EXPANDING OPTIONS FOR EARLY DEAF EDUCATION IN DELAWARE

PART 1: THE PROBLEM

Delaware is failing to meet the educational needs of the majority of its deaf and hard of hearing children in a manner consistent with modern research and with the language and cultural preferences of most families affected by childhood hearing loss. This paper reviews the literature, reports the results of qualitative research conducted in Delaware in 2009, and shows striking similarities between problems reported recently with those published in 1997. Part 2 of this series will discuss methods used in other educational jurisdictions and offer a new paradigm for Delaware.

Choices Delaware is a coalition of parents, educators, advocates, and health-care professionals. The Choices Delaware web site is http://choices-delaware.org/



FIGURE 1--LOGO OF CHOICES DELAWARE, A COALITION OF PARENTS, EDUCATORS, ADVOCATES, AND HEALTH-CARE PROFESSIONALS

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EXECUTIVE SUMMARY

This paper demonstrates a need for significant changes in Delaware's public policy on education of children with hearing loss. It raises four issues, analysis of which leads to the conclusion that Delaware's system for educating and promoting the language development of children with hearing loss does not meet the needs of families who want their children to be able to speak and hear—objectives that are attainable with modern technology and therapy. The chain of logic is as follows:

- 1. Early detection and intervention make it possible for most deaf and hard of hearing children to attain listening and spoken language at levels comparable to those of typically hearing age peers. Best results happen when children receive appropriate technology for hearing at the earliest age possible.
- 2. Providing a cochlear implant to an infant without also providing intensive auditory-oral therapy is like giving someone a musical instrument without lessons. The auditory cortex of the brain begins to lose its plasticity by age 3 ½. Best results for children whose parents want them to use listening and spoken language happen when implantation begins as early as 12 months and auditory-oral therapy begins as soon as possible thereafter.
- 3. The most effective outcomes for children's language and life skills occur when there is language homogeneity in the home. The deaf children of culturally Deaf parents most often thrive when they also use American Sign Language and become part of Deaf culture. Likewise, deaf children of hearing parents usually do best when they use listening and spoken language as their parents do. More than 95% of deaf children have hearing parents. It is therefore essential for the State to provide an auditory-oral therapy program for preschool children and to have a strong network of itinerants throughout the state in order to support children ages 6-21 in mainstream settings.
- 4. The State of Delaware's approach to deaf education is wrong. Delaware School for the Deaf (DSD), which does not have a program suitable for children whose parents want them to hear and speak, enrolls fully 39% of Delaware children who have hearing loss as the basis for individualized education programs. (The comparable number for New Jersey is 14%.) DSD employs at least 70 full-time employees for a student body of 113, and its cost structure will increase even more in 2011 when a new facility opens. Meanwhile, only one of every two Delaware school districts employs itinerant teachers of the deaf and hard of hearing or educational audiologists who can support children in mainstream settings.

A series of family interviews conducted in the spring and summer of 2009 revealed dissatisfaction remarkably similar to what an article in the March 16, 1997 issue of the Wilmington News Journal reported. Change is long overdue.

The nine authors of this paper form the core project team of Choices Delaware, the longer and more formal name of which is *Making Language Choices Available to Delaware Families of Children with Hearing Loss.* These nine individuals represent a variety of professions and roles shown in the list below. Some individuals play more than one role, and some roles have more than one player.

- Consultant in educational leadership
- Person with severe-profound lifelong hearing loss
- Parent of a deaf child
 - Do you see terminology with which you are unfamiliar? See our glossary, (which begins on page 11, if you are viewing a printed copy of this paper).

- Cochlear implant surgeon
- Researcher
- Expert on infant language acquisition
- Teacher of the deaf and hard of hearing
- Audiologist
- Epidemiologist

ISSUES

1. EARLY INTERVENTION IS CRITICALLY IMPORTANT IN CHOICE OF COMMUNICATION MODALITY AND LANGUAGE

Communication modes for families affected by childhood hearing loss exist on a continuum that includes Listening and Spoken Language, Cued Speech, various forms of syntactically and grammatically spoken languages such as English rendered manually, simultaneous communication (signing and speaking at the same time), total communication (signing and speaking interchangeably), and purely visual languages such as American Sign Language (ASL). It is important to note that American Sign Language is syntactically different from spoken English and that English is a second language for ASL users.

Identification of hearing loss needs to take place as quickly as possible after birth. Before intervention takes place, families need access to sufficient information about all the options in order to make a choice that is correct for the family and the child. Whether a family selects Listening and Spoken Language, American Sign Language, or something in between, access to skilled and experienced early intervention professionals is essential.

However, nationwide, nearly 40% of children identified with hearing loss and their families are not referred to the Part C early intervention system of the Individuals with Disabilities Education Act (IDEA). (Center for Disease Control and Prevention, 2008). Part C is the primary resource that enables families to link to medical, audiological, and other intervention services. Despite extraordinary advances in early identification, early access to sound through technology, and early intervention, there is widespread agreement among researchers, clinicians, program administrators, and policy makers that many children ages 0-5 with permanent hearing loss are not receiving the benefits of these advances. (White, 2007; White, 2004). We will show later that this problem is especially acute in Delaware.

Some programs have demonstrated that most children with hearing loss and no additional disability can achieve and maintain language skills within the range of children who have typical hearing (Moeller, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl,1998; Yoshinaga-Itano, Coulter, Thomson, 2000; Yoshinaga-Itano, Coulter, Thomson, 2001). When measured at 3 years of age, developmental outcomes for early-identified deaf and hard of hearing infants are similar for a variety of communication modalities. (American Academy of Pediatrics, Joint Committee on Infant Hearing, 2007).

Svirsky, Teoh, and Neuburger (2004) reported that children who receive cochlear implants (CIs) in the second year of life attain better speech perception and language development outcomes than those who receive implants later in life. Children implanted between 12 and 24 months of age exhibit

language skills similar to those of typical peers on some language measures administered at age 6. Data show that 90% of children born with a profound hearing loss who obtain a CI before 18 months of age attain intelligible speech. When the age of implantation is between 2 and 4 years of age, the rate is 80%. In contrast, only about 20% of children born with a profound hearing loss who wear hearing aids and not CIs attain intelligible speech. (Cole & Flexer, 2007).

In summary, the literature shows clearly that discovering hearing loss as early as possible and doing everything possible to remediate that loss through amplification or cochlear implantation is essential for all children whose families want them to be able to use listening and spoken language.

2. EARLY INTERVENTION MEANS MORE THAN IMPLANT SURGERY FOR FAMILIES THAT ELECT LISTENING AND SPOKEN LANGUAGE

The key to success, then, is early detection, diagnosis, and intervention. But what exactly constitutes early intervention? Cochlear implantation during infancy is certainly a critical component of early intervention. However, a cochlear implant by itself is like a musical instrument without sheet music or the lessons required to read the music. Babies are geniuses when it comes to acquiring language, but a one-year-old whose auditory cortex has received no prior input requires intensive therapy in order to learn how to make sense of stimulation of the auditory nerve by an electronic device instead of through natural sound processing by the ear.

Sharma, Dorman, and Spahr (2002) showed that there is a sensitive period of about 3 ½ years during which the human central auditory system remains maximally plastic. Plasticity remains in some, but not all, children until approximately age 7. This implies that the concept of learning ASL first and using residual hearing later on will not allow for appropriate development of the central auditory system.

Robertson and Flexer (1993) reported that children who were deaf or hard of hearing and developed spoken language through listening developed reading ability comparable to their peers who have typical hearing. Listening and spoken language programs seek to improve speech perception, speech production, and spoken language skills by teaching a child to listen. Children who hear identify phonemes that facilitate sounding out words, spelling, reading and vocabulary expansion. Improved hearing sensitivity (as provided by a CI) does not, by itself, guarantee the ability to discriminate between sounds or to interpret speech for oral communication purposes. Children who receive CIs continue to require intensive auditory, speech, and language training. (Wilkins & Ertmer, 2002).

Children with CIs who are in programs emphasizing listening and talking have higher speech production scores than children in programs that put less emphasis on these actions. (Toby, Geers, Brenner, Altuna, & Gabbert, 2003). Ultimately, elementary school children with CIs can function well in mainstream settings—at least twice as often as age-matched children with profound hearing loss who do not have CIs. (Francis, Koch, Wyatt, & Niparko, 1999). These findings are relevant to the high cost structure of Delaware's deaf education system (see Issue 4 below).

Let us consider two different philosophies for promoting language development in very young deaf and hard of hearing children. The first of these is in use at Clarke School and in other programs around the country that help young deaf and hard of hearing children learn to hear and speak. The second is a method in use at the Delaware School for the Deaf.

METHOD 1: AUDITORY-ORAL THERAPY

Auditory-oral approaches immerse the newly implanted child in Listening and Spoken Language. Prominent among proponents of the auditory-oral method is Clarke School, the nation's oldest oral school for the deaf. Several members of the Choices Delaware project team visited Clarke's campus in Bryn Mawr, Pennsylvania in July 2009. See Clarke's web site at https://secure.valinet.com/~csadmin/content/Clarke Pennsylvania/about.php. Clarke believes that providing an exclusive focus on the functions of speech, language, and hearing is the most effective way of helping young children achieve parity with their typically-hearing peers by the time they are ready to start school. Clarke's goal is to enable children who were born deaf to attend a mainstream school by the time they reach the age for kindergarten.

METHOD 2: THE BILINGUAL-BICULTURAL APPROACH

The goal of bilingual-bicultural education, the approach used at Delaware School for the Deaf, is to promote American Sign Language as the first language of a child and then to utilize ASL competence as the basis for developing English-language literacy. It is important to note that American Sign Language is syntactically different from spoken English, has no written form, and that English is a second language for American Sign Language users. While there is general agreement among researchers (Strong, 1988; Cummins, 1989) that literacy in one language supports acquisition of other languages, experts are divided as regards ASL as an effective platform from which to learn English since ASL has no written form (Mayer & Wells, 1996; Strong & Prinz, 2000). These mixed conclusions challenge the theoretical basis of bilingual education of deaf children.

Regardless of what one may think about the likelihood that American Sign Language proficiency promotes English literacy (i.e. proficiency in *written* English), it remains true that in bilingual-bicultural education, ASL is the first language and the language of instruction and that development of Listening and Spoken Language is not a primary goal.

In summary, providing a cochlear implant to a child whose parents want him or her to use listening and spoken language is not sufficient to enable that child to learn how to speak and listen. Children whose brains have received no auditory input during the first year of life need help to catch up with their typically hearing peers. The bilingual-bicultural method of language development used at Delaware School for the Deaf is intended to develop American Sign Language as a first language and to promote English literacy (i.e., the ability to read English). In contrast, the auditory-oral method used at Clarke School and at similar programs in other states helps most children achieve parity with their age peers by the time they are ready to start kindergarten.

3. SUCCESSFUL LANGUAGE DEVELOPMENT OCCURS MOST OFTEN WHEN PARENTS AND CHILDREN USE THE SAME LANGUAGE

Flexer (Choices Delaware, 2010) defines success in family communication as "reaching the outcome desired by the family." Typically, "the family and child can access each other most companionably if they use the same communication system/language. So, for example, it follows that the family who communicates within the family and community using ASL would have the most access to their child if the child also uses American Sign Language. If, on the other hand, the family uses spoken language to communicate, they will have the most access to their child if the child also communicates using spoken language."

Newport and Meier (1985) noted that deaf children, when exposed to an appropriate signing system such as ASL, learn it as effortlessly as hearing children learn spoken language. In the Strong and Prinz (2000) study (vide supra), deaf children from hearing families performed not as well on measures of English literacy as did deaf children from deaf families, a fact they suggested might be due to the presumed ASL-ASL homogeneity between parent and child. When hearing parents do not take steps to either develop LSL in their deaf children or expose their deaf children to sign language, the children resort to developing a gesture system as a medium of communication with their parents. (Goldin-Meadow, 1993). Gestures provide a makeshift means for individuals who speak different languages to obtain rudimentary communication, but they are not the basis for sharing culture, values, or intimacy.

American Sign Language is central to Deaf culture (Schein, 1989), just as the music, drama, language, and social customs of various ethnic groups provide shared meaning and understanding among the members of those subcultures. The language that parents use most naturally is the one that they will prefer to use with their children. If you as a parent are culturally Deaf and use American Sign Language, you will almost certainly use ASL to communicate with other deaf/Deaf people, including your deaf infants, who will thereafter become culturally Deaf. If you are a hearing parent, you will yearn to communicate with your children—deaf or not—with LSL. Figure 1 summarizes the four family configurations and the predicted outcome for each.

	Type1	Type 2	Type 3	Type 4
Parent	Deaf	Deaf	Hearing	Hearing
Child	Deaf	Hearing	Deaf	Hearing
Family language	Sign (ASL)	ASL	Variable	Spoken
Outcome	BEST	Variable	WORST	BEST

Figure 1: Language development: importance of family configuration.

Research performed as early as the 1960s (Strong, 1988) shows hearing status of parents as a predictor of educational success in deaf children. See Deaf children of deaf parents have a strong advantage over deaf children of hearing parents in their prospects for linguistic and academic attainment. However, fewer than 5% of deaf children have deaf parents, a lower percentage than previously reported (Mitchell & Karchmer, 2004).

Therefore, one can predict that a large majority of parents of children with profound hearing loss—i.e., parents who are able to hear—will want to communicate with their children using Listening and Spoken Language. And, indeed, there has been a major shift nationwide among parents in language preferences for their deaf children. In 1995 40% of parents surveyed expressed a preference for Listening and Spoken Language compared to 60% who chose a sign language option. Ten years later, the percentage of parents who preferred spoken language was 85% compared to 15% who chose sign language. (Brown, 2006). Increases in the effectiveness of CI technology and the general awareness of the difference that cochlear implants can make in outcomes for children are the likely explanation for this data.

The stakes are high. One study (Gallaudet Research Institute, 2003) reported the median reading comprehension level of deaf and hard-of-hearing 17- and 18-year-olds to be that of a fourth grader, a finding that portends poor lifetime earning potential.

In summary, deaf children of hearing parents face significant challenges if the school system places the child in an environment that promotes ASL as the child's primary language. Relatively few hearing parents of deaf children become proficient signers. In such homes, signing deaf children will not experience the language modeling that parents ordinarily provide to their children and which is essential for the development of typical hearing and speaking capability.

4. DELAWARE'S CURRENT SYSTEM FOR EDUCATING DEAF AND HARD OF HEARING CHILDREN IS UNRESPONSIVE TO THESE NEEDS

(A) THE INCIDENCE OF HEARING LOSS IN DELAWARE CHILDREN

As of December 30, 2009 the Delaware Department of Education reported that 289 Delaware children had Individualized Education Programs (IEPs) in which hearing loss was the primary disability. (Della W. Thomas, personal communication, April 7, 2010). However, when children have multiple disabilities—including hearing loss—they may fall into other categories. In addition there are deaf and hard of hearing children with Section 504 plans and students in private school or home school settings who are not included as deaf or hard of hearing because they are not receiving State services. Therefore, 289 cases is certainly an underestimate of the prevalence of deaf and hard of hearing children in Delaware. Delaware currently serves 23 deaf and hard-of-hearing children ages 0-3 through programs at DSD and in statewide programs at other locations. (Della W. Thomas, personal communication, April 27, 2010).

As of May 4, 2010, A.I. duPont Hospital for Children reported that 66 children who currently live in Delaware had received cochlear implants there. The total number of Delaware children who have cochlear implants, including those who received their implants outside of Delaware, is probably about

100. A vast majority of the children implanted at A.I. duPont Hospital were between the ages of 12 and 24 months.

(B) DELAWARE'S EDUCATIONAL SYSTEM EMPHASIZES AMERICAN SIGN LANGUAGE IN A SEGREGATED SCHOOL FOR THE DEAF

So far this paper has shown that:

- 1. More than 95% of children who are born deaf have hearing parents.
- 2. Parents want to communicate with their children in their own language (American Sign Language for parents who are culturally Deaf, a spoken language for those who are not).
- 3. Cochlear implants make possible the acquisition of listening and spoken language by profoundly deaf preschool children to a degree that is comparable to that of typically hearing children—provided that recipients have access to intensive auditory-oral therapy as very young children.

Given the legal requirement under the Individuals with Disabilities Education Act (IDEA) for a free and appropriate education in the least restrictive environment, one might assume that an intensive program of auditory-oral therapy for children ages 0-6 and a network of mainstream supports for older children would form the foundation of Delaware's program of deaf education. *One would be wrong.*

DSD is the cornerstone of deaf education in Delaware. As noted earlier, DSD utilizes a bilingual-bicultural philosophy in which ASL is the language of instruction and spoken English is made available as a second language. One cannot be a member of the DSD community without knowing American Sign Language.

Only about half of Delaware's 19 school districts possess itinerant staff (educational audiologists and teachers of the deaf and hard of hearing). So the hearing parents of deaf children in Delaware have no place to obtain early intervention based on intensive auditory-oral therapy in the manner provided by Clarke (a private school). Once children are school age, their choice is either a segregated setting in which their children receive instruction in a language different from that of their families, a supported mainstream school (for which they may be unprepared, not having received suitable early services), or nothing, if they live in a school district without itinerant resources.

Unlike most other states, Delaware is deeply mired in a twentieth-century mindset of deaf education that's based on sign language and segregated schools. Table 1 compares Delaware with one of its neighboring states, New Jersey.

Table 1: Children Ages 3-21 with IEPs Based on Hearing Loss

Population	Delaware	New Jersey
Total children with hearing-based IEPs	289 (a)	1,712 (b)
Enrollment in the state school for the deaf	113 (a)	234 (c)
Students in the state school for the deaf as % of total	39%	14%

(a) Data from Della W. Thomas, Delaware School for the Deaf (personal communication, April 7, 2010).

- (b) Data from the U.S. Department of Education (2006).
- (c) Data from Margaret Provost, Enrollment Coordinator, Marie Katzenbach School for the Deaf, Trenton, NJ (personal communication, January 11, 2010).

Table 1 shows that Delaware has proportionately nearly three times as many students in a segregated school setting as New Jersey does. Delaware School for the Deaf employs more than 70 full-time staff (excluding individuals assigned to the separate Deaf-Blind program that resides in the building) to support the 113 students there. DSD does not meet the needs of most Delaware families of children with hearing loss. And yet, at a time when Delaware faces grave financial conditions, the already high cost structure of DSD will grow considerably when a new \$43 million residential facility opens in 2011.

In summary, Choices Delaware wants to see Delaware School for the Deaf remain healthy and available as an option for families that want to use American Sign Language. However, the current imbalance between funds invested in education appropriate for culturally Deaf children and funds invested in education appropriate for the deaf children of hearing families that want to use listening and spoken language is unconscionably large.

THE EXPERIENCE OF DELAWARE FAMILIES

The Choices Delaware project team thinks there's something wrong with Delaware's infrastructure and processes for deaf education. So do some stakeholder families, as revealed by qualitative research that the project team conducted in 2009.

The Wilmington News Journal (Rivera, 1997, March 16) long ago documented controversy and dissatisfaction among some Delaware families. This article is reproduced on the Choices Delaware web site at http://choices-delaware.org/wp-content/uploads/2010/04/News Journal 3-16-1997 PA1.pdf, A common theme among the families who were unhappy was a lack of information about different options for their children. For example, Sharon Collier withdrew her son from DSD so that he could utilize cued speech, an oral method that uses hand signals near the face to fill in missing sound information. Cued speech was not something that DSD officials told them about. Maureen and John Bard in 1989 learned only about the merits of ASL from DSD officials.

Remarkably (or perhaps not), the failure to discuss alternatives to ASL emerged as a common theme among the families that the Choices Delaware project team spoke with 12 years later. For example, one mother reported being in tears after a representative of Statewide Services for the Deaf and Hard of Hearing, told her in 2008 that her daughter would need to attend DSD, become part of Deaf culture, and might never speak or listen to music. This woman rejected what she heard. She and her husband took their daughter to Clarke School at their own expense. By the age of 3 their daughter had the oral and aural communication skills of a typically hearing five-year-old.

Read more on the experience of Delaware families at http://choices-delaware.org/stories from delaware.

CONCLUSION

It is possible for many children who are born with profound hearing loss to attain listening and spoken language skills by the age of 6, enabling them to participate in mainstream school settings. This is an outcome that most hearing parents of deaf children desire; and because most deaf children have hearing parents, it is the outcome of greatest absolute frequency.

What makes this outcome possible are three elements: early detection of hearing loss, early cochlear implantation, and intensive auditory-oral therapy in preschool years. The first two of these three elements are available in Delaware. The third one is not, at least on a systematic basis from within the public education system. Consequently, most deaf and Hard of Hearing Children in Delaware are not well prepared for any school other than DSD. Those who do attend other schools may or may not have the services of a teacher of the deaf and hard of hearing or an educational audiologist depending on the school district.

Children who use American Sign Language fare best if their parents are also fluent users of ASL. Children whose parents do not sign well or at all typically do not do well in school. As other states develop more

modern methods of improving the educational and language proficiency of deaf children, reading comprehension scores of young deaf adults will improve. But they will not improve in Delaware until the State abandons a 1970s educational model that does not meet the legal mandates of IDEA or the needs of most families.

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GLOSSARY OF TERMS

- American Sign Language—a visual form of communication used mainly by people who became deaf before the age of about 3 and those who communicate frequently with such people.

 Abbreviation: ASL. American Sign Language has a grammar and syntax of its own, distinct from that of English. American Sign Language is based on an earlier language that originated in France. Utilization of American Sign Language dates to the early 19th century.
- **ASL**—an abbreviation for American Sign Language.
- **Auditory-oral therapy**—a method that helps children develop listening and spoken language ability by emphasizing technology-aided residual hearing and the use of speech instead of manual methods.
- **Bilingual-bicultural method**—a method of educating children with severe-profound hearing loss in which American Sign Language is used for instruction and spoken English is taught as a second language.
- **Cochlea**—a spiral-shaped part of the inner ear that translates sound that comes from outer parts of the ear into nerve impulses that go to the brain via the auditory nerve.
- **Cochlear implant**—a device that provides the sensation of hearing for someone with severe-profound sensorineural hearing loss. A processor worn external to the ear converts sound to radio signals. The signals are received by the implant which then converts these signals to electrical impulses. An electrode array stimulates various portions of the cochlear, each of which handles a specific frequency range of sound.
- **Cued speech**—a method of communicating in which hand signals generated in the vicinity of the head supply information that a person with hearing loss may not be receiving from the speaker's voice.
- Deaf culture—a reference to the shared beliefs, values, social structures, and communication practices of individuals who lost hearing before the typical age of onset of spoken language. Members of Deaf culture also includes hearing people who have been accepted as a part of the culture by its non-hearing members. Use of American Sign Language is a defining characteristic of Deaf culture. The capitalized term "Deaf" refers to members of Deaf culture, whereas the lower-case term "deaf" is used in a clinical sense. As a clinical term, "deaf" technically refers specifically to those with no useful residual hearing. However, in common usage, it often refers more broadly to everyone who has significant hearing loss of any degree. Therefore, it is possible to be "Deaf" without being "deaf." And it is possible to be "deaf" without being "Deaf."
- **DSD**—Delaware School for the Deaf.
- **EHDI**—Early hearing detection and intervention. EHDI programs are state-run under the auspices of the Federal Department of Health and Human Services, Centers for Disease Control and Prevention. One component of EHDI is UNHS, which stands for universal newborn hearing screening.

Listening and Spoken Language—a method of communication in which people with severe-profound hearing loss use residual hearing and hearing technology in order to listen and speak as do those with typical abilities. Abbreviation: LSL. Research has shown that a majority of young children with sensorineural hearing loss at birth can achieve listening and spoken language skills with a combination of technology and auditory-oral therapy.

LSL—an abbreviation for Listening and Spoken Language.

Manually coded English—A family of visual methods of communication in which the grammar and syntax of English (rather than that of American Sign Language) is employed.

Sensorineural hearing loss—hearing loss caused by deterioration or death of so-called hair cells in the cochlea. In persons with typical hearing, the vibration of hair cells stimulates the auditory nerve, resulting in communication of information to the brain.

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