reSources

This article is the second installment in a series of articles about nurturing social skills and facilitating friendships. Part 3 will appear in the next issue of reSources.

Part 2: Developing and Maintaining Community Connections and Friendships
By Maurice Belote, CDBS Project Coordinator

"A good life is a human life. A human life is a social life. The essence of human nature is to be in the company of others—companionship, fellowship, and connection to others are essential to our well being."

–Al Etmanski
Author of *The Good Book*

Friendships are critical to a person's happiness. Families tell us that a primary goal for their sons and daughters is that they will have friends. Students tell us that spending time with friends is one of the main reasons—if not the most important reason—that they look forward to going to school everyday. Even as adults, current research tells us that we are more likely to be effective employees in the work place if we have a good friend at our place of employment.

The role of social connections changes over time, just as a child's perspective of school life is likely to change over time. When children are young, their identity is established by factors mostly outside of their control (e.g., who their parents are, what neighborhood they live in, what school they attend, who their teacher is, what their brothers and sisters do, etc.). In a sense, individual identity at this age is assigned by adults. As students age, individual identity is connected less to those external factors and is more closely linked to the idea of groups: who the student knows, friends of those people's friends, and what activities they are good at and enjoy. Many high school students tell us that afterschool activities are more highly motivating than the classes they take. They tell us that they endure the coursework and strive for good grades so that they have the freedom to participate in activities like athletics, drama, marching band, tech clubs, student government, 4H, or any of the other countless activities that students enjoy. During the teen years, these extracurricular activities seem to provide the setting for most enduring friendships.

The following are some general points to consider when thinking about an individual's friends and social connections. It is a complex topic and it would be difficult to include strategies that would address all situations for all children and youth with deaf-blindness. My goal is to use this article as a starting point for a discussion on the topic. I encourage readers to use the "comment" feature on the CDBS website to add to this discussion.

Overlapping academic years. Many students with deaf-blindness continue their education for up to four years after their peers without disabilities graduate from high school. As a result, friends who graduate at age 18 scatter to higher education, jobs, and new relationships. It is one of the good arguments for placing transition programs for 18-22 year olds on community college campuses, so that individuals with disabilities move at the same time into college settings with many of their friends and acquaintances from high school.

Neighborhood schools. In terms of building and maintaining community connections, there are significant advantages to considering enrollment in a neighborhood school (i.e., the school the child would attend if he or she weren't deaf-blind). Community connections are still possible for students who travel out of their neighborhood for school, but there will be challenges that need to be addressed in order to support the child with deaf-blindness. Here is one of my favorite quotes on this topic. It is from the January/February 2004 issue of *TASH Connections* and the writer is Pat Amos, a parent and advocate:

> "Just being there—showing up regularly—is vitally important in building the basis for friendships. People who come and go have great difficulty in being seen as real members of a classroom or community. They are perceived differently and, although there may be no harmful intent, group members often interpret a fluctuating presence as a message that this person belongs elsewhere and does not require their personal investment…Presence is a powerful statement of belonging…"

Complex communication modes. Individuals with deaf-blindness may have receptive and expressive communication systems that include multiple modes (e.g., signs, speech, photos, line drawings, objects, natural gestures, iPads and other electronic devices, etc.). There may be training required for peers so that they feel comfortable using some of these communication strategies. Whenever I see peers who are hesitant to interact with an individual who is deaf-blind, I always assume this hesitancy is simply based on lack of knowledge and experience with the communication system, and not unwillingness on the part of the peers to make a social connection with the student.

Idiosyncratic behaviors. Knowledge is power. I have always believed that there is tremendous power in explaining to peers why a student with deaf-blindness might engage in certain behaviors that to others may seem peculiar. If peers understand that certain behaviors have important functions for the student (e.g., providing information about where the student's body is in space, calming the student when the environment gets to be too stimulating, helping the student know who is nearby, etc.), then the behavior seems much less strange because peers will understand its function. This is where ability awareness training for classmates will be beneficial. Ability awareness activities provide opportunities for children to experience highly structured activities through simulation of hearing and vision loss. I have seen good ability awareness activities change the attitudes and behaviors in children as young as preschool. (CDBS staff can provide information on ability awareness activities suitable for specific grade levels from pre-school to high school.)

Perceptions of disability. I have had the privilege of serving students with deaf-blindness for many years, and I frequently have to remind myself that some people may have had limited or no experiences interacting with individuals with sensory differences. Their anxiety and lack of comfort with interacting with a child or youth who is deaf-blind is simply a result of lack of exposure and experience. This is changing slowly, as more children benefit from having children with disabilities fully integrated to general education programs. Yet I often hear parents say that they had never before interacted with a person with a disability until their son or daughter was born.

Geographic isolation. The power and potential of online networks has changed the way many of us think about geographic distance, and while networks can facilitate and support specific activities, they have not proven to be a substitute for getting to know people on a more personal level. And it is important to remember that it is possible to feel alone, regardless of whether you live in a rural setting with wide spaces between neighbors or live in a high-rise apartment building in the middle of Los Angeles. Issues of transportation will always be key to overcoming some issues of isolation. I have seen examples of high school clubs taking on the responsibility of making sure a student with deaf-blindness has a safe ride to and from an extracurricular school event like a football game or a dance, and someone to hang out with while at the event.

Frequent class/school moves. Children with disabilities may move schools and/or classrooms more frequently than those in the general education population. There are many reasons cited as the need for these moves (e.g., more appropriate educational settings, presence of language models or peers, etc.), and these are important. Our challenge, however, is to ensure that any discussion about a school or classroom move also considers the impact the move will have on the student's social connections. Some social connections with other children take a long time to develop, and social skills in one setting may not generalize easily to other settings. Transitions from program to program are inevitable, but we need to remember the friends the child is leaving behind and the need to develop new friendships.

Development of friendships may require some level of facilitation. For many children and youth with deaf-blindness, social connections may not develop naturally but instead must be carefully facilitated by peers, family members and teachers. This is normal, it is okay, it isn't a sign of weakness, and it's not bad. It is a myth that physical presence by itself will result in individuals with deaf-blindness having friends. There are school clubs whose primary purpose is service to others. I have experienced examples of service club members making a yearlong commitment to ensuring that a classmate with deaf-blindness will have opportunities to participate in extra-curricular activities at a school. I have seen examples of high school students starting clubs for the sole purpose of supporting classmates with sensory and other disabilities. Here is another quote I like from Pat Amos:

> "People often respond with greater confidence and comfort when they are asked to include someone in a specific, mutually enjoyed activity than when faced with a more nebulous request to befriend that person. Since friendship doesn't appear or grow in a vacuum, it is difficult to contemplate in the abstract. When people

are supported to pursue a common interest directly, friendships may develop tangentially out of that interest."

Remember that friendships are more likely to occur when children and youth who are deaf-blind are doing the same activities as others, at the same time, at the same place, with the same materials, and with the same consequences—good or bad—for their actions.

Why can it be so hard to ask for help? From the time I was a young child, my parents instilled in me—for better or worse—a very strong sense of self-sufficiency. To ask for help was a sign of weakness. There was an expectation that you should be able to handle whatever comes your way, and to take care of it quietly and without a fuss. It's no surprise, then, that many people have a hard time asking for help. But because friendships between children and youth with deaf-blindness and others rarely occur naturally without some level of facilitation, it will probably be necessary to turn for help from others to get these relationships started. And that leads to the next bullet…

People want to help! Yes, it is true. People enjoy helping others, and many seek out opportunities to help. Clearly there is a benefit to the person being helped, but the helper also experiences significant benefits. Helping others improves our mood, increases motivation, and has a positive effect on our general outlook that can last long after the experience has passed. It is important to remember this when asking for help—that you are not burdening someone with your request but rather setting up a situation that will have a long-lasting, positive impact on the helper.

Community connections. When it comes to community connections, it really is about who you know. For most people, community connections play a huge role in opportunities for work, relationships, living situations, and recreational activities. Consider the following statements—they are not in any way extraordinary, and each illustrates the power of connections:

> "I have a good friend who manages an apartment building. I'll ask if she has any vacancies."
> "My cousin is in town for a couple of weeks. Maybe you could ask her out this weekend?"
> "I noticed my corner market has a "DELIVERY PERSON WANTED" sign in the window. I know you're looking for some work. Do you want me to put in a good word for you?"
> "Our community softball team really needs an equipment manager. I know you don't like to play but would you be interested in joining the team as a manager? It's a great group of people and a fun way to spend a couple of evenings each week."

Don't ever underestimate the people you know and their ability to help make things happen.

Quantity vs. quality. This is the Facebook era, and never before has it been so easy to amass "friends" and then publicly announce—to the exact number—how many friends a person has.

When it comes to individuals with disabilities, however, it is probably more important to nurture and maintain friendships than to spend time adding people to an individual's to a person's circle of friends. A strategy called activity-based relationships plays an important role in nurturing existing friendships. In activity-based relationships, specific activities are identified for the individual with deaf-blindness and a friend to engage in together. This gives the two people a common set of experiences to share, communicate about, remember, and build on to generate new activities.

Bibliography

Alsop, L. (Ed.) (2002). *Understanding Deafblindness: Issues, perspectives, and strategies.* Logan, UT: SKI-HI Institute.

Amado, A. (2004). Lessons learned about promoting friendship. *TASH Connections, 30,* 8-12.

Amos. P. (2004). Supporting friendships: One parent's reflections. *TASH Connections, 30,* 8-12.

Carter, E.W., Swedeen, B., & Kurkowski, C. (2008). Friendship matters: Fostering social relationships in secondary schools. *TASH Connections, 34*, 9-12.

Downing, J.E. (2008). *Including Students with Severe and Multiple Disabilities in Typical Classrooms: Practical Strategies for Teachers.* Baltimore: Paul H. Brookes Publishing Co.

Downing, J.E. (2005). *Teaching communication skills to students with severe disabilities.* Baltimore: Paul H. Brookes Publishing Co.

Etmanski, A. (2000). *A Good Life.* Burnaby, British Columbia: Planned Lifetime Advocacy Network.

Hunt, P., Doering, K., & Maier, J. (2011). Three building blocks for designing and implementing social supports for students who use AAC. *TASH Connections, 37,* 16-21.

Schleien, S., Green, F., & Stone, C. (2002). Making friends within inclusive community recreation programs. *TASH Connections, 28,* 16-23.

Miles, B. & Riggio, M. (Eds.) (1999). *Remarkable conversations: A guide to developing meaningful communication with children and young adults who are deafblind.* Watertown, MA: Perkins School for the Blind.

Petroff, J.G. (2001). *National transition follow-up study of youth identified as deafblind: Parent perspectives.* Monmouth, OR: National Technical Assistance Consortium.

Sacks, S.Z. & Wolffe, K.E. (Eds.) (2006). *Teaching social skills to students with visual impairments.* New York: American Foundation for the Blind Press.