autism issue

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what works
where we’re going

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Gallaudet University Press
Deafness & Autism

I'm very proud to introduce Odyssey's autism issue. Autism, or “autism spectrum disorder,” is a growing phenomenon in the U.S. The most recent figures (February 2007) indicate that one child in 150 in the United States has been diagnosed with autism spectrum disorder (Center for Disease Control and Prevention, 2007b). The best estimate of the prevalence of a diagnosis of autism among deaf children is approximately 1 in 76, or twice that. (Based on GRI: Annual Survey of Deaf and Hard of Hearing Children and Youth, 2006-2007). (Thanks, especially, for these particular statistics to Christen Szymanski and Dr. Patrick J. Brice, who have contributed an article based on their studies for, and work as, clinical psychologists.)

The articles in this special issue explore various aspects of autism in deaf children.

The personal experiences of Dr. Mei Yeh-Kennedy and Stefanie Ellis-Gonzales, both Gallaudet graduates and mothers of deaf children with autism, reveal the heartbreak this disorder brings to families who welcome a bright, outgoing infant only to watch the baby lose those qualities as he or she sinks into autism. Janet Weinstock, another Gallaudet graduate and mother of a deaf child with autism, offers tips for fighting back.

Lee Ann Bradley, Brandi Krakowski, and Ann Thiessen, three educators in Iowa, discuss what works as they develop schedules and programs for their deaf students with autism.

Gallaudet educator Dr. Margery Miller and Dr. E. Sumie Funayama, consultant from Ohio, offer their perspective on what happens after a deaf student with autism leaves school.

Gallaudet professor emerita Dr. Diane Morton points out that the field is fertile for research into all of the various questions arising from autism spectrum disorder in children who are deaf or hard of hearing.

Dr. Annie Steinberg, pediatrician, child and adolescent psychiatrist, and a clinical associate professor in the Departments of Psychiatry, University of Pennsylvania School of Medicine, expresses her hope that this issue “will challenge readers to learn more about the education of children who are deaf and have an ASD.”

We thank these wonderful authors for contributing their expertise and personal experiences. They, as we, hope their thoughtful essays can shed some light for any of our readers who face both deafness and autism in their families or schools.

—Michael Deninger, PhD, Interim Dean
Laurent Clerc National Deaf Education Center
Gallaudet University

We would also like to thank all of our student models from the CDC, the Team 4/5 Clerc Center classrooms, and the Student Activities Center at Gallaudet University for their assistance in helping to illustrate this issue of Odyssey. Thank you, also, to the organizers of Deaf Autreat 2006 for sharing their photos for use in this issue.

Odyssey would like to thank its former developer and editor, Dr. Cathy Carroll, for her years of unmatched contributions to the Clerc Center’s publications. In addition to her work for Odyssey, she developed World Around You and Celebrate! magazines. Cathy arrived at the Clerc Center in 1978 and loved every minute of interviewing deaf individuals and being able to share their stories. We wish her a joyous retirement.

We are also grateful to the organizers of Deaf Autreat 2006 for sharing their photos for use in this issue.
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LIFE AFTER HIGH SCHOOL FOR
DEAF YOUTH
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and E. Sumie Funayama

SPR/SUM 2008
The puzzle that is autism is both difficult and intriguing. More frightening, what we call "autism" has no cure, and the number of children affected is rising rapidly (see www.cdc.gov/ncbddd/idd/addmprevalence.htm). Those of us reading this issue of Odyssey are probably familiar with deafness. But what is involved with autism?

At the most basic level, autism is a neurological disorder that most likely involves a distinct abnormality in brain structure (see www.nichdnih.gov/news/releases/autism_affects_brain.cfm), that affects a child's abilities in two areas: communication and social development. It also is marked by repetitive or stereotypical behavior. Most commonly, the form autism takes in people's minds is that of a child who is unresponsive, has echolalic speech or signs (immediately and involuntarily repeats the speech or signs of others immediately after they're uttered), shows no emotions, and constantly engages in self-stimulating behaviors. Then we see a book cover showing actress Jenny McCarthy (2007) holding her autistic son—he is smiling and making eye contact with the camera. At first glance one might say, "This is not an autistic child." But the various manifestations of autism range from children who are mildly affected, who are quite gifted academically, or who do show emotions, to children who are deeply disabled and functionally retarded.

Because of the variability in the causes of deafness as well as autism—genetics, maternal exposure to viruses, toxins, birth and developmental issues—the simultaneous effect of both autism and deafness creates a more intricate puzzle. For example, the most basic need of deaf children in regard to communication—eye contact—is severely compromised in a deaf child.
Diane D. Morton, PhD, has served for more than 30 years as a clinical psychologist, school psychologist, and counselor working with deaf children and their families. The majority of her career has been spent working in schools for the deaf, often with children diagnosed with autism spectrum disorders. She also serves on the board of the National Deaf Academy, which also serves autistic children and adolescents.

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with autism. The lack of eye contact that is common in autism creates a great barrier for the deaf child in acquiring language, developing social skills, and learning and internalizing appropriate behavioral controls. When one considers the potential number of genetic changes that cause autism and the potential number of genetic markers that lead to deafness, along with the stressors (toxins and viral assaults) that can trigger one or both, a puzzle of huge magnitude emerges.

As the number of deaf children with autism grows, the impact on deaf education and the deaf community is of great concern. There is a tremendous need for additional training for teachers focusing on deaf autistic individuals at all levels. At the preschool and elementary levels, where autism is first identified and behavioral programs are initiated, teachers need to be provided with state-of-the-art teaching techniques and enhanced skills for developing programs to maximize the attention, appropriate behaviors, and learning potential of deaf autistic children in the classroom.

Secondary school teachers and those at community colleges need to be ready and equipped to handle high-functioning autistic deaf students and their often inflexible and socially odd behavior. Vocational rehabilitation counselors, placement specialists, and job coaches should be prepared for a new kind of comprehensive evaluation for deaf autistic clients that focuses on the capacity to function in the work environment and the variability in individual behaviors, including rigid and stereotypical behaviors that can lead to difficulties on the job. For teachers, administrators, and parents, increased knowledge and training can translate into increased success for deaf autistic individuals.

This issue of Odyssey focuses on deaf children with autism, or autistic children who are also deaf. In many cases it is difficult to ascertain which is the primary diagnosis, although autism is generally the most pervasive and disabling of the two. Within these pages you will find articles on personal experiences, educational programs, and support groups for parents with autistic children who are deaf.

To date, little has become known or has been written about autistic children who are also deaf. The identification, assessment, treatment, education, behavior, communication, and social development of deaf autistic children is a fertile field for research and development. Hopefully, this issue of Odyssey will steer us in the right direction.

Reference
After years of battling for recognition of America Sign Language (ASL) as a legitimate language, some school administrators now claim that although individuals with conditions such as autism that limit expressive language are using signs, this somehow does not equate with language. Unfortunately, in regard to schools that are specifically funded to serve children who are deaf, this paradoxical view has been used to justify inclusion—and exclusion—of children who are deaf and have additional disabilities.

Paradox also characterizes much thinking when it comes to the concept of “least restrictive environment.” Many feel that for students dependent on sign language, a deaf school is the least restrictive setting. But some of the same professionals who fight for the deaf student to have this access to language suggest that the child or adolescent who is deaf and has autism be denied it. As a result, these 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.

This issue of Odyssey will help to advance the field of special education, particularly for children who are deaf and have other disabilities such as an autism spectrum disorder (ASD), by bringing the perspectives of parents and educators to a broad readership. Parents have played an enormous role in supplying evidence and support for research to the field of autism in the past decade. Now it’s time to do the same for children who are deaf and have an ASD or other developmental disability affecting language and social development. Professionals in deaf education need significant support to learn about these complex disorders. With this support, they not only can help their students with multiple disabilities achieve their full potential but can also feel empowered to educate and collaborate with others who lack their specialized training in deafness.

By Annie G. Steinberg

**AN INTRODUCTION TO THE ODYSSEY SPECIAL ISSUE ON AUTISM AND DEAFNESS**

Annie G. Steinberg, MD, is a pediatrician and child and adolescent psychiatrist practicing in Narberth, Pennsylvania. She is also a clinical associate professor in the Department of Psychiatry at the University of Pennsylvania School of Medicine. She has cared for children with neurodevelopmental disabilities for more than 25 years and especially loves working with children, adolescents, and adults who are deaf or hard of hearing.

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Children With Multiple Disabilities: Diverse Attributes, Diverse 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 experiences. Many issues must be addressed if we are to speak intelligibly about best practices in these children’s education. Beyond learning capacities, the issues include poverty, race, culture, media influences, parenting style, family supports, family dynamics, and the 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, these educators’ original aspirations when they entered the field, and their ongoing opportunities for training and professional growth all play a part now in how well they can meet the educational needs of each child with multiple disabilities.

The National Institutes of Health and the U.S. Department of Education were directed in 2001 by the National Academies to promote routine early screening of children for ASDs, much as it is promoted for the identification of hearing loss. Since then, research has demonstrated that early identification and immediate educational intervention result in significant improvements in the child’s communication, social, and cognitive skills. Programs have been established across the country to identify children with these developmental disorders and to intervene effectively. But what happens if the child is
also deaf? Who are the professionals best equipped to facilitate communication and help the family to connect with and engage their child with autism by means of language?

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 three 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 may continue to develop throughout the life cycle, with social fine points 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 is necessary for deaf individuals with other language learning disabilities. Other visuospatial and multimodal therapies, however, also may be important in facilitating the ultimate acquisition of language.

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 with 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 this 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 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. The Individuals with Disabilities Education Act of 1999 (Public Law 101-476) and Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112) mandate early intervention and free, appropriate educational services for all infants and children who have hearing impairments, including those with ASDs. Education includes both specialized instruction and related services necessary for the student to benefit from the instruction; therefore, ongoing in-school intervention sessions (i.e., speech-language, communication, and occupational therapy, as well as audiologic services) are also part of the school day and should be provided by professionals who understand both deafness and autism.
Autism and Deafness: Distinct Entities, Though Inextricably Intertwined When They Coexist

Deaf children with autism present the same symptoms that hearing children with autism do. However, diagnosis of deaf children frequently occurs later than 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 may require additional adaptations to make communication and socialization accessible. Without this, the possibilities for social isolation are staggering. Autism is a mysterious condition that evolves over the developmental life of an individual; it cannot be assigned to a traditional trajectory. But the developmental outcome for the child who is deaf and has been diagnosed with autism will be poor without a dedication to inclusion and the provision of accessible language, and without flexible notions of language competence and positive predictions of the future.

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. When there are conditions such as language disorders or autism, the child and family’s strengths, capacities, and vulnerabilities and the larger social, linguistic, educational, cultural, and environmental contexts must come together to allow for an accessible environment where the deafness itself does not further impede developmental gain or place an individual at an additional functional disadvantage. The diagnosis of an ASD 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.

Deafness and autism are primarily and inextricably related with regard to appropriate linguistic and educational interventions for all children and adolescents who have these conditions.

I hope this issue of Odyssey will raise many questions and will challenge readers to learn more about the education of children who are deaf and have an ASD or other developmental language disorder.
when autism and deafness coexist in children

WHAT WE KNOW NOW

By Christen Szymanski and Patrick J. Brice

In February 2007, the Centers for Disease Control and Prevention (2007a) released new statistics on the prevalence of autism in 8-year-olds. Using data from a multistate national sample, the CDC concluded that approximately 1 in 150 children in the United States had been diagnosed with an autism spectrum disorder, a significant increase over the previous estimate of 1 in 166, released six years earlier (Centers for Disease Control and Prevention, 2007b). Either figure represents an astounding change from earlier estimates. As the CDC (2007b, para. 3) reports, “For decades, the best estimate for the prevalence of autism was 4 to 5 per 10,000 children.”

While many explanations have been offered for the increased rate of autism, the true cause remains unknown. Nonetheless, in the United States, diagnoses of autism are increasing faster than any other diagnosis of developmental disability in children. But this statement, like others pertaining to the characteristics of autism and the relevant intervention services, does not tell the whole story for all children diagnosed with autism. Every day, our knowledge grows about autism in those children who are hearing; researchers and educators develop new strategies, new programs, and new diagnostic instruments to serve these children. But research and intervention, as well as fund-raising and media attention, typically exclude those who have additional disabilities or do not speak English. Thus, the question becomes, “What do we really know about those children who are deaf and have autism?”

Though No Two Children With Autism Are Alike, Common Characteristics Exist

Both children and adults with autism generally display a particular set of common characteristics. The most commonly recognized include interactive difficulties (an absence or insufficiency of smiling, laughing, and eye contact), limited communication
abilities, insistence on routines and sameness (surprises and other changes are difficult), repetitious play, difficulty with make-believe play, challenges in interacting with peers, and behaviors that disrupt daily living. A diagnosis of autistic disorder is made when a child has impairments in his or her social interactions, communication abilities and style, and behavior. Each child who is affected by autism is unique—in no two children with autism are the severity and intensity of the impairments they encounter alike.

**Does Autism Look Like Deafness? The Importance of Diagnosing a Hearing Loss**

Before characteristics of autism and deafness can be described, it is necessary to understand the importance of knowing if your child has a hearing loss. This knowledge is essential because of the possibility that a hearing loss is masking autism. For example, several of the characteristics of autism may look like hearing loss and vice versa. If a child cannot hear, he or she will not respond when called by name—often a key item on checklists of autism, but also a characteristic of deafness. And if a child cannot hear, social interactions with peers may be difficult—due to an inability to hear conversations, not because he or she has autism. Likewise, does the child engage in self-stimulating behaviors because he or she cannot hear and thus plays independently?

Knowing if your child has a hearing loss is not always simple. And the fact that hearing loss is not always simple. And the fact that hearing loss often is not diagnosed until a child is 2 or 3 years old—the same time that autism is often diagnosed in children—does not make this conundrum any easier. Children who do not have access to communication or who do not express themselves—as is sometimes the case with children who have an undiagnosed hearing loss or deafness—may grow up linguistically, communicatively, emotionally, and socially isolated. This outcome is essentially the same as the core dimension of autism, a situation that contributes to the complexities of diagnosis for these children.

**How Many Deaf Children Have Autism?**

The rising estimate of the number of children with autism does not include children who are deaf. To begin to estimate the number of children who have both hearing loss and autism, one can look at the *Annual Survey of Deaf and Hard of Hearing Children and Youth*, which is conducted by the Gallaudet Research Institute.

In the survey for 2006-2007, researchers reported that there were 37,352 deaf and hard of hearing children in special education programs in the United States, including both residential programs and public programs. Of that 37,352, in-depth information was available for 35,706. Using the data from this national summary report, one can conclude that 469 deaf and hard of hearing children in the United States also had a diagnosis of autism. In other words, 1 deaf child in 76 was receiving services for both a hearing loss and autism, about twice what is currently believed to be the national prevalence rate, 1 in 150. It is important to remember that the *Annual Survey of Deaf and Hard of Hearing Children and Youth* does not account for every deaf child in the United States. Thus, these data may underrepresent the population of children with a hearing loss and autism.

**Can It Be That Autism “Does Not Exist Outside of Culture”?**

In countries other than the United States,
prevalence rates of autism vary. In *Unstrange Minds: Remapping the World of Autism*, Roy Richard Grinker (2007) suggests that a disability such as autism “does not exist outside of culture” (p. 11), and that the examination, diagnosis, and understanding of autism must come from within a culture and not from an outsider’s perspective. With this notion, one could argue that it is possible that a child who is deaf and has autism may look very different from a hearing child with autism. Unfortunately, only limited research is available to justify this position. In fact, the only available research indicates that deaf children with autism demonstrate the same symptomatology as similarly diagnosed hearing children (Roper, Arnold, & Monteiro, 2003). The countless variations among deaf and hearing children in educational achievement, informational exposure and access, and social interaction underscore the need for further research.

Nonetheless, it is clear that children who are deaf are also being diagnosed with autism, and at a far greater rate. We also know that there is an increased prevalence of hearing loss in children with autism. The increased prevalence of deafness in children who have autism, while startling, is not new. Therefore, one would expect that we should know much more about autism in children who have a hearing loss. Unfortunately, the very opposite is true—we know much, much less about children who are deaf and have autism.

**Deaf Children Get Autism Diagnoses Later**

On average, a child who is deaf will be diagnosed with autism later in life than a hearing child with autism. In one study, deaf children were diagnosed an average of 1 year later: deaf-autistic group, 4.1 years old; hearing-autistic group, 3.1 years old (Mandell, Novak, & Zubritsky, 2005). In another study, deaf children were found to be diagnosed with autism at a far greater rate. We also know that there is an increased prevalence of hearing loss in children with autism. The increased prevalence of deafness in children who have autism, while startling, is not new. Therefore, one would expect that we should know much more about autism in children who have a hearing loss. Unfortunately, the very opposite is true—we know much, much less about children who are deaf and have autism.

**Possible Autism Red Flags for Children Who Are Deaf**

- Resists being held or cuddled.
- Doesn’t reply to his or her own name when tapped or when attention is shared.
- Has difficulty engaging in shared attention. Nonautistic children often will visually track objects in a room or look in the same direction that a caregiver does. Children who are deaf do this often. A child who is deaf and has autism may not.
- Has difficulty imitating facial expressions and actions of caregivers (smiling, sticking out the tongue, clapping).
- Makes limited use of eye contact even though it is needed for communication.
- Has difficulty understanding others’ needs and feelings. (If someone is hurt, does the child ask if the person is okay?)
- Has unusual reactions to the environment that cannot be attributed to hearing loss, for example, fear of flashing lights, avoidance of smells and certain textures, refusal of hearing aids because of sensory sensitivity.
- Lags behind peers in language development; signing skills develop slowly even in an inclusive signing environment.
- Has difficulty understanding sign language or verbal language unless it is simplified.
- Does not play in the same way as same-age peers. Play is rigid and unimaginative.
- Shows an intense interest in a particular activity or object.
- Has difficulty interacting with other deaf and hard of hearing students, even with language access.
- Resists changes in routines, even though changes are clearly communicated.
between their fifth and sixteenth birthdays, while hearing children were diagnosed between their fourth and eleventh birthdays (Roper et al., 2003).

The substantially later diagnosis of autism in children who are deaf is alarming. Researchers and educators speculate that the reason behind delayed diagnoses is the difficulty encountered in distinguishing characteristics of deafness from characteristics of autism, as well as limited resources for parents and educators guiding the identification of autism and deafness. Also, it is possible that deaf children are diagnosed later because there are relatively few psychological tests that have been made for or even include considerations for children who are deaf. In fact, there are no approved instruments for making a diagnosis of autism in a child who is deaf. The current “gold standard” for diagnosing autism, the Autism Diagnostic Observation Schedule, includes a specific statement that it may not be used with children who are deaf.

**Socialization Milestones**

**Birth–6 months:** Babbles, coos, and laughs, even if deaf; looks at others and smiles.

6–12 months: Enjoys games that involve reciprocal interaction and expressions of enjoyment by the child such as “peek-a-boo” and “Where’s baby?”; should raise his or her arms to get picked up.

1–2 years: Is very curious about other people and surroundings; will point, show, and bring objects to others.

2–3 years: May cry or throw tantrums to get attention but is consoled when held. Can answer simple questions, asks others simple questions, and begins to understand language play (for example, rhymes). Begins pretend play with others.

**Communication Milestones**

**Birth–6 months:** Babbles, coos, and laughs, even if deaf.

6–12 months: Understands “no,” recognizes his or her own name, can wave “bye-bye.” Uses “mama” or “dada” signs and words.

1 year: Has well-developed gestures and eye contact; is able to request or refuse.

2–3 years: Can take turns in conversations and understands what sharing and helping are. Develops the ability to copy and internalize signs and words, and begins to develop two-word sentences (age 2 years) and ask questions (age 3 years). Vocabulary grows rapidly, from 200 or more words at age 2 to more than 900 at age 3.

3–4 years: Understands the perspectives of others and can empathize with them; can tell stories and understand plays on words.

**Behavioral Milestones**

**Birth–6 months:** Can smile and look at others in his or her visual field.

6–12 months: Can look for hidden objects, explore the environment, and repeat behaviors that get praise.

1–2 years: Can recognize himself or herself in a mirror, looks at pictures in books, and begins to explore. Shows affection—will offer hugs and kisses. Begins to parallel-play with others, not necessarily interacting but playing alongside them.

2–3 years: Begins to pretend and engage in make-believe play with other children and adults; wants to be independent and begins to understand others’ feelings.

An Ironic Development: The Success of Sign Language with Children with Autism

The use of signing with children who are autistic has been gaining recognition and acceptance for more than 40 years, even during times when using any visual language with deaf children was prohibited. It seems ironic that the use of sign language has been successful with children who have autism, since the terrible difficulties with eye contact experienced by people with autism would appear to prevent or interfere with any visually oriented learning.

Some suggest that children with autism have language difficulties because they struggle with cross-modality—converting auditory information to vocal utterances (Bonvillian, Nelson, & Ryne, 1981). Others have suggested that children with autism have severe auditory processing deficits (Ruttenberg & Gordon, 1967). Therefore, vocal languages may not be usable for communication or even understood by the child with autism. Instead, a visual communication system—for example, the Picture Exchange Communication System, or PECS (Frost & Bondy, 2002)—or sign language may be helpful, enabling the child to bypass any difficulties with spoken languages. Some researchers believe that communication with an autistic child is impossible without gestures and facial expressions such as those used in sign language (Chamberlain & Mayberry, 2000).

Sign language requires not only eye contact but a skilled language model. Sign language is often taught in public schools to hearing children with autism and other disabilities with success but in many cases on a limited basis because the language model is not fluent. While
research shows that hearing children with autism acquire sign language and can use it to communicate on a limited basis, one could theorize that with continuous access, a child who is deaf and has autism would have even more exposure and be able to learn even more. After all, most deaf and hard of hearing children rely on visual skills (Rosenhall, Nordin, Sandstrom, Ahlsen, & Gillberg, 1999). If visual skills are essential to the deaf child, and visual skills and visual languages are essential to the child with autism, then the communication needs of the child who is deaf and has autism would appear to be best served visually.

While not much recent research is available on the use of sign language with children who are deaf and have autism, early studies found that teaching sign language led to spontaneous use of communication in social situations and some social interactions, as well as unprompted responses (Fulwiler & Fouts, 1976). More recently, in 2007, in a predissertation study, the lead author of the present article (Szymanski) found that children with a sign language vocabulary of more than 50 words did significantly better than those with more limited vocabularies (less than 50 words) on questions relating to stereotypical autistic behavior, difficulties with communication, social concerns, and interpersonal relationships.

**Between Deaf and Hearing, Do Socialization and Behavior Patterns Differ?**

There has not yet been a published study solely investigating whether socialization or behavior patterns of children who are deaf and have autism differ from those of children with autism who are hearing. The only available information comes from Britain, where researchers reported that spontaneous social responses and reactions of children who are deaf and have autism appear to be the same as those of children who are hearing (Roper et al., 2003). However, in that study, the deaf sample used only a few signs or gestures. None of the deaf sample used sign language; most communicated with pictures while all the hearing children used spoken language, a difficult comparison. The experience of the world by children who are deaf is different from the experience of children who are hearing. Therefore, it would make sense that differences in behaviors or socialization patterns would be found; yet at this time there is no definitive evidence of such. It also may be possible that socialization differences exist but are difficult to recognize for researchers and educators not familiar with deafness. For example, a child who is deaf and has autism may bang on the table or wave to a classmate to get his or her attention. But how is this being interpreted? As a method of social interaction (attention getting) typical of a deaf child? Or as a behavior oddity in a child with autism?

**What Do Children Who Are Deaf and Have Autism Look Like?**

The biggest question remains: What do children who are deaf and have autism look like? Right now we are still not sure, but promising research, both recent and in the works, is slowly beginning to provide some answers. In Szymanski’s 2007 predissertation project, 19 parental reports of deaf children with autism were examined. Sixteen responding parents were deaf and 3 were hearing. All of the children included in the study had an existing diagnosis of autism. But, as has been suggested previously, the complexities of distinguishing deafness from autism may very well mean that some of the children included did not meet all of the diagnostic criteria for autism. However, all children did meet the criteria for services within the school system. Items on the survey included those that typically appear on currently used measures of autism. All of the children scored high for interaction deficits with family members, peers, and others around them. But parents who were deaf reported that problems with communication skills and behavior skills interfered far less with their child’s life than socialization problems. Parents who were hearing reported that behavioral problems and socialization were the most problematic areas. But the question becomes why are there differences? Parents who were deaf reported that their children did not have the same behavioral characteristics (repetitive behaviors, self-injurious behaviors, twirling, staring through people) that one would expect from a child with autism. Neither did these children have the same characteristics reported by hearing children who are deaf and have autism appear to

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**The Facts**

**FACT 1:** Deaf children are diagnosed more often with an autism spectrum disorder than what is currently considered the prevalence rate of 1 in 150 children (Gallaudet Research Institute, 2005).

**FACT 2:** Research has shown that hearing loss occurs more often in children who have autism than in children without autism (Rosenhall et al., 1999).

**FACT 3:** Visual methods of communication (e.g., sign language and PECS) appear to be easier for children with autism to understand and use than spoken language.

**FACT 4:** There are no known instruments for diagnosing autism in a child who is deaf.

**FACT 5:** Development is just beginning of an understanding of how children who are deaf and have autism are best served, what they look like, and which interventions are effective.
parents of their deaf children—especially in the areas of behavior and language. Knowing that these differences are out there makes it important for us to persist, finding out not only why but also how best to serve these children.

In the End, Just What Do We Know?

What we know about children who are deaf and have autism is limited (see Box on page 14). Some of the information may be controversial and other information still only ideas and hypotheses. We are not sure of the communication, socialization, and behavioral implications of deafness for autism and vice versa. We are not sure how to test these children and even where to educate them—in deaf programs or mainstreamed programs. We also are still not sure which professionals are best suited to work with these children.

Though we have far to go, some small steps have already been taken. Residential schools are hiring increasing numbers of qualified aides for children who need them, and public schools are inviting researchers to share information on interventions. Young scholars are taking up the challenge of understanding language development in children who are deaf and have autism in Texas, while educational interventions and practices for these children are being explored in Missouri and Utah. Other researchers are looking to the neurological sciences to explain why children with autism who sign do better than children who do not on specific psychological tests. Research into the developmental characteristics of children who are deaf and have autism is occurring in hopes of answering the essential question, What do children who are deaf and have autism really look like? And there is that group of dedicated parents who have embarked on their own effort to understand their children by establishing Autreat, a gathering for families of children with both hearing loss and autism (see http://www.deafautism.com/autreat.html).

What we really do know without a doubt is that researchers, educators, and parents are more aware of the concerns related to autism in all children, and that in the future, children with both deafness and autism will be guaranteed to have a group of adults dedicated to making sure their needs are met.

References


it’s a matter of learning what works in teaching students with deafness and autism

By Lee Ann Bradley, Brandi Krakowski, and Ann Thiessen

The development of language and literacy is the foundation for all other learning: That’s our guiding philosophy at the Iowa School for the Deaf (ISD). At ISD, we believe that intensive, highly structured early intervention and education work best to support cognitive and communication development in our students. However, little research exists on the needs of students with both autism and deafness. Thus, for ISD students with this combination of conditions, we draw on best practices related to deafness as well as those that apply to autism when we do our planning.

When Signing Isn’t Enough

Teachers at ISD who work with students with autism consider it vital that we use sign language. However, “through the air” communication can sometimes be ineffective, especially when unproductive behaviors occur and escalate. In such cases, we’ve found that using a companion communication method such as the Picture Exchange Communication System, or PECS (Frost & Bondy, 2002), helps a student calm down and refocus so that learning can continue.

PECS facilitates expressive communication through pictures that teachers and students use together to help students express their wants and needs. For example, a student can use PECS at snack time to communicate which of the various food options he or she prefers. The primary goal is to help children initiate communication.

Photos courtesy of Lee Ann Bradley
Building Structure Into the Day

We’ve found that incorporating TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children) techniques throughout the school day gives our students with autism the structure they need in order to learn. TEACCH is North Carolina’s statewide program serving people with autism spectrum disorder and their families (Division TEACCH, 2006; Mesibov & Howley, 2003). Among others, the principles of Structured Teaching, a component of TEACCH, include structuring the physical environment, as well as using visual supports to make the sequence of daily activities predictable and understandable and to make individual tasks understandable (Mesibov & Howley, 2003).

For example, some of our students have individual work areas. Here, work tasks are defined clearly so that students know what is expected of them in addition to what happens after the work is completed. Work tasks are placed in clearly labeled baskets, boxes, or folders so that students can see the work that needs to be done. These tasks are set up so that the individual student independently takes the correct box, completes the work at his or her work area, and returns the box to the designated area. A picture cue then tells the student what he or she needs to do next. In our experience, organizing students’ space in this way helps them understand expectations and promotes independence.

Many of our students with autism benefit from a visual schedule that helps them organize, predict, and transition among activities throughout the school day. If pictures or photographs are too abstract for a student, visual schedules can be adapted by means of tangible objects—that is, three-dimensional objects that have a clear relationship to actual activities. Examples of tangible objects include a straw or plastic spoon to indicate snack time, a cup to represent drink, or a minibook to stand for the library. Miniature items, such as dollhouse furnishings, can be used to represent locations throughout the school or home.

It can be helpful for the student to participate in the creation or discussion of the schedule each morning. Developing a routine to acknowledge each transition is also important—for example, crossing off or checking off what was completed,
turning a picture over, or putting the completed activity in a special box or envelope to show that it has been finished. Sometimes it helps to start preparing a student for schedule changes—field trips, fire drills, even a substitute teacher—a day in advance.

**Teachers and students can develop and use schedules in different ways:**
- A single schedule can be used for an entire class.
- An individual schedule can be attached near a student’s desk.
- Schedules can be carried from room to room.

**Making Choices More Visual Can Make Choosing Easier**

Often, a signed presentation of choices isn’t enough for our students. They may not attend to the whole message or may not be able to retain the message. To counter these and other unproductive behaviors, we often use choice boards. The primary purpose of a choice board is to present a concrete, visual display of options. This helps students begin to make choices about their activities, especially during free time or other less structured periods. Choice boards give teachers the opportunity to teach appropriate requesting behavior, broaden the range of choices available to a student, and improve communication.

When we use visual displays such as choice boards, students pay more attention, are more motivated to communicate, receive immediate reinforcement, and experience an opportunity to control what they get. They have time to see all the possibilities, think about their decision, and check the options as often as necessary before making the decision.

**Taking Students Beyond Imitation When Teaching Social Skills**

We’ve learned that we need to teach social skills directly to our students with a combination of deafness and autism. This may be because people with autism have difficulty with imitation. By structuring their play and other leisure activities, we give students the opportunity to practice communication and social skills such as turn taking and waiting. This kind of practice requires the adult working with a student to organize the needed materials, model the skills to be taught, and prompt appropriate use of these skills. For example, with young children, routine scripts can be implemented for toys. These scripts can involve recreating the face of a Mr. Potato Head toy from a picture model, building a simple block structure from a model, or using a dump truck to pick up and drop off items. Over time, it is important to incorporate turn taking into the routine, first with adults, then with other students.

**There Are Lots of Tools Out There—Use What Works!**

We’ve found that using a variety of strategies enhances the acquisition of language and communication skills in children with both autism and deafness. Sign language, gestures, speech, facial expression, body language, mime, pictures, PECS (as appropriate), written words, and fingerspelling are all effective tools for putting this strategy to work. An added benefit is that this comprehensive approach can address the needs of all simultaneously—both children who are deaf or hard of hearing and children with a combination of autism and deafness.

Even though limited resources are available to guide our work with students who have a combination of deafness and autism, we’re making the most of the situation by blending common sense, proven teaching strategies for students who are deaf or hard of hearing, and the expertise of a variety of other educational fields. Trial and error is important, too—at ISD, even as we teach, each of our students teaches us something new.

**References**


bring books to—and sharing them with—children with autism:
janet’s tips

By Janet S. Weinstock

Leave books everywhere. Place books in boxes or on shelves all over the house. Carry books in the car and in favorite backpacks. Be ready to enjoy books with your child anyplace, anytime—while waiting for appointments with the doctor or dentist or even at a sports event.

Give your child choices. Let younger children choose from at least two books. Choose books that will hold your child’s attention. As your child gets older, increase the number of books and pages. The goal is to have enough books so that he or she has a choice, but not so many that he or she can’t make a decision or gets overwhelmed about deciding which one to share and read.

Never say no. If it is financially possible, always let your child buy a book when he or she wants one. Bookstores, book fairs, and garage sales are fun places. Buy used books at bargain prices at garage sales or used-book sales at your local school or library.

Give a heads-up. When you are getting ready to read with your child, let him or her know ahead of time to ease the transition. Remind your child again a few minutes before the session begins. The best time to share books is when the child is most relaxed—before nap time, after a bath, or before bedtime.

Encourage eye contact. Let your child know that he or she needs to look at you while you read. Distract your child from wandering by getting him or her to look at an interesting part of the book by pointing at it. If your child looks away, move the book to the child’s eye level. Move your body, if necessary.

Don’t be afraid to repeat. If your child didn’t appear to see your signs, perhaps he or she really didn’t. Re-engage eye contact and repeat the signs before continuing. When appropriate, have your child copy your signs, or have him or her expand the signs with additional information to expand his or her language (i.e., classifiers).

Create poetry related to the book’s theme. Create a poem or a short story in American Sign Language (ASL) about the book’s theme. This activity can be considered summary or retelling. For example, with Sleepy Bear, by Lydia Dabovich, mime the action of the bear as he goes through the rituals between seasons. When reading Eric Carle’s The Very Hungry Caterpillar, you can describe the transformation of the caterpillar by using only classifiers—especially how it eats different food, then turns into a colorful butterfly.

Photo by John Consoli
I remember Selah’s third birthday party two years ago as if it were yesterday. It was supposed to be a festive, joyous, and lighthearted occasion celebrating my beautiful daughter’s embarkment upon another year of life surrounded by her friends and family. Instead, it was the most heartbreaking party I’d ever been to.

Just a couple of weeks before, we had discovered that Selah was not the child we envisioned. Our view of her would never be the same, and her future would forever be redefined. Our many dreams for her were shattered. We had learned that Selah had autism.

During the birthday party, it was all I could do to hold back my tears, keep a smile on my face, and hide the pain that seared my heart. Every now and then, I would find an excuse to leave for a while—I’d go to the kitchen to get some more food, or, if I found my resolve to keep this party from turning into shambles starting to crack, I’d slip into the bathroom, take some deep breaths, and try desperately to regroup.

All the parents and the children at the party had no idea anything was amiss—the only ones who knew were my husband, Len, me, and Selah’s grandparents. Throughout the party, we kept seeing all the signs that pointed to autism: Selah’s odd way of interacting (or lack thereof) with her peers, her obsessive interest in playing with her toy cars (rather than jumping with the other children on the bouncer we had rented for the occasion), and, hardest of all, her absolute lack of interest in the pile of presents that would fill any child with anticipation of what was under the bright, cheery wrapping paper.

Len and I could not wait for the hellish day to be over, for everybody to just
go home, so we could be alone in our desperate grief. When the final guest left, happily dragging his goody bag behind him, we closed the door, held each other tight, and cried our hearts out as we stood amid the remains of what appeared to be a typical birthday party: crepe paper hanging across the room, balloons, and the remains of a birthday cake. Our daughter had autism. Autism. We were shaken to the core; our souls were racked with grief. We were terrified of what lay ahead of us. Everything seemed so unknown, so foreign to us—even our own daughter.

Doing So Well at First
Throughout her first year of life, Selah hit all of her milestones at the appropriate ages. She flashed her beautiful grin for the first time at 2 weeks of age, held her head up while lying on her tummy at almost 3 months old, rolled over at 4 months, and, at 5 months, began to sit up. She crawled at 8 months and took her first steps at 11 months, and I remember so well how outrageously proud she was of herself, and how the world suddenly and wonderfully was within reach now that she could venture over to explore whatever captured her attention. Selah signed her very first word at 8 months old in her high chair as she eyed a jar of mashed bananas. Her chubby little hands moved together perfectly, making the sign for “more.” We would have given her all the mashed bananas in the world, we were so proud of her. Selah loved looking at picture books and would ask us to read to her endlessly. She began putting two words together at 11 months old. She was incredibly curious, attentive, and observant. At 22 months, she began the infant-toddler program and simply adored it. She would sign “Time go school now!” in the morning as I dressed her. In her class, Selah was able to recite the song “Tick Tock” from start to end, could identify every one of her classmates at circle time, and took absolute delight in playing with her friends. She was your typical happy-go-lucky and curious toddler. But then things started to become quite different.

Warning Flags Start Unfurling
When Selah was 26 or 27 months old, Len and I began to notice peculiar behaviors and mannerisms emerging. Our daughter would become fixated on the most mundane things: opening and shutting the doors of her play kitchen repeatedly, constantly putting things on the shelves and taking them out, pushing her dolly stroller throughout the house, retracing her exact steps over and over again until we became dizzy just watching her. At school, she started withdrawing from her friends and going off to a quiet corner more often to play by herself. We all thought that maybe it was a phase she was going through. “Chase” was still her favorite game in the whole world; when her friends chased her around, she was ecstatic. That relieved us; she still enjoyed being with her friends after all, so we told ourselves that this was probably a stage that would pass.

It was also around that time that Selah started to develop the strangest habit: She would rock her body from side to side while lying on the floor or in bed. She would do it for the longest time, until we had to stop her, distracting her with some other activity or toy. I asked her pediatrician about this behavior and got this response: “That is what is called self-soothing behavior; toddlers develop strategies to comfort themselves when they are faced with challenges or uncertainty, or when they become overwhelmed. It is normal behavior for children that age.” We believed that made perfect sense, for Selah’s little brother had just been born, so her perfect little world had been thrown topsy-turvy with his arrival. (Having to share attention is never easy.) We swept our mounting concerns aside (or at least
Over the next few months, as Selah downhill at a dizzying rate. Her eye contact deteriorated rapidly. We could hold her attention for hardly more than a few seconds. She would not take a second look at picture books she used to pore over, and she no longer demanded that we read with her. Her language declined as well—she went from five- to six-word sentences to a mere one or two words at a time. Her behavior became worse, too—she would throw fits if she did not get what she wanted. Selah also became increasingly preoccupied with getting as messy as possible, whether it was painting, drawing with markers, or playing with bubbles or lotions. She would seek out anything gooey and smear it over any surface and all over her arms, legs, tummy, face, and feet.

My husband and I consulted a team of educational specialists about these concerns. They told us that they suspected that Selah had sensory processing disorder (SPD). Simply put, this means that the brain is unable to process information from the senses properly. As a result, children with SPD misinterpret everyday sensory information, such as touch, sound, and movement. Many children with SPD feel so overwhelmed by information that they end up seeking out more intense or longer sensory experiences to regulate themselves. Selah’s craving for anything she could smear could be considered an example of this. In some cases, children with this disorder try to cope with it in the exact opposite way: by avoiding sensory information.

The specialists’ diagnosis made total sense to us; we felt that it described Selah perfectly. The team then determined that our daughter would benefit from attending to her sensory needs first and foremost. Once these needs were met, she would be able to focus better on other tasks and acquire more skills. The team recommended that she obtain occupational therapy to address this problem, and that we provide her with as many tactile opportunities as possible at home as well.

This was an overwhelming period for us, but we refused to waste any time, so we set out to learn as much as we could about SPD. We bought books on the subject, researched for hours on the Internet, and ordered hundreds of dollars worth of sensory equipment and toys to provide Selah with the stimulation she craved. We would do absolutely anything for our precious daughter and would stop at nothing to help her.

Toward the end of the school year, Len was offered a position at the California School for the Deaf (CSD)–Fremont, so we decided to go for it and put our house up for sale. To characterize that summer as a whirlwind would be a tremendous understatement—we managed to sell the house, pack up, move, then unpack and get settled into our new home in a matter of a few months—all with an extremely active toddler and a baby. To this day, I still don’t know how, but we managed to get through it. Everything went by in a blur, and before we knew it, summer was over.

And then the time came for Selah’s first day of school at CSD.

The Diagnosis—Or “D” Day
Selah was three months shy of her third birthday when she started in the infant-toddler program at CSD. Len and I went with her to take the usual photos and videos of this special occasion, and to help with the transition. We expected some anxiety and uncertainty on Selah’s part, as we knew that everything would be new and overwhelming for her. However, what we saw struck us as very odd. Instead of standing in a corner and observing the goings-on around her as a shy new student would, or exploring her new environment and the things that
surrounded her like a curious toddler, Selah ran around the room with no purpose whatsoever, seemingly searching for something, yet there actually was nothing she was looking for. Neither we nor her teachers could get her to make eye contact with any of us. She barely acknowledged any of the other children in the room. Then she took a pillow from one corner of the classroom and began her rocking ritual on the floor. Her teachers simply said that change was difficult, and there was so much newness in her life: new brother, new house, new neighborhood, new school, new classroom, new teachers, new classmates, new routine. It would take some time, but she would adapt.

But I went home with an incredibly heavy heart; for the rest of the day I couldn’t stop the tears from falling. A feeling deep down in my core kept gnawing at me, growing stronger and more urgent—we were somehow, for some reason, slowly losing our daughter. I knew we had to find out what it was and get help—fast.

I promptly requested a psychological evaluation. A few weeks had gone by, and Selah did not seem to be adjusting any better. Her IFSP (Individualized Family Service Plan) meeting was coming up, and we needed to do one before she turned 3 years old. Our school district sent us to see a clinical psychologist who, fortunately, was able to sign relatively well, so there was no need for an interpreter. Dr. Johnstone, direct and matter-of-fact, wasted no time. She began by interviewing Len and me, collecting reports from us and from Selah’s teachers, and examining our daughter’s previous reports and academic documents. She also gathered medical information from before I got pregnant with Selah.

Dr. Johnstone administered a number of tests. These included the Bayley Scales of Infant Development (BSID), the Southern California Ordinal Scales of Development (SCOSD), the Autism Diagnostic Observation Schedule (ADOS), and the second edition of the Behavior Assessment System for Children (BASC2). She also reviewed an existing video of Selah.

Dr. Johnstone began her clinical observation by running a few tests with Selah in her office, most of which included doing puzzles, matching colors, playing simple games, and generally attempting to engage our daughter. After that evaluation, I insisted that Dr. Johnstone observe Selah in her more “natural” environments as well, that is, at school and at home, a request to which she acquiesced.

The third and final clinical observation took place at home a couple of weeks later. It was November 1, 2005, just before Selah’s third birthday. Dr. Johnstone and I were sitting on the floor in Selah’s bedroom while Selah was making faces at herself in the mirror and laughing. With anticipation building to the point where it was almost overwhelming, I asked Dr. Johnstone point-blank what she thought Selah’s issues were. I was ready to know. I wanted to know. She looked at me with this sympathetic face and said she did not like to share results without first consolidating the data to be certain. I told her to just tell me, I needed to know. What was it, please? I remember the exact words as she formed each one. Time stood still, and everything suddenly became chillingly clear, yet surreal. I felt as if I had been struck head-on by an 18-wheeler going at top speed.

“Selah has autism.”

Sharing Our News

Shortly after Selah’s disastrous (or so it was to us) third birthday party, we decided to share the news with our extended family, friends, and the Deaf community. If there was one thing we knew, it was that we had to open up to the people around us, even though our immediate gut instinct was to do just the opposite in order to protect Selah and give her privacy. However, we are a part of the deaf world, and since the fabric of our community is so tightly interwoven, keeping Selah’s diagnosis to ourselves would be impossible. We accepted that right away. We needed to be completely open and honest, mainly so that Selah could lead as normal a life as possible, and because we wanted to help the people in her life understand her. We needed to remove the stigma surrounding autism; we wanted Selah to have a secure place in our world where she would be accepted, loved, and supported unconditionally.

Each time we broke the news to people about Selah’s autism, we felt as if our wounds had been ripped open again, over and over—especially as we dealt with the various reactions and the questions. But slowly it began to get easier—until at some point, it actually felt cleansing to talk about it. The more we opened up, the more we found that others were even more willing to embrace Selah and make every effort to reach out to her. That was truly heartwarming. The Bay Area deaf community’s response was so receptive and positive; we already knew how wonderful this community was, but to experience it so powerfully through our daughter simply confirmed how
fortunate we were to be part of it. As we learned, it would be an impossible feat to make this journey by ourselves—a close-knit community and a solid support system are key to providing a sound foundation for raising a child with autism.

No Time to Waste

Now we had to decide on the best plan of action for Selah. The team for her Individualized Education Program—Len and me, Selah’s teachers at CSD, the early childhood education principal at CSD, Dr. Johnstone, the assistant director of special education for our school district (Pleasanton Unified School District, PUSD), a program specialist, and an occupational therapist—met to discuss placement options. The team was in unanimous agreement that Selah was a deaf child, first and foremost, who had an autistic disorder. Selah had a deaf family and communicated in ASL, and for that reason she belonged in a signing environment where deaf culture, continued language growth opportunities, and social development among deaf peers would contribute to her total development.

We also knew that Selah needed additional services directed toward her autism, since early intervention was essential. Dr. Johnstone’s recommendation was that Selah receive 25 hours of applied behavior analysis (ABA) a week. There was, unfortunately, no ABA program specifically serving deaf children with autism in the area, so we were caught between a rock and a hard place. We also determined that Selah would receive occupational therapy for 25 minutes twice a week to address her sensory needs, as well as speech therapy once a week for 20 minutes.

We must have had angels looking out for us when we made our decision to live in Pleasanton—before we even found out about Selah’s autism—for it turned out that PUSD had a wonderful program for children with autism: LASS (Language and Social Skills). Employing the verbal behavior approach, a derivative of ABA, it is one of the better-known ways to teach language skills to children with autism. There must have also been a VIA (Very Important Angel) looking after us because Dr. Mark Sundberg, an autism expert and the coauthor of the ABLLS-R (Assessment of Basic Language and Learning Skills), a popular and effective tool for creating an individualized program for teaching language, worked for PUSD as a behaviorist. To top it off, Dr. Sundberg himself knew how to sign, which helped us feel more comfortable about the idea of placing Selah in his program, armed with the knowledge that he would be able to communicate directly with our daughter and monitor her programming.

So although we were filled with trepidation about placing Selah in the LASS program since she would be the only deaf child in the entire classroom, we also knew that she needed the “autism expertise,” additional support, intensive work, and structured environment that this program provides. We hesitantly agreed that Selah would attend the LASS program three days a week as long as PUSD provided an ASL-fluent aide or other support person to serve as the primary individual working with her under the supervision of Dr. Sundberg in addition to the classroom teacher.

PUSD also agreed that this support person would go to CSD with Selah on the two days of the week when she was part of the prekindergarten class there. We have since come to recognize that this support person’s role is absolutely critical. She functions as a bridge between both programs and is responsible for implementing the same standards and expectations so that there is as much consistency for Selah as possible as she alternates between her two schools throughout the week. The support person performs many roles, including encouraging Selah to stay focused on tasks at hand, since she has a tendency to get distracted and to resist work if it is challenging or insufficiently motivating. The support person also helps to facilitate the development of stronger social skills by modeling appropriate reciprocal conversation and encouraging appropriate play with peers. We truly do not know what we would do without this classroom support person. Without her, Selah would have been utterly deprived of the quality, equal education and services to which she is fully entitled.

What is good about this arrangement is that Selah is able to immerse herself in
a typical deaf classroom surrounded by ASL-fluent peers and teachers who provide her with the total communication, language access, and socialization she needs in order to thrive. She also is able to take advantage of the additional services and support provided by the LASS program under PUSD—an excellent team of experts and professionals in the field of autism. On the flip side, Len and I still struggle with the fact that there is no program in our area that specifically serves deaf children with autism because Selah does have her share of challenges at either placement. There are specific language, communication, processing, and socialization needs that would be more adeptly addressed for deaf children on the autism spectrum if such a program existed. We constantly have to be Selah’s strongest advocates; we often find ourselves in the position where we have to stand up and speak out for her best interests, no matter how difficult or uncomfortable it is.

How Far We’ve Come...and How Far We Have to Go

Selah has grown a great deal since her diagnosis. She is now 5 years old and continues to improve slowly but surely in every aspect of her life. Of course she has her ups and downs, but don’t we all? She has a large vocabulary base and is working on forming simple sentences (noun and verb pairings); answering basic, specific questions and making independent requests; and developing writing skills.

Selah has a knack for acquiring new information and applying it later, and she’s extremely observant of her surroundings and the activity around her. She is also more assertively trying to engage and socialize with her peers, and her eye contact has improved to the point where she can sit and attend (with reinforcement) for as long as 20 minutes at a time. She continues to have a passion for cars or anything with wheels but seems to have outgrown her fascination with pushing her dolly stroller around.

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Two years have passed since Selah’s diagnosis rocked our lives and thrust us into a completely new world that we never knew existed. My husband and I are amazed at how far we have come since then, and how much we have grown individually, as a couple, and as a family. We are the same, yet we are very different. Selah’s autism has redefined many things for us. We know that a long, difficult, and often bumpy road with many detours, obstacles, and potholes lies before us. Yet we are as prepared as we can ever be to walk that road, armed with what has carried us thus far: our unwavering love for our daughter and our faith that everything works out as it is meant to.

Yes, Selah has autism, but we have learned that autism does not have her and it does not define her. Autism is not who she is, nor does it make up her entire personality. Selah is like a complex mosaic, composed of many distinctive pieces, each making up varying aspects of her, so intricately interconnected that one has to look closely to fully appreciate all that she has to offer. She is our daughter: our beautiful, shining, loving, independent, headstrong, and unique Selah, and that is forever who she will be.

Food for Thought

Throughout our journey as parents of a deaf child with autism, we have come across many startling truths. The saddest thing we have learned is that there is a dire lack, first and foremost, of research and information concerning deaf children on the autism spectrum. There is also a shocking lack of resources, services, training, and programs for these children and their families. The number of children with autism is skyrocketing in the United States: Recent statistics indicate that 1 out of 150 children, and 1 out of 94 boys, has autism (Centers for Disease Control and Prevention, 2007). There can be no doubt that there will be a parallel increase in the incidence of deaf children with this disorder.

If our teachers are going to be properly equipped to work with deaf children with autism, they will need more teacher training programs, special-topic seminars, and conferences specifically focused on this population. Early childhood education teachers must be provided with appropriate training in order to be able to identify the red flags and other warning signs of autism because early diagnosis and intervention is critical. Because teachers from primary school though the college level deserve to be armed with knowledge and appropriate training on how to work with deaf students with autism, the topic merits in-depth treatment in their graduate studies.

Because there are so many underlying or hidden issues associated with a deaf child’s development (for example, late exposure to language), those who are qualified to diagnose have to have better diagnostic tools and better training. Autism can be easily overlooked or misunderstood in very young deaf children—clinicians can mistake their lack of eye contact or language for other developmental delays.

The lack of resources does not end with educators and other professionals. Families of deaf children with autism often find themselves at a loss as to where to turn for resources and professional assistance, and where to find other families like themselves for mutual understanding and encouragement. It can get very lonely at times. For this reason, families and caregivers sorely need increased support.

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Brady and His Family Enjoy Smooth Sailing at First
I first held Brady on February 20, 2003. The first week was a bit rough—he had to be treated at the hospital for jaundice—but after that, it was smooth sailing. Brady was an easygoing baby, always happy and attentive. My husband and I did notice that he met physical milestones at least a few months behind his peers, though. For example, he sat up at 8 months, crawled at 10 months, and walked at 15 months. But our doctor assured us that this was fine because our son was still within the normal age range for achieving these milestones. (Readers can get more information on developmental milestones and developmental delays from First Signs, a nonprofit organization, at www.firstsigns.org.)

Brady had awesome eye contact, and he loved it when we read books aloud to him. By the time he was about 20 months old he could recite the alphabet; count to 20; label many items, including farm animals and body parts; and sign words such as movie, sit, and finish.

Inattentiveness and Language Loss Signal That Something May Not Be Right
As Brady approached the age of 2, we noticed that he hadn’t started making two-word combinations, and that it was increasingly difficult to get his attention. We thought he might have a hearing loss, since it runs in both of our families. Even though he’d had a hearing screening at birth, we took him for more hearing tests, three in 6 months, which prompted the audiologist to tell me, “You have to accept that Brady is hearing!” Actually, I wasn’t worried about him being hearing at all, but my mother’s intuition told me that something didn’t seem right. We struggled to understand what it was. Was Brady’s language being affected because we, his parents, were deaf? Was he getting insufficient exposure to an auditory environment?

We didn’t dwell on these questions for long, however, because Brady gradually started to lose language. He wasn’t labeling as much as before. We also noticed that we had to put a lot of effort into getting eye contact from him. He started walking back and forth by the TV, repeatedly taking one or two steps forward and then one or two steps backward, sometimes while clapping his hands. He declined to a point where we knew we needed to get help.

We sought evaluations, but the people we spoke to didn’t seem to understand what was happening either. A psychologist told us, “Brady does not have autism because he interacts with people well.”
On top of all of this, I was due any day with my second child.

**Growth in Autism Awareness Outstrips Medical System’s Coping Ability**

Autism awareness is spreading like wildfire. Diagnoses have increased at an astounding rate. The statistic most often quoted is that 1 child in 150 has autism. By comparison, the rate for childhood leukemia is 1 in 25,000, childhood muscular dystrophy 1 in 20,000, and juvenile diabetes 1 in 500. Yet autism receives less than 5 percent of the research funding of many less prevalent childhood diseases (Talk About Curing Autism, 2008). As if the high rate of autism diagnoses were not worrisome enough, many doctors are not properly trained, or kept up to date, on how to detect autism at the earliest possible age. And in many cases, once parents learn that their child has autism, the medical system has little to offer beyond that diagnosis.

Even though there are many good books and websites that describe autism and how to detect it early, parents still face the tremendous challenge of obtaining early intervention and other forms of support. This is probably why celebrities such as actress Jenny McCarthy, whose son, Evan, has autism, have become outspoken advocates of better services.

There is no known cure for autism, but there are stories of children who have recovered through early intervention and biomedical approaches. There is no known cause, either, though the medical field claims that several factors, including genetics and environment, may be responsible. It is also a controversial question whether vaccines play a part in causing autism symptoms.

Brady received all the usual vaccinations until age 3, at which point we decided to stop. Our younger son did not receive any vaccinations after the age of 6 months.

**Brady Gets a Diagnosis**

Acting on a recommendation from an acquaintance, we contacted a state agency, the Interagency Council on Early Childhood Intervention, ECI. (We were living in Maryland at the time.) We learned that Brady was eligible for service because of his expressive language...
Dear Friends:

I am a deaf mother of a deaf son with autism. In the spring of 2006, I established the very first Autreat for Deaf and Hearing families with deaf or hearing autistic children along with my co-chairperson, Stefanie Ellis-Gonzales, a fellow deaf mother of a deaf child with autism. This groundbreaking retreat was held at Camp Lakodia in South Dakota on April 7–9, 2006.

The autreat was such a tremendous success that it was truly a rewarding experience for all. A total of 22 parents, 16 children, and 8 speakers were part of this first-ever event. Information, ideas, and encouragement were shared during those few days that could not have been possible elsewhere.

Plans for the Second Deaf Autreat in the spring of 2008 have been put on hold due to the tremendous demands put on the original committee that created the initial Deaf Autreat.

The response by attendees of the Deaf Autreat resulted in a demand for assistance and information to meet the needs of:

- Deaf autistic children of deaf parents
- Deaf autistic children of hearing parents
- Hearing autistic children of deaf parents

The Deaf Autreat Committee needs to restructure the original goals and priorities to meet the above needs mandated by the attendees of the first conference. The committee also is in the process of working with the American Society of Autism (ASA) to obtain collaborative support as groups with mutual interests. Therefore, the second Deaf Autreat conference plans will be announced at a later date.

The logo as seen above was designed by a deaf parent of a deaf autistic child who participated in the Autreat. The sign in this picture is the new official sign for autism. The hand that is going inside symbolizes the autistic person’s inclination to be engaged within the own self, and the cupped hand represents his world, or a protective layer, where the autistic person retreats. The sign also represents “inclusion and involvement” in which the autistic individual serves as a reminder of how vital it is to give and receive love and attention, which are essential to humanity.

For more information about Deaf Autreat, please feel to contact me at deafautism@hotmail.com

With warm regards,

Rosangela George
Deaf Autreat Chair

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Join a new study on Autism Spectrum Disorders and Deafness

Has your Deaf Child been diagnosed with Autism?

Videotapes of your child’s First and Second Birthday are being collected to investigate early signs of Autism in Deaf Children

You will receive a $25 Gift Certificate for participation and a copy of your child’s birthday on DVD

Parents please email Christen Szynanski@gallaudet.edu for more information

*All videotapes will be returned*

This project has been approved by the Gallaudet Institutional Review Board
between the ages of 24 and 30 months:

**Social Skills**
- fails to respond to his or her name (not all the time, but enough for us to notice)
- has poor eye contact (began after age 30 months)
- appears not to hear at times
- resists cuddling and holding
- appears unaware of others’ feelings
- seems to prefer playing alone—retreats into his or her “own world”

**Language**
- starts talking later than other children
- loses previously acquired ability to say words or sentences (began after age 24 months)
- does not make eye contact when making requests (not all the time, but enough for us to notice)
- speaks with an abnormal tone or rhythm—may use a singsong voice or robotic speech
- can’t start a conversation or keep one going
- may repeat words or phrases verbatim, but doesn’t understand how to use them

**Behavior**
- performs repetitive movements, such as rocking, spinning, or hand flapping (the routine of walking back and forth by the TV began at age 30 months)
- develops specific routines or rituals
- becomes disturbed at the slightest change in routines or rituals
- moves constantly
- may be fascinated by parts of an object, such as the spinning wheels of a toy car
- may be unusually sensitive to light, sound, and touch

The point I am trying to make here is that parents shouldn’t wait for more than one red flag or accept a doctor’s assurances. As soon as parents notice even one of the signs, they must push for evaluations and assistance. It can take a long time to obtain a diagnosis, but you want your child to get all the interventions as early as possible.

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**Some Battles Are Lost, But More Are Won: Insurance, Treatment, and the Right School Setting**

At first it was a constant battle with the insurance companies to get the services Brady needed. Our health insurer kicked us off our health plan as soon as it found out about Brady’s formal diagnosis of autism. Brady now has his own health insurance through the Texas Health Insurance Risk Pool, for which applicants are eligible if no other insurance plan will accept them. The annual cost of Brady’s therapy is now nearly $45,000, but it is not covered by the Risk Pool insurance. As The New York Times has reported, “Most insurance companies do not pay for therapy for developmental disorders like autism, though a few companies offer reimbursement as part of their health benefits” (Tarkan, 2002, para. 23).

We didn’t agree with the school district in Maryland about the setting where Brady would be placed when he turned 3. We felt strongly that he would benefit tremendously from a peer learning environment where there was a good mix of levels, but the district wanted to place him in a less heterogeneous setting. We were already burned out from fighting ECI and the health insurer, so we didn’t waste a lot of time before we started looking for another school district.

Within a few months we decided to move to Austin, Texas, where our son now attends a mainstream preschool program within the Eanes Independent School District. His class has a good mix of normally functioning children and children with special needs. At the same time we were looking for a new district, we were eyeing a private clinic that provided applied behavior analysis (ABA) therapy. Much research has been published on the success of ABA therapy with children with autism. In a 1999 report, the U.S. Surgeon General wrote, “Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior” (U.S. Department of Health and Human Services, 1999, p. 164). Several other therapeutic approaches have gotten favorable reports, such as relationship development intervention, play therapy, and sensory integrated therapy. Children with autism also benefit from speech and occupational therapy, which typically is offered through school.

However, attending school and receiving ABA therapy was not the only treatment we wanted to pursue for Brady. We wanted to try other approaches as well while our son was young. It was overwhelming to try to figure out which to try. That was half the battle; the other half was getting Brady to willingly participate in the treatment. We took him to a doctor associated with Defeat Autism Now!, a project of the Autism Research Institute that educates parents and medical professionals about biomedical approaches to treating autism. He had a battery of blood tests done. The one thing I remember this doctor saying to us was, “Do you know who will be Brady’s best teacher?” We answered, “Us, his parents,” and he said “no,” and pointed to Brady’s youngest brother, who was 8 months old at the time. And he was right.

**With Clinic and School Settings in Place, Things Start Going Brady’s Way**

After living in Austin for five months, Brady finally started attending the private clinic 10 hours a week. He’d been on a waiting list since we’d moved. Perhaps it could have been worse. As The
to public eyes; for instance, he'll be able
public, we can never predict how Brady
him the first time. When we go out in
when Brady doesn't do what is asked of
Brady to participate and is very patient
years old, is his best teacher. He prompts
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please' to [a classmate]. Very sweet
arm or leg & he was saying 'more tickles
to chose if he wanted to be tickled on his
art center & she was tickling us with it.
[a classmate] discovered feathers in the

New York Times has reported
“Even parents who decide
to pay for treatment have
trouble finding private
specialists. Autism schools
and private behavioral
therapists typically have
waiting lists of more than a
year” (Tarkan, 2002, para.
26).

Brady currently attends his
mainstream preschool program in the
Eanes Independent School District 28
hours a week while continuing to go to
the private clinic 10 hours a week. He
keeps making progress. Two weeks after
he started school, his teacher wrote, "The
past few days he has gotten really sad and
even cried during [a particular] song. I
pulled him to the back of the circle today
when the song started and he walked
around the circle and then got right in
the middle and clapped his hands and
smiled the whole time. He dropped to
the floor and then got back up every
time the song called for it. Very
appropriate and engaged! We heard lots
of language today too!"

In May 2007 Brady’s teacher wrote,
“He’s been saying, 'I want _____' with
less prompts and following the arrival
routine with less prompts. He’s doing
better with 'look at me' but still needs to
work on it and also walk with me. His
correct production of words is difficult
for him, but he tries.”

This is from December 2007: “Today
[a classmate] discovered feathers in the
art center & she was tickling us with it.
Brady loved it! We were able to get him
to chose if he wanted to be tickled on his
arm or leg & he was saying 'more tickles
please' to [a classmate]. Very sweet
interaction!”

But as the doctor had predicted,
Brady’s younger brother, who is now 2
years old, is his best teacher. He prompts
Brady to participate and is very patient
when Brady doesn’t do what is asked of
him the first time. When we go out in
public, we can never predict how Brady
will behave. Some days he’ll seem normal
to public eyes; for instance, he’ll be able
to sit with us. Other days he’ll try to run
all over the place. Brady exhibits interest
in a variety of things, though he also
shows interest in specific things and has
his favorite items. Overall, he has shown
a good ability to rotate interest. He loves
the computer and is capable of
navigating through programs
independently. He also loves being
outside—running or being on the swing.
When he is home, he frequently engages
in self-stimulating behavior, or
stimming—which continues to consist of
walking back and forth by the TV. His
therapist has said that most families see
that because the child is releasing stress
from “behaving as the society expects”
during the day. This is what makes it
difficult for us to get Brady involved in
family activities at home. His expressive
language is still limited to asking for
what he needs. He is still not able to
initiate conversation or talk about his
day at school.

We Learn We’re Not Alone: Building Community With
Other Families Like Ours
As time passed, I talked more with the
doctor and read more, and the
information I’d been hearing finally
began to make sense to me. The Internet
was still our family’s main source of
information about resources and services
for children with autism. But as
informative as the Internet was, we
craved to learn more about how other
families, especially deaf families, were
doing with their autistic child. We
desired opportunities to meet with other
families to learn about what they did or
tried or heard about from others. But it
was a challenge to communicate face to
face with hearing parents. For the most
part, we did so by e-mail and video
relay.

In the last couple of years we
have begun to participate in Deaf
Autism, a web-based community
for families with members who are
defa or hard of hearing that have a
child with autism (see
http://www.deafautism.com). We and
the other parents involved with
Deaf Autism are working together to
meet a common challenge: incorporating
ASL into all aspects of our children’s
learning environments to help them
become fluent in both ASL and English.
These parents are a crucial support group
for our family.

We were thrilled when the first
Auatreat was held in 2006. Auatreat is a
retreat for families with deaf or hard of
hearing children with autism that is led
by Rosangela George in association with
Deaf Autism. Unfortunately, I was
unable to go, but parents who did attend
spoke highly of the face-to-face
opportunity to learn from and interact
with other families in our native
language and to share common
experiences within our culture. (For more
information on Auatreat, see
http://www.deafautism.com/auatreat.html.)
Like all families with an autistic child,
we hope we are on the right path to our
child’s recovery and that we will be able
to provide him access to every possible
opportunity for growth.

References
Latest autism statistics. Retrieved from
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therapy is called effective, but rare. The
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—Students from the South Hills High School Deaf and Hard of Hearing Program

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—Teacher Lia Vannerson from South Hills High School

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Children are much more likely to be diagnosed with autism than they were 15 or 20 years ago. One possible reason, researchers speculate, is increased diagnostic precision—a widening of the autistic spectrum disorder continuum to include mildly affected children who otherwise may have gone undiagnosed and unsupported, and whose behavioral patterns may have just been viewed as "odd" or unusual (Prior, 2003; Shattuck, 2006). Others attribute the increase to environmental factors such as exposure to chemicals, infections, and dietary changes (Byrd et al., 2002; Newschaffer, Falb, & Gurney, 2005).

As understanding grows regarding the varieties of autism and autistic spectrum manifestations, so too does the assessment field—which includes psychologists, speech-language pathologists, and other health and education professionals who in many cases have expertise in deafness. The result is more children who are identified as both deaf and autistic (Yeargin-Allsop et al., 2003).

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As understanding grows regarding the varieties of autism and autistic spectrum manifestations, so too does the assessment field—which includes psychologists, speech-language pathologists, and other health and education professionals who in many cases have expertise in deafness. The result is more children who are identified as both deaf and autistic (Yeargin-Allsop et al., 2003).

It's hard even to estimate the number of deaf and hard of hearing children and youth with autistic spectrum disorder, but the proportion is thought to be much higher than in the hearing population. What's more, this greater prevalence of autism in deaf children is consistent with a higher proportion of disabling conditions among the general deaf population. Estimates of the proportion of deaf children with disabilities fall between 15 and 50 percent (Davis, Fortnum, & Bamford, 1998; Holden-Pitt & Diaz, 1998, Karchmer, 1985; Mitchell, 2004). As high as it is, some researchers...
consider this range an underestimate.

Historically, special education professionals have disagreed over designation of the primary disability of children who are both deaf and autistic. For coding and educational placement purposes, is the child deaf (primary disability coding) with autism (secondary disability coding), or is the child autistic (primary disability coding) with hearing loss/deafness (secondary disability coding)?

In recent years, the deaf child with autism most often has been regarded as a deaf special needs student. Such a designation means that the primary visuospatial communication needs of the deaf autistic child—needs that are also so important for many nonautistic deaf children—can be met by using sign language as the primary communication mode. It also means that the deaf autistic child can be supported by experts with training or experience in working with deaf children with behavioral, intellectual, and related developmental issues (including autism).

The view that a deaf child with autism is just that—a deaf child first (because of the critical importance of communication) and an autistic child second—is the more prevalent today, especially in larger educational programs. But this was not always the case. In the past, placement decisions often were determined in the opposite way: Many deaf children with
autism or other developmental disabilities were placed in programs primarily for autistic or developmentally disabled children. They were educated with peers who had normal hearing ability, and only intermittent attention was given to the deaf child's hearing loss and visuospatial orientation, communication, and language input needs, or to subsequent issues related to modality and language assessment (Pollack, 1997).

**Getting Appropriate Educational Placements and Support Services: It’s a Battle**

Within the school system, parents are often the primary advocates for their deaf child with autism. They can spend years pursuing a proper diagnosis once they realize that their child is not keeping up developmentally with his or her “deaf-only” peers (deaf peers without developmental disabilities). This is often a time of great disappointment and confusion for families in this situation (Wright, 2006). The parents may have already accepted that their child is deaf and concluded that being deaf is another form of normal development. They may have begun to communicate effectively with their deaf child. They may have concluded that this child who is deaf has a limitless future and will have a complete level of personal independence once he or she reaches adulthood, just as hearing children do. Then, as other deaf children in the class continue to grow and develop, regulate their behavior, increase their interpersonal interactions, and advance in cognitive, linguistic, and academic skills, their deaf child starts to appear more and more different. Finally, there comes a time when the school and the parents both come to understand that the child is not only a deaf child who requires the expertise of teachers and specialists for deaf children, but also a child who is deaf and autistic.

Parents often struggle to find the right educational placement for their deaf child with autism so that the child’s communication needs are satisfied even as emphasis is placed on his or her behavioral, affective, linguistic, and learning needs. There is often a battle within the school district, especially when there are not enough deaf children with developmental disabilities to make a full class. The school may want to move the child from a deaf education learning environment to a placement with experts in autism and behavior management and teachers who may have...
little, if any, sign language skill. Parents often resist sending their child out of a deaf-friendly learning environment, and for good reason. They want their deaf child with autism placed in a rich linguistic environment that includes sign language. They want an educational environment that will make the most of the child’s learning potential and that uses a communication approach that not only enhances communication but also improves behavior, social skills, and self-regulation.

When a special needs class for deaf children is available, it still may take a few years before everyone understands the child’s individual needs and becomes comfortable with appropriate ways to meet those needs. After this transition time, the child, parents, teachers, school, and program administrators most often settle into a mutually satisfying program of coordinated efforts to attain the best possible outcomes for the deaf autistic child.

However, sometime around the beginning of high school, parents once again must face the task of locating and securing services for their deaf child with autism. Are transition programs and vocational training programs appropriate, or should the child stay in academic classes all day until graduation? Should the child graduate at age 18 and then transition to a special work or vocational training environment, or should education continue to age 21? Should parents enroll their child in a developmental program at a community college, if that option is available, or should work-related training now become the focus? A team of professionals, often called the transition team, can answer these questions in light of the student’s strengths, weaknesses, and long-term needs assessment. However, parents may or may not agree, and this can be another difficult time as they fight for transition services they feel are essential to their child’s success in life.

When graduation day arrives, any time between the ages of 18 and 21, families often encounter yet another challenge: locating appropriate postsecondary programs, vocational training, career coaching, and residential placement options for their deaf child (now a young adult) with autism.

**Postsecondary Options for Deaf Youth With Autism**

Often, each postsecondary possibility is eliminated for most deaf children with autism because of cognitive or linguistic delays, disorders sufficient to interfere with normal patterns of learning and academic achievement, and impairments in psychosocial and behavioral functioning. Parents once again start to feel pressured and isolated as they try to set up meaningful programs for the young adult who is deaf and autistic.

Often, particularly in less populated areas, parents once again face the dilemma of choosing from programs that are inadequate to meet the
Putting Together or Choosing a Postsecondary Program for Your Deaf Adult Child with Autism?

Here are some guidelines.

- **Get an early start.** The process may take longer than you think. Begin searching for programs for deaf adults with autism and other developmental disabilities while your child is in junior high or the first years of high school.

- **There’s lots of information out there—take advantage of it.** County, state, and federal offices can supply information about postsecondary vocational and residential programs for deaf individuals with autism. Among others, these offices can refer you to state vocational rehabilitation agencies and group home programs. Other useful sources of guidance include local, state, and national chapters of groups such as the National Association of the Deaf and state associations of the deaf. The Gallaudet University Regional Centers maintain up-to-date listings of program options in local areas.

- **Get organized.** Make copies of all pertinent records so that you can provide them to the professionals at the agencies and programs you contact. These records include transition plans, psychological assessments, medical records, and selected behavioral intervention plans and progress reports. Be sure that these records include information on “best practices”: techniques and approaches that have been most effective with your son or daughter.

- **Deal your son or daughter into the process.** To the extent that your child’s intellectual and communicative capabilities permit, include him or her in discussions and planning. Your child’s preferences for work and living arrangements need to be a large part of the decision-making process if you want it to succeed.

- **Get out and look around.** Visit vocational training programs and ask for a few trial days when you can observe your adult child. Or, see if you can arrange for your adult child to stay in the program for a few days without you being present in order to see if the program feels like a good fit.

- **Ask—otherwise, you’ll never know.** Explore all work settings that strike you as appropriate for your deaf child with autism. Find out if employers have a history of accepting workers with disabilities, whether in supported work situations (with job coaches, for example) or nonsupported situations.

- **Help your child get mobile.** Find opportunities for your son or daughter to become a proficient user of public transportation. Greater mobility means greater independence.

- **Set your standards.** Evaluate each program on the basis of:
  - Ease of communication for the deaf person with autism.
  - Frequency of signed communication and competence of sign language users in work or training environments.
  - Compatibility between behavioral, social, linguistic, and intellectual needs and the environment.
  - Availability of, or at least a willingness to include, professionals with expertise in working with individuals who are deaf and autistic so that plans, intervention programs, and assessments can be incorporated into the long-term planning for the young adult.
  - Certifications granted to the program or facility and any registered violations that remain uncorrected at program entry and throughout the period of involvement with a program or agency.
  - Turnover rate of clients and personnel. Residential training programs, and sometimes vocational training programs as well, tend to have high turnover rates. If that is the case for a program you’re considering, find out why. If clients or staff leave to advance to better situations, that’s not a problem. If they leave because of poor or inadequate programming, that should give you pause.

- **Compatibility matters.** It’s preferable, of course, that your son or daughter’s preferred communication mode be usable in the programs you’re considering. But don’t rule out programs in your area just because they may not include professionals who sign. For instance, if you want your adult child to be able to remain near the family even though no signing professionals are available in your area, see if it’s possible to incorporate sign language interpreters into a local program. Your child may not be used to using sign language interpreters because there was no need for them at school. But interpreters can play a critical role in programs where no signers are present by helping your son or daughter ward off the behavioral or social difficulties that can result from communicative isolation.

- **It’s OK to ask how it’s going.** Once your child is in a program, request assessments at regular intervals so that you can monitor his or her progress.

- **At all levels, connect.** Cultivate a network of parents in your locality and state, and connect with national organizations as well. Start new family programs in your area and work with the local Deaf community to provide special programs, activities, and projects for meeting the needs of the deaf adult with autism and other pervasive developmental disabilities.

- **It’s good to get out and play.** To enhance socialization, consider involvement in the Special Olympics if your son or daughter has an interest in competitive sports.

- **Inclusion starts with the family.** Even though your deaf child with autism is now an adult, it’s important to keep him or her involved in holiday gatherings, vacations, and other family activities. To make these occasions as meaningful as possible, keep working on your sign language and behavior intervention skills.
communication needs of their young adult deaf child.

We’ve compiled some guidelines to help make parents in this position feel not quite so pressured, not quite so isolated (see accompanying box on page 36). These guidelines emphasize being both practical and ambitious, and, above all, stress that the young deaf person with autism is a participant in the process.

Advocacy: A Continuing Role

Parents with deaf children who are also autistic have a history of fighting for services in the schools and demanding that professionals accept sign language as a prerequisite to all other programming choices. Parents must continue to be advocates for these adult children. The good news is that they can draw upon diverse resources such as other parents, professional organizations, Gallaudet University, and local, state, and federal government agencies. Together, young deaf adults with autism, their parents, and professionals who work with people who are deaf and autistic can meet the challenge of ensuring a successful transition to a satisfying work and social life beyond high school.

References


Like most teachers of deaf students, I begin preparing to teach my students a story by asking myself questions:

- How familiar are my students with the concepts and vocabulary in the story?
- How will I include all the new vocabulary words in the day’s learning to give students the repetition they need?
- What additional worksheets and materials should I make?
- What teaching method would work best with this story and this class?
- How can I make the learning experience challenging and fun?
- How much time will I need to plan the lesson and create materials in order to teach the story next week?

For many of us, the answer to this last question—How much time?—often dictates what finally happens in the classroom. Every day, we face the time-consuming task of adapting materials from curricula that don’t meet our students’ needs or match their learning styles.

**At Last, Ready-Made Literacy Units**

Recently, I completed two years of field-testing of literacy units specifically designed for teachers of deaf and hard of hearing students. The units were part of the Cornerstones Project, an activity of the WGBH National Center for Accessible Media. (The units were

*Photos courtesy of NCAM/Cornerstones*
developed with funding from Steppingstones of Technology Innovation for Students With Disabilities, a program of the U.S. Department of Education.)

The Cornerstones Project built the literacy units around three animated stories—*The Fox and the Crow; Click, Clack, Moo;* and *Joseph Had a Little Overcoat*—originally featured on “Between the Lions”, a long-running children’s TV program co-produced by Boston PBS affiliate WGBH, Sirius Thinking, Ltd., and Mississippi Public Broadcasting. Each unit is two weeks long, and immerses students in the language and ideas of one story. Students can download on-line video clips of each story (in Windows or Mac) in whichever communication mode they prefer—ASL, Cued Speech, or Signing Exact English (SEE). Free downloads are available at the Cornerstones website, http://pbskids.org/lions/cornerstones.

Students can also download a hypertext version of each story. (The stories are also available in their original picture book format at local libraries and booksellers.) By clicking on the highlighted words, they can see additional meanings or uses of the words, each with a matching a picture.

The three units also offer interactive games that reinforce target words and concepts in ways deaf and hard of hearing children will find meaningful.

**Effective Teaching Practices and Multiple Activities in Each Unit**

A downloadable Cornerstones lesson guide for each literacy unit includes a day-by-day sequence of learning objectives and lessons, with a wide range of classroom and seat work activities, all of which reinforce lessons within each story. Downloadable teaching and assessment strategies supplement the lesson guides. These printable resources include exercises, storybook templates, work sheets, writing prompts, flash cards, and lots of games—all designed specifically for children who are deaf or hard of hearing!

Generally, students who are deaf or hard of hearing have not been exposed to as many English words and concepts as hearing children have, and they often must learn many new words in order to be able to read even short selections. The ready-made Cornerstones materials offer a sustained, systematic approach to teaching vocabulary and strengthening students’ reading skills. This allowed me to devote more time to teaching, and I loved having so many choices. In the first unit I taught, I was so overwhelmed by all the materials that I ended up choosing familiar activities like concentration games and story-writing prompts. However, as I grew familiar with the materials, I began trying new approaches.

**Building Vocabulary a Chunk at a Time**

Cornerstones suggests that a class spend five or six days exploring each story, with one key difference: Instead of having students learn all of the targeted vocabulary before reading the story, Cornerstones recommends that teachers break the vocabulary into smaller chunks of new words to be learned each day. As the class progresses through the story, each Cornerstone lesson reviews previously learned vocabulary and teaches new words.

When I tried this strategy, I found that building new vocabulary over several days made it possible for students to learn more words, and was far less overwhelming for them. Thanks to the daily vocabulary review and the re-reading of story sections, students were retaining the meanings of words and using them in their writing. Subsequently, I have applied this technique to my regular reading units and have found my students becoming more successful at retaining and using vocabulary.

**Free to Be Creative**

As my students progressed in learning new vocabulary through chunking and reinforcing activities, they also engaged in complex discussions about character, motivation, and plot. The Cornerstones materials gave me the freedom to add new learning objectives and use creative teaching strategies.

For example, during one unit my students were learning how to use quotation marks around dialogue. I created a series of mini-lessons about English and ASL grammar using the Cornerstones “Character Match-Up” activity. First, the students matched the sentences to characters, as described in the teacher’s manual. Then I asked the students to sign the dialogue in ASL, and we discussed how ASL uses role shifting to indicate dialogue, just as written English uses quotation marks. Next, I asked the students to create their own short dialogues for the characters in ASL, then to translate the dialogues into written English using quotation marks. Next, I asked the students to create their own short dialogues for the
characters in ASL, and translated their dialogues into written English using quotation marks. The students loved reading and signing their dialogues to each other.

**Signed Versions of the Animated Stories**
At the start of each unit, the Cornerstones lesson guide previews the animated story in a video clip. Students select the communication mode—either ASL, Cued Speech, or SEE. With my own class, I chose to begin by using the picture book itself, which allowed me to observe and address how each student approached authentic print. Later in the lesson, I used the video clips to lead the students in a discussion about how and why the storyteller chose specific ASL signs—in the same way that hearing children might discuss a specific word choice in a written description. We also made a game of viewing a section of the video clip and then locating the matching passage in written English in the storybook.

**Word Games and Activities to Reinforce Learning**
My students particularly enjoyed the games in each Cornerstones literacy unit—“Lionel the Sentence Maker,” “Library Destination,” and others—and they loved exploring the interactive activities on the website. Having all of these activities available for a unit meant that I could count on students seeing and using the words they were learning without having to create the materials myself. Because there were so many choices, I could break the students into small groups to work on creative and reinforcing activities that matched their skill levels and individual learning styles. These activities gave me more time to observe and assess how each student used and understood the target vocabulary and concepts. I could then adjust my teaching accordingly.

**Building a Bridge Between ASL and Written English**
While I can and will apply many of the Cornerstones teaching techniques to other stories, it’s hard to overstate the benefits of having ready access via the Cornerstones website to such visually engaging, fully featured materials. I would love to see additional units developed using the Cornerstones approach: building a bridge between ASL and written English by encouraging children to explore identification of words in print, word knowledge (including multiple meanings), and story comprehension. Especially if enough units were developed for a full year of teaching across grade levels, the impact on deaf students’ reading abilities and how these children are taught could be tremendous.

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One of the greatest challenges we face as teachers of deaf students is how to teach students to write effectively. We want them to plan, organize, and relay meaning in a coherent way, but we also expect them to develop a sense of control over English writing conventions and mechanics. It is probably no surprise that we are constantly looking for and testing the kinds of instruction that succeed in teaching these writing skills to students who are deaf or hard of hearing.

At Michigan State University, primarily through the work of Drs. Carol Sue Englert and Troy Mariage, we learned of an instructional approach the local schools are using with great success to apprentice students into independent and competent writers. Because of its balanced nature, we became interested in investigating its use in deaf education classrooms. The instructional approach, called “Morning Message” by the teachers who use it, is a guided interactive writing activity. Some of the underlying principles include:

- use of teacher modeling and think-alouds of writing strategies
- active student participation in co-constructing and monitoring text
- provision of organizational structures
- provision of scaffolds to support students in advance of independent performance
- rereading of the text for monitoring purposes
- transfer of control from teacher to students over time
- writing for authentic audiences

Since we learned about Morning Message, we have focused our efforts on adapting this activity to better accommodate the specific needs of students who are deaf or hard of hearing.

**Data Show that Morning Message Works with Deaf Students**

Morning Message was implemented in three deaf and hard of hearing classrooms in Michigan, at the elementary, higher elementary, and middle school levels. The teachers of these classes were seeking their master’s degrees in deaf education at Michigan State University. As part of a course in writing instruction, teachers received training in the
key principles of Morning Message, how it is implemented in the classroom, and the adaptations that may be necessary when conducting the activity with deaf and hard of hearing children. Once they had implemented Morning Message in these classrooms, the teachers collected data to note any improvements in students’ writing and reading achievement. Each teacher used the Morning Message writing activity on 21 different occasions.

From pretests to posttests, all students showed gains (Wolbers, 2007). There were significant improvements in both higher-level writing skills (e.g., ability to organize information in a coherent manner, incorporation of appropriate text-structure elements) and lower-level writing skills (e.g., correct use of prepositions, fewer run-on sentences or sentence fragments). In addition, the students made significant gains in reading achievement and improvements in editing and revising skills. These findings indicate that Morning Message is a very promising practice in apprenticing deaf children to write effectively and independently.

**What Morning Message Looks Like in Practice**

Morning Message typically happens daily during a 15- to 30-minute period. One student serves as the day’s author, but all students are involved as legitimate participants. To begin the activity, the author suggests a topic for the day from his or her own experience (e.g., a fishing trip with dad). This is formulated into a topic sentence that is written on a displayed writing surface such as an easel. Subsequently, text is co-constructed and revised with the help of the author’s peers and the teacher.

To gather more information for the text, students can ask the author questions (i.e., who, what, where, why, how) about his or her experience. These question words are often placed on a visual scaffold to help prompt students in a manner that will generate supporting details. It should be noted that we are describing the use of one text structure—telling and describing a personal experience. However, Morning Message does allow for the teaching and learning of various genre types, such as exposition. For other genres and text structures, there are more appropriate scaffolds that can be used to support the writing and organizing of ideas.

The students cooperatively build and revise the text by making suggestions and then reaching a consensus. When new sentences or phrases are offered by students to be added to the text, the teacher writes them word for word (including grammar and meaning errors as they are communicated) on the easel. After writing, the teacher opens the floor for further generation of ideas, or allows discussion of a revising or editing component. Writing is taught as a recursive process, with students fluidly moving back and forth among text generation, revising, and editing. The text is reread often throughout the activity by the teacher or in unison with the students to prompt awareness of any part that does not “sound right.” Students discuss potential composing, organizing, or revising approaches through the use of varied communicative tactics such as suggesting, explaining, defending, questioning, or providing a rationale for opposition.

When introducing Morning Message, the teacher may devote more time to direct instruction, prompting, scaffolding, modeling of language and thinking, or guided questions. As students are apprenticed in (1) ways of acting, (2) ways of talking, (3) ways of thinking, and (4) ways of doing writing, they begin to internalize the strategies used by others who are more expert. The teacher facilitates this through a series of “step back” and “step in” moves: stepping back to position the students as the expert decision makers and evaluators of the quality of the text, and stepping in, when necessary, to provide support or instructional guidance (Englert & Dunsmore, 2002). The transfer of control of the writing
process leads students to greater self-regulation, higher confidence, and more independence with writing.

The final written product is published for an authentic audience. This may be a newsletter that is sent home and shared with parents or a school bulletin that is distributed to peers and staff.

Adaptations Make Morning Message More User-Friendly for Deaf and Hard of Hearing Students

Although Morning Message has proven to be an effective instructional practice with hearing children (Englert & Dunsmore, 2002; Mariage, 2001), we foresaw specific challenges in using the writing activity with deaf and hard of hearing children. After pinpointing areas of potential difficulty, we brainstormed alternative practices that teachers could adopt. The deaf education teachers in the study all implemented adapted versions of Morning Message. These versions adhered to the key instructional principles but were more accessible and responsive to deaf and hard of hearing students.

The first challenge we noted was the writing of the message itself. Typically, the teacher writes a student’s expression when it is offered. Many deaf students, however, communicate using ASL, which has no formal written form. It is because of this difficulty that we proposed the use of a “two easel” approach. When students offer an idea in ASL, an additional step becomes necessary. First, students collaboratively discuss whether an offered expression is ASL or English-based sign (i.e., capable of being written). If the expression is ASL, the teacher notes the concepts on the “ASL easel.” This is merely a holding place for the idea so that it is not forgotten. The teacher may capture the idea the best he or she can using gloss words, symbols, pictures, or any other mechanism, making sure to note movements, use of space, and expressions in addition to sign vocabulary. The class then discusses ways to translate the ASL concept into a written form. If necessary, the teacher may need to model or think aloud the principles of each language and possible translation techniques until students begin to internalize the approaches. The translated idea is then recorded word for word on the “English” easel.

Morning Message translation could be considered a challenge and a benefit at the same time. Although the process undoubtedly lengthens Morning Message, it does help to build necessary metalinguistic awareness of both ASL and English.

The second challenge was the rereading of the message. Typically, the teacher rereads the text while pointing word by word as he or she speaks. To do this while signing is difficult, to say the least. However, it is critical that the text be repeated again and again to instill a rhythm and a pattern in the written language. Just as hearing students read along with their teacher, deaf children should also be signing (or fingerspelling when there is difficulty matching sign to the English constructions). This is a vital step in teaching students to reread and monitor their texts. Students start noting patterns and are able to recognize “what looks right” in written text, much as hearing children develop a sense of “what sounds right.” Therefore, we proposed that teachers point with one hand and sign with the other when rereading the text.

Third, when working with young deaf children it can be difficult to elicit experiences through language. Students with language delays may encounter difficulties when taking on the role of the author and expressing their experiences. One suggested adaptation to counter this problem is to establish a common ground where the students and teacher can hold a discussion. It may be that the teacher has to create an authentic event (e.g., a visit to the grocery store) involving all the students in the classroom and then encourage the students to use that event as the topic for their Morning Message. Again, this would ensure that all the children had background knowledge of the topic and had been exposed to some of the vocabulary.

If, however, a student is given the opportunity to contribute his or her individual experience, it may be appropriate for the teacher, in conjunction with parents, to devise a
planning tool by which Morning Message topics can be better understood and communicated. This may take the form of a journal or semantic map that is sent home to parents to guide a brief description of an event the student recently experienced. Parents record ideas in the journal or on the map in collaboration with their child, perhaps even reviewing vocabulary that will aid the student’s expression of the message in class.

**How Morning Message Benefits Deaf Students**

With Morning Message, students are apprenticed in ways that promote the appropriation of higher-level and lower-level writing strategies. When teachers model or use think-alouds, ways of thinking about writing are extended into a shared space that is accessible to all participants. For example, after repeated exposure to the thoughts of others concerning the handling of grammatical errors, students will increasingly develop an ability to self-monitor for the same errors.

A second benefit of Morning Message is that it offers a framework to help deaf and hard of hearing children make the necessary connections between their growing linguistic competency in ASL and the written English print that is part of the world around them. Much like the widely used Language Experience Approach (Schirmer, 1994), it allows students to offer their own personal experiences in sign language and see how they are then expressed in English.

Finally, teachers using Morning Message bridge students’ background knowledge and experiences with the expected content knowledge of the grade and subject area. By being cognizant of the writing curriculum and objectives, teachers can use Morning Message as a way to integrate necessary subject-matter instruction into an authentic writing activity.

**References**


Five years ago, one of the authors of this article was the head of the deaf department in a large urban high school. Parent/family workshops consistently revealed parents’ concern for the safety of their teenaged children when they were away from home unsupervised. Because of the difficulties in communicating at a distance at that time, the children couldn’t call for help, access emergency services, or even report a change in plans. Parents’ reluctance to let their deaf teens go out unaccompanied resulted in the children’s social isolation. This, in turn, left the teens with restricted opportunities for independent problem solving and socialization. What’s more, the children’s need for privacy often could not be met because of these safety concerns.

The students at this urban high school were concerned about developing their own independence. Most of them had limited literacy skills, and many were unable to communicate effectively through print. Because they often were accompanied and directly supervised by their parents at later ages than is typical in our society, the students voiced dissatisfaction with their opportunities to make decisions for themselves, be responsible for their actions, and have some freedom.

Photography by John Consoli
THE PILOT PROJECT

The Rotary Club of Toronto Eglinton had a history of working with one of the deaf and hard of hearing programs of the Toronto District School Board (TDSB) by providing technological devices such as vibrating alarm clocks and wristwatches, portable TTYs, and flashing-light alarms and "doorbells." The Rotary Club also provided initial funding for translation of letters to parents who did not have English as a first language, as well as contacts with Motorola, CI Investments, General Electric, and Bell Canada.

Motorola initially approved a donation of 250 two-way PageWriter 2000X Motorola text messengers, and Bell Canada donated five years of monthly services and maintenance and repairs. Three years into the project Motorola discontinued its product line, so a switch
was made to Blackberry devices, which were donated by CI Investments and General Electric. Including not only the three school sites in the TDSB but also York University in Toronto, which provided research time and expertise, this represents the largest educational partnership in the district.

The study took place at two large inner-city public high schools and in grade 8 of their feeder school. The vast majority of the students in the study had severe to profound congenital hearing loss and were being educated in congregated settings by teachers who were specially trained to teach this population. At each school, there is a deaf education department staffed by teachers of the deaf, interpreters, and educational assistants. On average in any given year, there are 30 to 40 students in each high school’s deaf department, and five or six deaf or hard of hearing students in grade 8 of the feeder school. Students have the opportunity to take courses both within the deaf department (in small classes with the teacher of the deaf and hard of hearing) or in the mainstream with support services. The students represent multiple cultures, and many come from homes where English is not spoken, or not spoken much. Some of the students communicate orally, and others through sign (or some combination of speech and sign); many of the parents of these students do not know enough sign language to communicate easily with their child. Moreover, the target student is typically the only deaf or hard of hearing person in his or her family. As is the case with many deaf and hard of hearing students, the literacy levels of the students in our study were not commensurate with those of their hearing age-peers.

Participants in the study included:

1. All students in the deaf and hard of hearing programs at the two high schools and grade 8 of the feeder school (n = 90).
2. The staff of the deaf departments at the two high schools (n = 17). The staff at both schools included both deaf or hard of hearing and normally hearing individuals.
3. The parents or guardians of the students (n = 95). All of the students’ parents were hearing.

Before using the equipment, each participant took part in a pre-use survey designed to elicit thoughts on how the participants thought the two-way text messengers might be used prior to actually having any experience with them. After four months of two-way text messaging use, the participants were invited to a feedback meeting to report on how they used their text messengers and to see if there were any changes in either their concerns or their expectations, based on experience with the equipment. A second feedback meeting was conducted five months later.

The overwhelming majority of the students expressed satisfaction with access to the technology: Only 4 out of 90 expressed dissatisfaction.

What We Learned
Not surprisingly, prior to using the two-way text messengers, both the students and their parents expressed concerns about personal safety. They needed to know that they would be able to contact each other in case of emergency. The parents wanted to be able to know where their child was, whom their child was with, and how to guide the child to safety if he or she got lost. With the text messaging system in place, the students believed that they would be able to go out at night without their parents and to manage in case they got lost. The parents and staff reported that they were able to have direct communication with the students and with those among the parents and staff who were deaf or hard of hearing. This eliminated some safety concerns about fire alarms and emergency procedures and contributed to the ease of coordination of everyone’s activities.

While the parents naturally needed to know if their child’s plans changed, they also were concerned that they be able to contact their child if their own plans changed. They wanted to know if their child was going to be late coming home or whether he or she needed a ride. They were also concerned with their child’s insistence on privacy when they were effectively out of contact with him or her.

The overwhelming majority of the students expressed satisfaction with access to the technology: Only 4 out of 90 expressed dissatisfaction. However, this dissatisfaction was not with the technology but with the increased levels of independence these students wished they had. They said they would prefer to have “much more freedom,” and they wished they could go out more often. In these cases, the students were not accruing the anticipated benefits of the technology.

Students mentioned that they used their two-way text messengers not only to communicate with their parents, school staff, and each other, but for other things as well. Following are two typical comments taken verbatim from the students’ written survey responses:

- “The pagers helped me to send my dad and my dad is less worry. After school I allowed to play basketball, hall hockey with friends.”
- “The pagers help me that alarm helps me to homework, meet friend, and birthday. Help me to remains medican, I feel good to help me the alarm. I feel more satisfied that I have often go out somewhere.”

Many students reported that two-way text messaging was their main link to their friends. A few became experts at text messaging and helped to run workshops for both students and parents. One also became the troubleshooter for broken equipment and was able to identify problems and correct them so that malfunctioning devices did not need to be sent back to the manufacturer for repair.

The parents were uniformly satisfied and were gratified that
the two-way text messengers had been introduced into the deaf and hard of hearing program. They indicated that they were less worried about their children. Other benefits the parents reported were being in contact with their child more often, being more aware of their child’s movements, and keeping connected to other people through e-mail.

The staff, particularly those who were deaf or hard of hearing, also expressed empirical satisfaction, stating that they were now able to coordinate schedules more easily and to contact each other. One staff member, who was in charge of cooperative education placements off campus, wrote, “My Co-op students have many questions and concerns regarding their work placements. In addition to discussing issues in class, they contact me via … telephone and TTY, … e-mail, … [and] pager system.” (Among the school staff, the two-way text messaging system was often referred to as the “pager system.”)

It was easier to communicate with the students and to make them responsible for their whereabouts. For example, if a student were absent, an interpreter might not be needed for a particular class and would therefore be free to work with another student or in the office. This information could be communicated easily via the pager.

**The Policy Implications of Our Research**

In a climate in which the rights of people with disabilities have become central to public discourse, there is a place to think about the ways in which two-way text messengers and other such technologies provide access and remove barriers for deaf and hard of hearing individuals. One of the central features of the Individualized Education Programs of the vast majority of deaf and hard of hearing students is the requirement to make note of the accommodations that must be provided for any particular student in order for that student to have access to the program and to be successful. Particularly for students who have minimal English skills, curriculum could be developed that focused on the functional literacy that two-way text messengers allow. Equipment accommodations can include “any type of item of equipment or any electronic product or system, whether commercially produced, adapted, or custom-made,” that the student needs (Ontario Ministry of Education, 2006), and should include technologies like sound field systems, TTYs, and signaling devices. If it can be shown that text messengers afford students access in the way that other technologies have done, then it would be reasonable to suggest that two-way text messengers be added to the list of recommended accommodations. An additional aspect of adding two-way text messengers to this list would be an expectation that they would be made available and funded by the government or school system. Beyond accommodations for students, an argument could also be made, at least in the United States, for the funding of two-way text messengers for deaf and hard of hearing staff in the schools through Section 504 of the Rehabilitation Act of 1973.

Text messaging naturally works best among people who have at least a minimal level of English literacy skills. We do not know what that minimum is. Low English literacy levels among many of the families may have influenced frequency of use within the family. The students did express a wish for other languages (i.e., orthographic systems such as Cyrillic, Chinese, or Tamil) to be available on the two-way text messengers. Even so, low English literacy levels did not stop parents from communicating as best they could in English. For example, one parent reported that “it changed us better to have pager like to contact my son from pager. It did help us pagers and it helped us to know where my son is.”

The TDSB has purchased two-way text messaging devices for all staff working with students who are deaf or hard of hearing throughout the school board as a result of seeing the safety benefits to the student participants in our study. It would appear that this technology has much to offer deaf and hard of hearing students and is making an impact beyond what it was originally designed to address, either by the manufacturers or by this study.

**Notes**

We are grateful for the support of the Rotary Club of Toronto Eglinton, the Toronto Council of Rotary Clubs, Bell Canada, Motorola, Inc., Research in Motion, CI Investments, and GE Commercial Finance. Any errors of fact or interpretation are the authors’ alone and do not represent the policies of any of the sponsors. Further information on this project can be found at http://www.rotary7070.org/eglinton/projects/projects_tods.html.

**References**


By Susan Flanigan

A collaborative workshop and field trip of students and teachers of SOAR-High and geologists at the University of Massachusetts, Amherst researching Fault System Evolution, May 4-10, 2008

This year the Faults in the Field expedition members will travel to southern California May 4-10, where 16 students from seven schools for the deaf and their teachers will explore faults. They will visit sites along the San Andreas Fault and other fault systems in the area between Long Beach and Palm Springs. This is the third and final expedition to be led by Dr. Michele Cooke, a deaf geologist from the University of Massachusetts, Amherst as part of her National Science Foundation grant.

Students have been conducting collaborative research on fault systems using a sandbox model developed by Cooke. As with previous trips, the expedition to California will provide the students and teachers with an opportunity to apply what they have observed in the classroom experiments to actual fault sites in the landscape.

Joining this year’s expedition is an MSSD alum, Marie D’Angelo, who went on both of the previous trips. D’Angelo, who now volunteers as an EMT in her home state, will provide information on local community earthquake disaster plans to the members of the expedition. On the final day, the students will work in teams with geologists to develop a presentation about what they learned and present their findings at University High School in Irvine.

While in California, team members will send out a student blog from on site as they have on previous trips so that students can share daily news and discoveries with their fellow students back at their home schools and with their families and friends.

THE SCHOOLS PARTICIPATING IN THE CALIFORNIA EXPEDITION ARE:

- Model Secondary School for the Deaf
- North Carolina School for the Deaf
- Iowa School for the Deaf
- Indiana School for the Deaf
- University High School
- Kansas School for the Deaf
- California School of the Deaf-Riverside

You can read more about the five-day expedition, including the schedule, here:

The judges of this year’s Gallaudet National Essay, Art, and ASL Contest faced a bumper crop of entries from students expressing their vision of the theme, “Yes, I Can!” All told, there were 623 submissions from elementary and high school students across the country—double the number from last year. Students competed for scholarship awards and cash prizes and will have their work published in Celebrate!, a magazine published by the Clerc Center.

“This has been a real “can do” year for the contest. The students have definitely shown how they apply the “Yes, I Can!” theme in their everyday lives,” said Timothy Worthylake, contest coordinator for the Clerc Center. “We are especially pleased to see the number of ASL [American Sign Language] submissions increase. We started the ASL entry category last year and received 30 entries. This year there were 126. The judges will have a difficult time deciding on winners as there are so many top quality entries in all three categories of the contest this year!”

The judges for this year’s contest bring a high level of expertise from their own professional and personal experience to their evaluation of the student submissions. This year’s judges for the essay entries are: Dr. Cathryn Carroll, adjunct English professor for Montgomery College; Aaron Fudenske, program analyst for the U.S. Department of Transportation; and Dr. Jane Norman, professor of Communications at Gallaudet University. For the art entries, the judges are: Fred Beam, artist/actor with Invisible Hands, Inc.; Scott Carollo, associate professor in the Art Department at Gallaudet; and Shawn Richardson, production assistant at the National Historical Trust. For the ASL entries, the judges are: Leticia Arellano, assessor/evaluator in the Assessment and Evaluation unit at Gallaudet; Becky Church, Southeast Regional Admissions Counselor for the Admissions Office at Gallaudet; and Larry Gray, instructor in ASL and Deaf Studies at Gallaudet.

The contest results will be announced in April 2008.

Mr./Miss Deaf Teen America Pageant: Inspiring Teens for a Decade

On March 8, 2008, the Mr./Miss Deaf Teen America (DTA) Pageant celebrated its tenth anniversary. The theme for this year’s pageant, hosted by the Model Secondary School for the Deaf (MSSD), was “The Celestial Decade.” This popular event drew teens from all across the country who came to show off their talents, test their leadership skills, and make new friends.

THIS YEAR’S WINNERS WERE:
Mr./Miss DTA 2008—Colin Analco and Jenna Misko-Smith, from the Indiana School for the Deaf
1st runners up—Juan Munoz and Amanda Weiser, from the Texas School for the Deaf
2nd runners up—Sean Berdy and Montana Murphy, from the California School for the Deaf-Riverside
3rd runners up—Ray McCall and Karlee Gruetzner, from the Michigan School for the Deaf

“To be eligible for the contest, students must be from a mainstreamed program or school for the deaf, and must be deaf or hard of hearing. The contestants represent their school as good role models,” said Roberta Gage, the DTA coordinator for MSSD.

Deaf teenagers, ages 13 to 19, from schools and programs for deaf students across the United States can participate in this special event. The participating schools for this year were: California School for the Deaf-Riverside, Illinois School for the Deaf, Indiana School for the Deaf, Maryland School for the Deaf, Miss/Mr. Deaf Michigan Pageant Association, Western Pennsylvania School for the Deaf, South Carolina School for the Deaf, Texas School for the Deaf, and the Model Secondary School for the Deaf. For more information about the DTA Pageant, visit http://clerccenter.gallaudet.edu/DeafTeenAmerica.
Students to Present Collaborative Research at GLOBE Learning Expedition in South Africa

Students from the Indiana School for the Deaf (ISD) and the Model Secondary School for the Deaf (MSSD) are following in the footsteps of Nobel Prize-winner and former U.S. vice president Al Gore by helping bring about recognition of global climate change.

The theme for 2008 is “GLOBE Research for Sustainable Communities.” GLOBE students will present their research on topics such as environmental impacts on the quality of life and regional impacts of climate change at the GLE in Cape Town, South Africa, from June 22-27. Introduced in April 1994 by Gore, GLOBE is a worldwide network of K-12 students working under the guidance of teachers trained to conduct hands-on study and research of the Earth’s environment.

ISD’s Joshua Self and Tyler Crace and MSSD’s Lateefah Patterson and Kelsey Wessman will present their winning entry, “A Comparison of Green Up in Two Locations at Similar Latitudes: Indiana and Washington, D.C.” The students undertook a collaborative research project to see if there is a time difference in springtime budding of trees at the students’ two locations. They also investigated whether environmental factors are controlling the timing of the budding (called budburst).

NASA’s GLOBE selected the ISD/MSSD students as one of five winning U.S. teams to present their research at the South Africa expedition. They will be accompanied by ISD science teacher Teresa Huckleberry and MSSD science teacher Mary Ellsworth.

During their stay in Cape Town, the teams will have the opportunity to mingle and share information with more than 300 GLOBE students and 200 GLOBE scientists and educators from GLOBE’s 109 partner countries. Along with student presentations and discussions, students will have an opportunity to work side by side with international scientists conducting field studies, see a selection of student art displays, and attend a variety of cultural events.

To view the students’ full research report, visit: http://csc.gallaudet.edu/soarhigh/GreenUp/greencover.html.

“Good Morning America” Showcases KDES and MSSD Dancers to National Audience

The ABC television show “Good Morning America” featured Kendall Demonstration Elementary School (KDES) and Model Secondary School for the Deaf (MSSD) student dancers in a broadcast shown on March 24. The show featured the students in a segment about deaf Oscar-winning actor and Gallaudet University trustee Marlee Matlin’s participation on ABC’s “Dancing with the Stars.” ABC sent a camera crew and reporter to KDES and MSSD to interview students and film them dancing. They came to find out if Marlee Matlin was an inspiration to the students and to ask how deaf dancers learn their performance routines.

For the dancing segments, the ABC crew filmed KDES students rehearsing a hip hop dance under the direction of Tara Downing, a family educator and dance teacher at KDES, and they filmed MSSD dancers performing “Classroom Antics,” a selection from their recent winter dance concert. The crew was impressed with how the students use eye contact, counting, and teamwork to develop their dance skills.

To view the film segment and read the article on ABC news, visit: http://abcnews.go.com/Video/playerIndex?id=4511890. A captioned version of the ABC film clip is available at: http://billcreswell.wordpress.com/2008/03/26/marlee-matlin-on-gma-3-24-captioned/.

CLERC CENTER SUMMER INSTITUTE TO OFFER INTEGRATED GLOBAL SCIENCE TRAINING FOR TEACHERS

July 14-18, 2008  Washington, D.C.

This year’s training covers two rich topic areas, GLOBE Seasons and Biomes Project and Faults in the Earth System. The GLOBE Seasons and Biomes Project is an inquiry-based project supporting student investigation into seasons and changes in climate. It connects students, teachers, and local communities with educators and scientists. The Faults in the Earth System training will introduce teachers to the research sandbox for modeling the growth of geologic fault systems and the formation of mountains. The training provides middle to high school teachers and participating students opportunities to be involved with research, scientists, and data to enrich students’ science experience.

For more information on the Summer Institute, visit: http://clerccenter.gallaudet.edu/TPD/summerinstitute.asp.
Alumni of the Model Secondary School for the Deaf (MSSD) Performing Arts Program are earning great accolades as they move into professional roles in theater, movies, and television.

**AARON KUBEY ’94—New Executive Director of National Theatre for the Deaf**

MSSD reveals another star in its alumni crown with the appointment of Aaron Kubey, Class of 1994, as the new executive director/president of the National Theatre of the Deaf (NTD).

Prior to his appointment at NTD, Kubey was the artistic director of the New York Deaf Theatre in New York City. He recently produced and directed the show *Beyond Therapy*, which received a great review by *The New York Times*. Throughout his career, he has worked on numerous television, film, and theatrical productions. Following his graduation from MSSD, he earned his BFA in theatre studies at DePaul University in Chicago, where he was the first deaf student to be admitted to and to graduate from the University. In succeeding years, he worked with the NTD’s Los Angeles Little Theatre of the Deaf, Deaf West in Los Angeles, and the Centerlight Theatre in Chicago before joining the New York Deaf Theatre.

While at MSSD, Kubey performed in the Road Show under the direction of the former artistic director, Timothy McCarty. As part of the Road Show, he traveled to more than 15 states, the Netherlands, and Puerto Rico. Kubey gives much of the credit to his years at MSSD for starting off his theatrical career on a strong footing.

**MICHELLE BANKS ’86—Returns to MSSD as Guest Director of Sondheim Play**

This fall Michelle Banks, renowned stage and TV actress, producer, and director, returned to MSSD to direct students in a performance of Stephen Sondheim’s *A Funny Thing Happened on the Way to the Forum*. When MSSD applied for permission to produce the show, it caught the attention of *The Sondheim Review*, a national theatre magazine devoted to productions of Sondheim’s works. The magazine tracks theatre companies who are interpreting Sondheim’s works in new and usual ways. When the *Review* saw from the rental listings that the MSSD was planning a production, they contacted theater critic Brad Hathaway to write an article about how students who were deaf would produce the musical. Hathaway came to interview Michelle Banks, attended one of the performances of the show, and wrote an article about how Banks and the students converted the written script and songs to a visual performance through the use of American Sign Language. The article currently appears in the spring edition of the *Review*.

**ALUMS PERFORM IN THREE QUESTFEST PRODUCTIONS**

This January, local area theater critics have praised the productions of Questfest, a two-week extravaganza of visual theatre coordinated by Tim McCarty, former director of MSSD’s Performing Arts Program for more than 21 years and founder of Quest: arts are for everyone. McCarty has been instrumental in encouraging the careers of a number of MSSD graduates, including alumni in three of this year’s Questfest shows:

**Alice**, an interpretive work of *Alice in Wonderland* by McCarty, starred Bellamie Bachleda (’01) as Alice. Alumni Anthony Jones (’88) and Greg Anderson (’96) also were in the cast.

**The Snow Queen**, based upon the children’s story of the same name, featured Monique Holt (’85).

**Mosaic**, Quest’s Wings Company’s internationally acclaimed pieces, focusing on individual identity, included alumnus Marc Bowman ’85 in the cast.

*Washington Post* writer Michael O’Sullivan wrote of Questfest, “Bringing together troupes from around the world, the festival offers a lineup of stories told through mime, dance, sign language, puppetry, animation, and the circus arts—‘Anything,’” in the words of founder and director Tim McCarty, “based on a ‘series of images coming at you’ rather than line of spoken dialogue.”

For information about current theater and dance productions at MSSD, visit: http://clerccenter.gallaudet.edu/mssd/performing-arts/spring-play.html.
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or phone: (202) 651-5340 (V/TTY).
Upcoming Conferences 2008

**June 12-15**
Hearing Loss Association of America Convention 2008, Reno, NV. To be held at the Grand Sierra and Casino. [www.shhh.org](http://www.shhh.org)

**June 13-25**
Deafness Research Foundation 50th Anniversary International Conference, Bethesda, MD. To be held at the Hyatt Regency. [www.drf.org](http://www.drf.org)

**June 18-21**

**June 23-July 17**
2008 Rehabilitation Counseling with Deaf and Hard of Hearing Adults, Monmouth, OR. To be held at the Western Oregon University. [www.wou.edu/education/sped/rrcd.php](http://www.wou.edu/education/sped/rrcd.php)

**June 27-30**
AG Bell Convention: Somethin’ BIG is Brewing in Milwaukee, Milwaukee, WI. To be held at the Midwest Airlines Center. [www.agbell.org](http://www.agbell.org)

**July 7-11**
49th Biennial National Association of the Deaf Conference, New Orleans, LA. To be held at the New Orleans Marriott Hotel. [www.nad.org/NADconference](http://www.nad.org/NADconference)

**July 21-24**
Texas Statewide Conference on Education of the Deaf and Hard of Hearing, Galveston, TX. To be held at the Moody Gardens Hotel, Spa & Convention Center. [www.swced.org](http://www.swced.org)

**August 11-13**

**October 5-8**
2008 Deaf and Hard of Hearing Adolescents Conference, Clayton, MO. To be held at the Crowne Plaza St. Louis Hotel. [grcdirect@aol.com](mailto:grcdirect@aol.com)

**October 23**
National Institute on Deafness and Other Communication Disorders Research Symposium, Bethesda, MD. To be held at the National Institutes of Health. [www.nidcd.nih.gov](http://www.nidcd.nih.gov)

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Start a Shared Reading Project... We’ll Show You How!

**Keys to Success Training for Site Coordinators**
March 16-20, 2009
Gallaudet University, Washington, D.C.

The Shared Reading Project is the Clerc Center’s nationally acclaimed home tutoring program. The five-day training program shows participants how to set up the Shared Reading Project at their own school or program.

For more information, contact: training.clerccenter@gallaudet.edu

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“Few children learn to love books by themselves. Someone has to lure them into the wonderful world of the written word; someone has to show them the way.” —Orville Prescott, *A Father Reads to His Children*
Upcoming Clerc Center Workshops and Trainings

2008

June 7
Sexuality Education: An Emotionally Intelligent Way of Teaching Human Sexuality to Deaf and Hard of Hearing Students
Workshop offered June 7 during Family Weekend (below)
June 6-8 Deaf Family Learning Weekend
Great Falls, MT.
To be held at the Montana School for the Deaf.
Note: Open to families in Montana

June 6-8
Deaf Family Learning Weekend
Great Falls, MT.
To be held at the Montana School for the Deaf.
Note: Open to families in Montana

June 9-12
American Sign Language, English, Math...How Does It All Jive?
Workshop offered June 10-11 at the Intermountain Special Studies Institute
Pocatello, ID.
To be held at Idaho State University.
www.isu.edu/issi

June 29 to July 4 (one week)
July 6 to July 11 (one week)
EQ Training for Families
Brooklyn, MI.
To be held at Holley Family Village.

June 23 - July 18
(13 different trainings offered)
Clerc Center Summer Institute
Washington, DC.
To be held at Gallaudet University.

July 20
Spoken Language and Sign: Optimizing Learning for Children with Cochlear Implants.
Sioux Falls, SD.
Pre-conference to be held during the Midwest Conference on Deaf Education (July 20-22).
To be held at Augustana College.

July 22
Beyond the Birds and Bees: Sexuality Education for Deaf and Hard of Hearing Students,
Galveston, TX.
To be held during the Texas Statewide Conference on the Education of the Deaf and Hard of Hearing Students at Moody Gardens Convention Center and Hotel.

July 22
Family Portfolios: Looking at Today and Preparing for Tomorrow,
Galveston, TX.
To be held during the Texas Statewide Conference on the Education of the Deaf and Hard of Hearing Students at Moody Gardens Convention Center and Hotel.

August 4-5
Portfolios for Student Growth: Collect, Reflect, Decide, Achieve,
Bettendorf, IA.
To be held at Mississippi Bend Area Education Association School District.

October 8
1) Adolescent Sexuality Education
2) Suicide among Deaf/Hard of Hearing Adolescents
EQ workshops at Conference 2008 Weaving Common Threads and Diversity among Deaf and Hard of Hearing Teens, St. Louis, MO.
http://www.flagler.edu/page1.asp?id=2560

October 10-11
1) Adolescent Sexuality Education
2) Power Struggles with Teens
3) Suicide among Deaf/Hard of Hearing Adolescents
EQ Take-Out Series Regional Training, Clarkston, GA.
To be held at the Atlanta School for the Deaf.

2009

March 16-20
Shared Reading Project: Keys to Success,
Training for Site Coordinators.
Washington, DC.
To be offered at Gallaudet University.

FOR MORE INFORMATION ON CLERC CENTER TRAININGS, VISIT:
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Social and Emotional Development

- Sandtray Play Therapy Techniques
- Play Therapy Techniques
- Sexuality Education: An Emotionally Intelligent Way of Teaching Human Sexuality

Literacy

- Literacy It All Connects
- Sharing Books Using ASL and Deaf Cultural Literacy Practices: Preschool-Grade 8
- Reading to Deaf Children
- Read It Again and Again

Transition

- Portfolios for Student Growth: Linking Academics and Self Awareness for Life-Long Learning

Visual Phonics and Cochlear Implants

- See the Sound: Visual Phonics
- Spoken Language and Sign: Optimizing Learning for Children with Cochlear Implants

Science and Technology

- Integrated Global Sciences: GLOBE Seasons and Biomes Project and Faults in the Earth System
- TecEds Digital Storytelling
- Lego Robotics Teacher Training

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