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Above: A two-month-old infant receives her loaner hearing aids through the WISHES program.

the time is now: wisconsin's journey towards improving early intervention services

By Marcy Dicker

1990

Katie was diagnosed with a profound hearing loss at 26 months of age. Her communication skills were delayed and a hearing loss had been suspected earlier. Her pediatrician, in response to her mother's concerns over the past several months, noted, "Katie laughs out loud, so how could she be deaf?"

Several months later, Katie received hearing aids. Her mother was also referred to the county's Birth to 3 Program. In Wisconsin, Birth to 3 Programs were based out of the Department of Health Services, and each county had its own program. Katie was the first deaf child on the service coordinator's caseload. Due to the significant language delay, the Individualized Family Service Plan (IFSP) team determined the need for early intervention. Neither the early interventionist nor the speech therapist on the team had ever worked with a deaf child. The speech therapist, however, knew 10 signs and was assigned to provide services to Katie. Several months later, at 3 years of age, Katie transitioned to the public school system with a vocabulary of 10 signs and behavioral issues stemming from lack of communication.

Katie was bright and should have entered school with communication skills commensurate to her peers so that she was ready to learn within a classroom environment. Instead, she was linguistically delayed and behavioral challenges were evident. Fortunately for other deaf and hard of hearing children and their families in the state of Wisconsin, early intervention services there have undergone significant changes over the past 20 years.

Photos courtesy of Marcy Dicker



Left: Early intervention in Wisconsin begins as soon as the child is identified.

Wisconsin faced numerous issues in this evolution. Many of the county Birth to 3 Programs were not able to provide trained and/or experienced personnel to address the unique needs of a child with hearing loss. The low incidence of this population, the size and rural nature of the state, the lack of qualified personnel, and the structure of Wisconsin Birth to 3 services were contributing factors to the challenges in adequately serving this population. This article describes how these challenges were addressed to improve early intervention services in the state.

The First Stage

In 2000, the Joint Committee on Infant Hearing (JCIH) Position Statement established a national evidence-based framework to ensure that all infants born with congenital hearing loss have the opportunity to benefit from early intervention services by 6 months of age. The JCIH goals were to: 1) Screen all babies prior to hospital discharge, 2) diagnose babies as deaf or hard of hearing by three months of age, and 3) enroll them in effective early intervention programs no later than 6 months of age.

The state of Wisconsin aligned with and supported the goals of the JCIH and the national Early Hearing Detection and Intervention (EHDI) efforts. In 1999, the Wisconsin State Legislature passed an unfunded directive that supported the importance of early identification of hearing loss. The Wisconsin State Division of Public Health applied for and received grant funding to assist in the implementation of a comprehensive system of EHDI. A new program—Wisconsin Sound Beginnings (WSB)—was established to develop and implement EHDI standards, protocols, resources, and services in the state. Shortly thereafter, in 2001, the state's outreach program—Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESP-DHH Outreach)—was established.

WSB hosted a Parent Summit, an invitational conference for Wisconsin families with children between the ages of 0-8 who were deaf, hard of hearing, and deafblind. The newly established WESP-DHH Outreach was invited to participate in this summit. The goal of the summit was to provide a forum for families to make recommendations that would become the foundation for a statewide parent network plan. These

recommendations to increase parent connection arose from the summit:

1. To establish an annual event to connect families
2. To provide direct parent-to-parent support
3. To establish a statewide website and/or listserv for families
4. To provide unbiased information available in one place

Based on these recommendations, WESP-DHH Outreach established a variety of support services for young children and their families. Over the years, other gaps and needs were identified, and additional programs evolved to complement and support Birth to 3 Programs. These programs include:

- **DEAF MENTOR PROGRAM:** Twenty-five to 30 deaf mentors around the state of Wisconsin provide families with in-home sign language instruction using an immersion (bilingual-bicultural) approach.



- **FAMILY CONFERENCE:** Now in its ninth year, this annual statewide conference has grown in attendance to more than 500 participants and includes workshops, family activities, childcare, and support groups. A variety of role models who are deaf, hard of hearing, and deafblind present and/or work at the conference. The first Family Conference, in 2003, resulted in the formation of a Wisconsin chapter of Hands & Voices (www.handsandvoiceswi.org) and a statewide listserv for parents.
- **GUIDE BY YOUR SIDE PROGRAM:** WSB and Wisconsin Families for Hands & Voices collaborated to establish the first Guide By Your Side Program, which matches families of children who have newly diagnosed hearing loss with Parent Guides (trained and more experienced parents of children who are deaf, hard of hearing, and deafblind). Hands & Voices National has since adopted this program model and

helped establish Guide By Your Side programs in other states.

- **BABIES & HEARING LOSS: AN INTERACTIVE NOTEBOOK FOR FAMILIES WITH A YOUNG CHILD WHO IS DEAF OR HARD OF HEARING:** This comprehensive and unbiased overview of options and resources available to families, specific to Wisconsin, is updated and distributed on an ongoing basis.
- **WISCONSIN INFANT/CHILDREN'S STATEWIDE HEARING AID EXCHANGE SERVICE (WISHES):** The WISHES program loans hearing instruments (hearing aids and/or FM systems) for a six-month period to newly identified children who are deaf or hard of hearing. This temporary assistance can bridge the gap between identification of a hearing loss and obtaining the financial means to purchase personal amplification or for children awaiting cochlear implant surgery.
- **IN-HOME EARLY LISTENING PROGRAM (HELP):** HELP provides specific short-term training and guidance for parents in the area of auditory development, by specially trained mentors, in order to support the development of effective listening and spoken language skills.
- **WISCONSIN DEAFBLIND TECHNICAL ASSISTANCE PROJECT (WDBTAP):** WESP-DHH Outreach runs this program with a federal grant award from the Office for Special Education Programs. WDBTAP provides a variety of supports to families of young children who are deafblind and the professionals that work with them, including trainings and workshops, coaching, the Birth to 3 Program, and family support.
- **BIRTH TO 3 PROGRAM CONSULTATION:** WESP-DHH Outreach consultants provide support to Birth to 3 Programs statewide in the assessment process, development of IFSP goals, provision of appropriate resources, and staff training on the specific needs of the child and his or her family. Areas of focus include: communication strengths, needs, and choices; speech, language, and auditory development; the impact of hearing loss on all areas of development; parent education needs; and transition from the Birth to 3 Program to the public school system.

2005

If Katie had been born in Wisconsin 15 years later, she would have been diagnosed within a month of her birth and received an array of services:

- *She would have been fit with loaner hearing aids by the age of 3 months.*
- *She might have received a cochlear implant at an early age.*
- *Her audiologist would have provided her family with the comprehensive parent notebook, Babies & Hearing Loss.*
- *Her family would have been referred to Birth to 3 and Guide*

By Your Side. Within two weeks of diagnosis, the family would have met with a parent guide. The parent guide would have reviewed the information covered in the notebook and provided emotional support and guidance to the family as they began to navigate the system, looking for appropriate programming and supports.

- *Katie would have been enrolled in her county Birth to 3 Program by the age of 6 months (though she demonstrated no developmental delays).*
- *Katie and her family would have had support for her auditory development through HELP, support for visual communication and sign language development through the Deaf Mentor Program, and ongoing parent support via the Family Conference and Wisconsin Families for Hands & Voices.*

Yet despite the many supports through WESP-DHH Outreach, Katie's direct services through the county's Birth to 3 Program may still have been inadequate to help her achieve age-appropriate development by age 3. Although Wisconsin was identifying children who were deaf and hard of hearing in Wisconsin through Universal Newborn Hearing Screening, families were still not consistently receiving direct services within Birth to 3 Programs from professionals who had experience with and understood the unique needs of young children with hearing loss and their families.

Identifying and Addressing Systemic Issues

Given the low incidence of the population and the size of the state, it appeared that a regionalized system of service delivery would more effectively address the issue of service provision from providers with appropriate training and experience. In 2008, personnel from WESP-DHH Outreach and WSB created a document entitled *The Time is Now*. It highlighted key issues and current system strengths and needs required to effectively serve young children who are deaf, hard of hearing, and deafblind and their families. After presenting progress to date, existing systemic needs, and research to support the provision of early intervention services with trained and qualified providers, the document emphasized the need to consider systemic redesign in order to meet the unique needs of these children and families. As a result, WESP-DHH Outreach gained approval from the Wisconsin Birth to 3 Program and the Department of Public Instruction to move forward in a planning process (not implementation) for an alternative regionalized educational service delivery model.



Above: Family education and involvement are key components to Wisconsin's programming.

A two-day intensive planning meeting, the Birth to 6 Redesign Summit, was convened to develop and solidify the concepts for redesign. Over 50 participants represented a broad stakeholder group, including parents of children who are deaf, hard of hearing, and deafblind, early interventionists, early childhood educators, childcare representatives, social workers, audiologists, physicians and allied health care providers, policymakers, schools of medicine and education, research institutions, state planning agencies, community service providers, and advocacy organizations. This summit was highly successful; in addition to identifying a variety of success factors



and system variables, it helped connect key stakeholders across the state, from a variety of systems, by their common desire to redesign the system in order to serve better the state's youngest children with hearing loss, their families, and the programs that serve this population. As a result of the energy and direction of the summit, the Wisconsin Birth to 3 Program awarded American Recovery and Reinvestment Act (ARRA) funds to WESP-DHH Outreach to implement the concepts that evolved from the summit and create a two-year pilot redesign of the system.

This ARRA-funded project became the Western Regional Birth to 6 Redesign Pilot. The goal of this pilot project is to show the benefits and efficacy of restructuring the current delivery system. This pilot system differs from the current system in that a regional team composed of providers, recruited from school districts, educational cooperatives, county Birth to 3 Programs, and other programs, will be able to cross county and school district lines in order to provide services within the entire region. Identified providers for the regional team have an interest in serving this population and have some background knowledge and/or experience. This regional system will support

responsibilities of the state outreach program, in conjunction with CESA 10, include:

- Identifying regional team members.
- Hiring and overseeing a regional services coordinator to ensure consistency and linkages within the region as well as assisting in facilitating the necessary creative collaborations between agencies and programs to allow a qualified provider in one county or program to provide services to another county or program.
- Designing and providing training for the regional team.
- Designing of the process for families to obtain services.
- Promoting the project at a state systems level.

The pilot project is now in Year II, the implementation phase. Regional team members have been identified and have received training and materials from the SKI-HI program out of Utah. This year is dedicated to restructuring service provision, ensuring creative collaborations and sharing of resources, as well as data collection to determine the impact of these restructured services. Given positive outcomes for this project, it is hoped that this design can be replicated in all regions of the state.



the overarching goal of ensuring that every child identified with hearing loss in the region with Birth to 3 services receives services from qualified and trained providers.

WESP-DHH Outreach is collaborating with CESA 10, an educational agency in the western area of Wisconsin, to implement this pilot project with a focus on serving the children and families in the western region of Wisconsin. The

2010

Imagine Katie was born 20 years later. She was diagnosed with hearing loss by 1 month of age, fitted with hearing aids by 3 months of age, and connected to parent-to-parent support and Birth to 3 Programming by 6 months of age. Her Birth to 3 providers have been identified (although they are from another county and school district) as individuals who are able to provide support for Katie's development of sign language and auditory skills as well as attend to her overall communication and social-emotional needs. Katie's family also receives support from the WISHES program, HELP, Guide By Your Side, and the Deaf Mentor Program. WESP-DHH Outreach's Birth to 6 consultant has worked with Katie's IFSP team to ensure appropriate expectations and outcomes. Katie is making great strides in her development. Her parents are well educated about their options, and they are involved in supporting Katie's development in all realms. They are also in contact with many area parents through Wisconsin Families for Hands & Voices and the annual Statewide Family Conference as well as with adult Deaf role models. We have every reason to believe that when Katie reaches her third birthday, her communication skills will be commensurate with those of her peers. Katie will enter school ready to learn. Her parents will be prepared to make

educated choices and decisions along the way using Katie's strengths and needs to chart her course.

The past decade has truly been a journey for the state of Wisconsin. New collaborations have been established, and there is a growing awareness of the need to redesign service delivery in order to truly meet the needs of our youngest students who are hard of hearing, deaf, and deafblind. This will not be a short journey, nor will there be easy solutions, but the time to make a change in Wisconsin is now. The National Deaf Education Reform Movement has adopted Victor Hugo's slogan, "There is nothing more powerful in this world than an idea whose time has come." In Wisconsin, our time has come.

To access the contents of the parent notebook, visit www.wesp-dbb.wi.gov/wesp/out_parent_notebook.cfm.

To access the contents of *The Time is Now*, visit www.wesp-dbb.wi.gov/B_3/The_Time_is_Now.pdf.

To access more information about the Birth to 6 Redesign Summit, visit www.wesp-dbb.wi.gov/wesp/out_b6summit.cfm or e-mail marcy.dicker@wesp-dbb.wi.gov.

For more information about WESP-DHH Outreach, visit www.wesp-dbb.wi.gov/wesp/.



Reference

Joint Committee on Infant Hearing. (2000). Year 2000 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 106, 789-817.



Left: The Western Regional Birth to 6 Redesign team.

Below: Children and families served by the Western Region Birth to 6 Redesign Pilot project reside in the western region of Wisconsin.

