

LOOK WHO'S BEEN 'VOTED OFF THE ISLAND' NOW: EXCLUSION AND THE EDUCATION OF DEAF CHILDREN WITH AUTISM SPECTRUM DISORDERS AND OTHER DISABILITIES

Annie Steinberg, M.D.

Clinical Professor, University of Pennsylvania School of Medicine

Tanya Brown, M.A.

School Counselor, Engage Program, Pennsylvania School for the Deaf

ABSTRACT

In the United States, school systems are required to provide students with a free and appropriate education in the least restrictive environment. Some schools for the Deaf have found it challenging to do so for Deaf students with additional disabilities, and increasingly avoid this legal mandate. This paper addresses the irony of excluding a deaf child from the language accessible environment that serves as a foundation for all learning. Some of the same professionals who fight for deaf students to have full access to language deny this right to the child who is deaf with additional disabilities, the limited expressive use of sign language used to justify their exclusion. As a result, Deaf children with additional disabilities end up in mixed special education classrooms in hearing schools, reliant on teachers who know only a few signs, exempted from the access to language their deaf peers are granted.

For children who are Deaf and who have an autism spectrum disorder or additional disabilities, linguistic and educational interventions are particularly and inextricably linked. The diagnosis of the additional disability renders the facilitation of shared language access a foundation for all other interventions. Until there is evidence to suggest another approach, we posit that the academic curriculum and classroom environment in a program designed for children who are deaf can be modified to be relevant for each child with additional needs, presuming the proper supervision and support of the teaching professionals who are already knowledgeable about the importance of language.

INTRODUCTION

The 'Least Restrictive Environment' (LRE) is a concept first defined by the Individuals with Disabilities Education Act, originally entitled, Education for All Handicapped Children Act of 1975 (EAHCA, 1975; IDEA, 1994). This law states that students with disabilities are to be given a free and appropriate public education in the least restrictive environment. As per a more recent iteration, it specifically states that, "to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care

facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily” (IDEA, 2004). While the courts have generally deferred to school officials on LRE matters and ruled in favor of more restrictive placements, in some recent cases, the courts are finding that schools are not fulfilling their responsibility in providing the less restrictive environments for students with multiple disabilities.

Children who are Deaf present a unique challenge to the LRE concept in that many have fought to ensure that Deaf students not be mainstreamed in local hearing schools, rather, that a bilingual bicultural school for the Deaf is the least restrictive environment as it provides full access to language for students who communicate in the visual spatial mode. After years of battling for the recognition of American Sign Language (ASL) not only as a legitimate language, but *the* critical language in which all instruction should be conducted, some school administrators now claim that limited expressive sign language in individuals with comorbid conditions does not equate with *true language*. Despite designated funding to serve children who are deaf, the exclusion of these complex children is justified in this manner; this paradox characterizes thinking regarding the concept of “least restrictive environment.” The fundamental premise that a deaf school *is* the least restrictive setting for a Deaf child is set aside when the child or adolescent who is deaf has autism or other disabilities that limit expressive language fluency.

As a result, deaf children with autism, whose communication and interpersonal interaction must be maximally supported, end up relying on teachers who may know only a few signs, or interpreters who may not be available throughout the day. It is true that professionals in deaf education need significant support to learn about children who are deaf and have a developmental disability affecting language and social development. But with support, they can help their students with multiple disabilities achieve to their full potential, as well as feel empowered to educate and collaborate with others who lack their specialized and critical knowledge of and training in deafness.

Children With Multiple Disabilities: Diverse Attributes and Learning Needs

Children with multiple disabilities are an extremely diverse group of learners. Even an individual child has a diversity of learning abilities and day-to-day variability. To address best practices requires not only addressing individual learning profiles, but the impact of poverty, race, culture, media influences, parenting styles, family dynamics, family and community supports, as well as the personal characteristics and endowments of the individual student. Children with multiple disabilities have physiological, psychological, communication, and

interaction differences in addition to specific learning disabilities. The way in which educators of deaf and hard of hearing students perceive their roles, their original aspirations upon entry into the field, and their ongoing opportunities for training and professional growth all play a part in how well they can meet the educational needs of each child with multiple disabilities.

It is recognized that with increased early detection of autism spectrum disorders, (not dissimilar from the early identification of hearing loss), it is clear that early intervention and educational programming has resulted in very significant improvements in communication, social, and cognitive skills for children who are Deaf and have an autism spectrum disorder.

When the child is deaf and has additional disabilities, the professional who is supporting the family does so by facilitating communication, connection and engagement. The first step is developing a shared language for the child and family. Advances in technology add complexity here, as some professionals espouse cochlear implantation and the use of intensive speech and language therapies given the challenge of sustained eye contact, while others encourage the use of sign language, given that verbal expression is often delayed and challenging even for hearing children with autism. Parental decision-making is best supported by professionals who understand the divergent options from which they must choose. As the child enters school, the path for helping the child achieve to his/her potential often involves re-evaluation of earlier decisions and the addition of interventions to support language development including surgical (cochlear implantation), augmentative communication, and the introduction of sign language if not already utilized- anything that may draw out the child who remains internally focused and delayed in various domains.

There is no single curriculum for educating children with multiple disabilities. There is, however, a knowledge base and a syllabus that can be modified, adjusted, and re-created to be relevant for each child with multiple special needs. In the end, it is all about language and the opportunity to gain access to language. With language, interactions and relationships can be developed over time, and developmental growth can be realized. Without language, the child who is deaf and has an ASD is fated to a life of unrealized potential and isolation. Who can better serve this community of students than professionals working in the field of deafness who also understand the need for language?

For typical children exposed to an accessible language, the development of language follows a predictable course. The most intensive period of language development occurs during the first 3 years of life, a period when the brain is developing and maturing. Language skills appear to develop best in a world that is rich in sounds, sights, and consistent exposure to the language of others. However, for children and adults with autism, as well as those who are profoundly deaf, language will continue to develop throughout the life cycle, with social pragmatics often integrated last. Hearing individuals usually learn

language through speech. Many deaf individuals, however, learn language in the visuospatial domain, most often in signs. An accessible visible language may be particularly essential for deaf individuals with other language learning disabilities, even if only to bridge to speech production and the use of residual hearing. Other visuospatial and multimodal therapies, including augmentative communication may be important in facilitating the ultimate acquisition of a rich language system.

For typically developing individuals, a desire to communicate or interact with the world is at the root of language development. This motivation to communicate or interact with the world is often poorly understood in the case of individuals with autism. Children with autism and other developmental language disorders often require years of intense work to acquire language. Language learning is biologically driven. When there is a problem in language networks in the brain, constant exposure to language helps ensure that a child with this critical deficit gets the opportunity to obtain access to information and to develop the emerging capacity for language. This makes the deaf education professional a critically important team member in designing an appropriate program for the student with a dual disability.

Early intervention and education can provide significant advances for children who are deaf or hard of hearing and their families. Unfortunately, symptoms that may indicate other developmental problems often remain undiagnosed once a child's services have been tailored to his or her hearing loss. The overlap between the way ASDs and deafness present themselves provides a distinct diagnostic dilemma in the first few years of life. This is complicated further by coexisting developmental delays in motor planning, attention, and mood regulation. An emphasis on deafness to the exclusion of these other variables often leads to late identification of the other developmental issues. Suboptimal interventions with an emphasis only on traditional modes of instruction in deaf education may result in perceived failure. Consequently, deaf children who also have autism need an educational program that (1) identifies concerns early and (2) considers *both* the deafness and the autism so that appropriate, individually tailored interventions can be designed.

Communication and education are inextricably linked for the child who is deaf and uses sign language. Educational curricula are language based, and remediation for a deaf child goes far beyond amplification and speech-language therapy. This is likewise true for the child with hearing loss who also has been diagnosed with autism. Education includes both specialized instruction and related services necessary for the student to benefit from the instruction; ongoing in-school intervention sessions (i.e., speech-language, communication, and occupational therapy, as well as audiologic services) are an integral part of the school day and should be provided by professionals who understand *both* deafness and autism.

Autism and Deafness: Distinct Entities, Intertwined When They Coexist

Deaf children with autism present with many of the same symptoms that hearing children with autism do. However, diagnosis of deaf children frequently occurs later than the diagnosis of hearing children, in part because of diagnostic shadowing. Impairments of social communication and language, delays and abnormalities in play development, and restrictions of interest and activity occur in deaf children in ways that are identical to those seen in hearing children with autism. Who can better assess the development and play of typical deaf children than professionals in deafness?

The deaf child who has autism and is reliant on sign language often requires additional adaptations to make communication and socialization accessible. Without this, the possibilities for social isolation are staggering. While it cannot be assigned to a traditional trajectory, the developmental outcome for the child who is deaf and has been diagnosed with autism or other language or social disabilities will be poor without a dedication to the provision of accessible language, and without flexible notions of language competence and positive predictions of the future.

Multiple Disabilities and Academic Programming

Students who are Deaf and have a history of challenging behaviors that interfere with learning often have co-morbid intellectual, developmental and/or behavioral diagnoses such as Autism, Communication disorders, Sensory Integration Disorders, Traumatic Brain Injury, Cerebral Palsy, syndromes such as CHARGE, Goldenhar, Treacher-Collins, or Smith-Magenis, or intrauterine infections such as cytomegalovirus. For some of these students, there may have been multiple surgeries, lengthy hospitalizations, total dependency, and little opportunity for play or peer interactions for the first years of their lives. Educational goals for the elementary school years may need to emphasize baseline adaptive functioning including activities of daily living, reducing challenging behaviors and social skills deficits that interfere with daily life as well as learning.

Students with these conditions require adaptations to access the standard educational curriculum as well as daily life skill instruction. The student's educational needs include activities of daily living and self care skills including personal grooming, feeding, dressing, toileting, and later, cooking, cleaning and budgeting. Communication skills include initiating a communication, recognizing and understanding the communication efforts of others, and responding appropriately. Social Skills include interacting with family members, peers, adults, and others in the community safely and appropriately.

Adaptations for individualized specialized designed instruction typically include small classroom size, e.g., two to five students, slower paced rate of learning with high-frequency repetitions, extra visual supports and special emphasis on areas of skills deficits, including but not limited to functional academic, home, social, and later, employment and advanced personal skills.

Enhancements to the classroom environment to meet the student's special educational needs can involve additional visual supports, high frequency repetitions, 'chunking' concepts into smaller more manageable, and concrete steps, and addressing the student's needs as a whole. When challenging behaviors or barriers to learning are encountered, a child's needs must be understood, as these behaviors likely represent a form of communication. While rudimentary, this behavioral analysis is individualized, methodical and evidence based. Expansion of an instructional repertoire with a great deal of structure, simultaneous attention to social skills instruction, adaptive daily living, and ongoing self-regulation while bathing the student in a language rich environment is the essence of teaching Deaf students with additional disabilities.

Relationally, it is critical to teach students who are Deaf and have additional developmental disabilities to play and enjoy their engagement with the teacher. This level of engagement must begin before the work becomes adult directed. All too soon, limits and expectations have to be established and behaviors reshaped and replaced; thus, it is important to first teach that something 'good' will happen if the student makes an effort to connect and to learn. Positive behavior supports provide this motivation, whether a smile, a high five, a head nod, or encouraging signed social statements that evoke positive feelings, such as, 'right!', 'good!', 'nice work!', 'perfect!', 'Yes!', 'Wow', 'let me see that again!', etc. Patience, tolerance, and intentional responsiveness to both the student's desirable and undesirable behaviors is critical in maintaining the relational essence of teaching students with dual disabilities.

Whether teaching general concepts, academic, social or life skills, encasing the student's experience with and in sign language is critical and requires that instruction is slowly paced, as concrete as possible, sequential, positive and enjoyable. As all behaviors are communications, dysfunctional behaviors must be understood in terms of their function, so that a more appropriate expressive language based substitute can be devised as soon as the behavior emerges. The replacement may entail the repetition of a sign or phrase that can replace the non-functional behavior or the practice of modeling what is more appropriate. High frequency repetitions are possible in all environments because teaching opportunities are abundant if the tools and strategy are identified when teachable moments present themselves.

When the student can be supported with language based instructional strategies that facilitate shared communication within the school community, difficult behaviors diminish or resolve. Teaching simple things, like tapping or

waving for attention; maintaining eye contact; brief reciprocal daily rote and sequential social interactions help the student develop skills to successfully assimilate. Ultimately, the goal would be full inclusion but comfort in the cafeteria, social events, or hallway encounter through shared culture and communication is equally important; the student maintains citizenship in the Deaf community, and staff members acquire priceless professional growth.

Some schools for the deaf have unabashedly exclusionary admissions policies, such as *“does not serve students who need a custodial program, including but not limited to students who are severely to profoundly retarded, are autistic, or lack self-help skills. Students who lack self-help skills include those who are unable to learn simple mobility patterns around campus, are unable to communicate basic needs to staff members, are unable to respond appropriately to life-threatening situations, do not demonstrate the potential to eat and dress, or do not demonstrate the potential to attend to personal care/hygiene needs.”* With the decline of enrollment and closure of many residential and day Schools for the Deaf, a shift in the demographics of the student body can also be discerned. School districts are willing to place students in the more costly school for the Deaf when their needs are greater, such as when additional disabilities are present and the identification of a suitable local placement is more challenging. It behooves Schools for the Deaf and deafness professionals to embrace their unique skills and address the barriers to learning for special needs students who are Deaf, as well as to support the general education students to tolerate, understand, accept, develop sensitivity and ultimately embrace students who are deaf with differences as welcomed members of the community.

Conclusion

Hearing loss in childhood offers a unique opportunity to witness adaptation to perceptual impairment and resilience in the face of a disruption in communication channels. The diagnosis of an additional developmental disability renders interventions for deafness all the more critical, and the approach to each disability cannot be viewed without consideration of the impact of the other as they are primarily and inextricably related with regard to appropriate linguistic and educational interventions.

REFERENCES

Education for All Handicapped Children Act, 1975.

Individuals with Disabilities Education Act, 1994.

Individuals With Disabilities Education Improvement Act, 2004.