for my child. We learned how to communicate with our son and we felt welcomed into a whole new community that is opening the doors of communication for my son,” one parent reported.

Parents receiving support from DRMs see the tremendous potential of their child, learn to communicate more effectively with him or her, and so much more. Regardless of the educational setting or

communication path chosen by families, those who have a positive and enriching experience in EI and have access to the Deaf community demonstrate an open and positive attitude toward their child and the Deaf and hearing communities. We believe the impact DRMs have on the families will last a lifetime.



Additional Services

ISD Outreach also provides several other forms of early supports:

- A lending resource library
- A home demonstration room
- Playgroups, including Language Enrichment and Play (LEAP) and Families Learning in Play (FLIP)
- Family and professional workshops

ISD Outreach maintains an *Outreach Resource Manual* that lists the array of services and the model of early supports they use at www.deaf-kids.org. Programs evolve based on collaboration efforts and on the needs of families of deaf and hard of hearing children. Parents benefit from the variety of services available,

“When Lethia came to my home, I saw that there was hope for my child. We learned how to communicate with our son and we felt welcomed into a whole new community that is opening the doors of communication for my son,” one parent reported.

as shown in this comment:

“I just wanted to let you know how much we have enjoyed the LEAP Program for our son! Even though we are only there for a short time, it gives Braden a chance to play with other kids his age and get exposed to ASL. The instructors are so friendly and welcoming! I am so glad we have been able to get involved. We really enjoy interacting with the staff, kids, and parents!” (Parent of a 2-year-old, receives First Steps services, DRM, attends LEAP, and benefits from the lending library)

As this article goes to press, ISD Outreach is working with all three state agencies responsible for various components of the system on new initiatives due to budget challenges in Indiana state government and changes in the state’s First Steps system. During difficult economic times or when required to provide something that isn’t funded, collaboration becomes crucial to creating programs and initiatives. Lack of funding can lead to some synergistic results that ultimately benefit families. The best that can be done for families as professionals and

“systems” is to work together inclusively. To serve families in a state without a seamless system, the following tips are critical:

- As an outreach or EI service provider, get to know the system, including funding streams and relevant policies and protocols.
- Become involved in the system through committees, work groups, and professional organizations.
- Build relationships with all families and with other professionals who also serve families you work with.
- Be a bridge between the Deaf and hearing communities. Most hearing families have never had experience with the Deaf community and some find it overwhelming, yet they can appreciate learning a new culture and language.
- Never assume where others stand. Seek to understand and to find common goals for the benefit of families.

For more information about ISD Outreach, visit www.deafboosiers.com/Outreach/. To learn more about the SKI-HI curriculum, visit <http://www.skibi.org/>.

Resource

Watkins, S. (Ed.). (2004). *SKI-HI curriculum: Family centered programming for infants and young children with hearing loss*. Logan, UT: Utah State University, SKI-HI Institute.