

Recaps of Interviews Conducted by Nick Fina

Lynne, age 9; Bilateral cochlear implant. Interview date: June 19, 2009.

Lynne is currently doing well in a local elementary school. Parents had positive experience with Child Development Watch. Sterck agreed to provide auditory-verbal therapy (AVT) as long as they agreed to include ASL. When the parents followed the advice of Children's Hospital of Philadelphia (CHOP) and requested that Sterck provide AVT only, Sterck requested that they withdraw Lynne from Sterck School. At first, Sterck relented and agreed to provide AVT services, then changed positions and again denied services. Eventually, Sterck officials invited the parents to have Lynne participate in an oral group that was meeting at the school once each week. When Lynne turned 3, the parents severed the relationship with Sterck and enrolled her in the local school district. They continued having difficulty with local school officials who, for example, insisted on having her enroll in a very noisy school with children who had a different basis for their language delays. In the following year, Lynne's parents held her back from kindergarten, despite the school district's threat to pull services. A year later, the school district strongly resisted the parents' request for an FM system, a teacher of the deaf, and a paraprofessional, but eventually agreed to provide these accommodations.

Miranda, age 3; Cochlear implant and hearing aid. Interview date: June 30, 2009.

Miranda received a definitive diagnosis of profound hearing loss in January 2008 at age 15 months. Child Development Watch referred Miranda's parents to Sterck/Statewide Services. The Statewide Services representative informed the parents that their 15-month-old daughter would need to be at Sterck in order to be around other deaf people, from whom she would learn ASL—an assertion that greatly shocked and upset Miranda's parents. Although CDW continued to support the family in other areas where Miranda was experiencing challenges, it terminated support relative to hearing loss once the referral to Statewide Services took place. The parents worked with Sterck for three months. During this time, a Sterck speech therapist told the mother that Miranda “will never listen to music and may never speak.” A deaf preschool teacher from Sterck visited their home every second Wednesday at no charge. The interaction between Miranda and this teacher was of limited value because the teacher could only sign and Miranda would not sign back except as a last resort. Following a period of therapy at CHOP, where Miranda received a cochlear implant in August 2008, Miranda's parents enrolled her in the auditory-oral program at Clarke School in Bryn Mawr, PA, at considerable sacrifice of time and money. The State of Delaware refused to pay for this program, according to Miranda's mom, because the provider is not Delaware-based. Today Miranda is doing well, often speaking in sentences of 10 words or more. The future remains problematic, however, as Delaware's schools are not currently positioned to meet Miranda's special educational needs.

Chuck, age 22. Hearing aid. Interview date: July 6, 2009.

Chuck received a diagnosis of conductive hearing loss as a young child. Hospital personnel referred his parents to Sterck. By the time he was 2, he was riding a school bus to Sterck each day. During first grade, Chuck and all of his classmates attended McVey School. Although enrolled at Sterck, they were indistinguishable from other McVey students. First grade was by far the highlight of Chuck's eight years at Sterck. In second grade, the pullout process stopped, with no explanation from the school. In grades 2 through 5, Chuck's instruction was in a combination of spoken English and ASL. His mom recalls IEP meetings as long, with little or no active participation from family members. As Chuck got older, she recalls, school personnel said things like "if you get mainstreamed, you might not get the interpreter you need." She took this to be a concern on the part of the school with maintaining headcount. After 8th grade, Chuck left Sterck. He attended St. Elizabeth's High School in grade 9—a very difficult year for him because of the failure of both St. Elizabeth's and Sterck to help him make the transition. Grades 10 through 12 at Howard High went much better. Today Chuck is a young man with moderate hearing loss. His mother deeply regrets her decision to send Chuck to Sterck. "I could just kick myself for not taking him out sooner," she said. "But the way the system was set up, we were in it before we knew it. They didn't give us options."

Gina, age 6. Cochlear implant. Interview date: August 7, 2009.

Gina, who wears a cochlear implant, received her diagnosis of deafness before birth. The family pediatrician referred Gina's mother to Sterck School. The mom told Sterck that she wanted her daughter to learn how to talk. Until Gina was 3, her mother felt that Sterck was reasonably responsive to this request. Her teachers/therapists wanted Gina to sign first, but they did not discourage spoken language development. Things changed after Gina became 3 years old. Her pre-school teacher did not speak at all. Gina's mother saw a change in her. She stopped speaking to her parents and to children in her play group. Sterck personnel reacted negatively to the mother's decision to withdraw Gina from the school. However, today Gina is a first grader whose first language is English and whose second language is Spanish. Her mother wants Gina to make the decision about getting a second cochlear implant when she is older. Meanwhile, mom strongly feels she did the right thing by withdrawing her child from Sterck.

Amy, age 5 1/2. FM receiver. Interview date: September 4, 2009.

Amy contracted meningitis in September 2006. Her father said they believe the subsequent vision and hearing problems she experienced were caused by the meningitis. Her hearing loss was profound in one ear, borderline in the other. Prior to the onset of sensory difficulties, Amy had been developing speech and language quite well in a Montessori environment. The family received a referral to Statewide Services for the Deaf and Blind, which accepted her for services. Amy's eyes subsequently returned to normal, but her hearing loss remained. She received twice-weekly services from Sterck School in the summer of 2007. However, her progress speech and

language development began to slow, and the Montessori school held her back in September 2007. Although Amy could hear reasonably well in one ear, her Sterck teachers did not permit her to talk. The family felt that experts on both sides were overwhelming them with conflicting opinions about whether she belonged in a sign language environment. Two Sterck officials encouraged them to keep Amy at Sterck. People at A.I. DuPont Hospital advised otherwise. Eventually, the family decided to withdraw her from Sterck at the end of calendar year 2007. One Sterck teacher decided to help the transition back to Montessori by counseling Amy's Montessori teacher on working with children who have hearing loss. She continued in Montessori thereafter, eventually resuming the pace of speech and language development that she had been experiencing before she attended Sterck.