

Working Together for Angelica

Betty Collins, SD Teacher
Kings River College

My experience with Deaf-Blind individuals has been as an Adult Transition teacher for the Fresno County Office of Education. I am assigned to the class for students with severe disabilities at Kings River Community College. My students range in age from 18 to 22 years. The program is designed to provide continued instruction in the Individualized Education Program areas such as academics, socialization, self-help skills, psycho-motor, health, speech-language and others. It also emphasizes vocational and employment skill development and adjustment.

During my twenty-three years of teaching I have had only one student, Angelica, who is deaf-blind. I would be the first to admit that I was totally unprepared for a deaf-blind student. However, with the help of the speech therapist, the hearing specialist, the vision specialist and my wonderful staff at Kings River Community College, we have and are continuing to develop a more extensive program for Angelica.

When Angelica entered my program in August 1995 I initially concerned myself about work sites from which Angelica could benefit and I decided that the college cafeteria had the most possibilities. Angelica initially learned "to know her work area." She learned to rinse and rack dishes and trays, to put them through the commercial dishwasher and to sort the silverware into appropriate bins. We are also working on sorting and collating activities.

One of the major concerns in developing a vocational program for Angelica has been safety. We have a number of work sites that we use with students to develop work skills, but they were not appropriate for Angelica.

During the past year Joan Van Deelen (Speech Therapist), Helen Porter (Itinerant Vision Specialist) and I have worked on a program for Angelica. This has been a difficult and rewarding experience. It has taken us a great deal of time to coordinate our activities and to develop a focused program. There are no organized or structured programs developed for deaf-blind students being served by the Fresno County Office of Education. Vocational training for these individuals is one where you create a program as you go. I feel that with all of us working together with Angelica we will be able to develop a program from which other students will benefit in the future. One of my concerns has been what will be available for Angelica when she leaves my program. I spoke with Debbie Rose of the Department of Rehabilitation. She said that they have counselors for the deaf and for the blind but not one specifically for deaf-blind. She

also said that deaf-blind is a very small population. They have a mobility specialist who will go into the home to assist the individual who is deaf-blind and their family. Becky Wade of the Vocational Advocacy Communication Center said they would love to provide services, but they have no funding and no training site. She asked me to call her if I found out anything beneficial.

I also contacted two adult service providers to ask what was available for post school individuals. Hart Bonsel of the Association for Retarded Citizens (in Reedley) said that they did not have any individuals who are deaf-blind at present but they would be happy to develop a program if they had a client that needed those services. Ann Marie of Employ America in Selma said if the need was there that they would develop activities for the individual. Both programs indicated that we could start this program development during the final year of schooling for an individual who is deaf-blind.

I feel very positive about the future. We will all continue to work together to develop a program for Angelica. I think that this will benefit all deaf-blind students in the future.

Roots and Wings

Bil Aulenbach, Father
Family Specialist, CDBS

I can still remember looking at our daughter 30 years ago as she lay on the floor, staring at the bright lights in the ceiling and making strange noises. I wondered: "What does the future hold for her?" She was almost two, did not walk and did not appear to have much going for her.

I would reflect on such questions as: "Would she be able to attend school? If so what kind? Would she be able to talk? How would we communicate with her? What would she do all day? Would she still be scooting on her back when she was 20 years old?" My wife and I did not have any answers but did have a basic philosophy which stated that we need to give all our children "roots and wings". By "roots" we mean those basics in life on which we build in order to do life reasonably well. "Roots" ought to be established by the time children are between 18 and 20. Then they need to start flapping their "wings" so they could move out and on.

This philosophy also included our daughter with dual sensory impairments, mild cerebral palsy and epilepsy. An extremely important "root" for our three daughters was a work ethic. This was not easy for someone like our daughter with special needs. But whatever her abilities were, we needed to start with the basics, such as:

Sharing Household Responsibilities

She had chores, very simple ones such as picking up toys, putting her dirty clothes in the laundry basket, taking her dishes from the table to the sink. (Yes, we lost a fair number of dishes.) As she became older the responsibilities and scope of work were increased. Carrying dishes to the sink translated into washing the dishes. (Yes, still more broken dishes.)

Meeting Time Lines

The tasks to which she was assigned had to be finished by a certain time. Did this cause problems? You bet! Sometimes I would think: “It would be a lot easier to do it myself!” But would our daughter learn anything by doing the task for her? Obviously not! But she did learn from suffering the consequences. (No TV that evening. Or, go to bed earlier. Or, no desert.)

Attitude

Most of the time our daughter did not really want to follow through with her responsibilities and would develop a negative attitude. Inevitably this would be counterproductive to her doing a good job. We tried to overcome this by suggesting that if we developed a negative attitude about all the things we do for her (meals, laundry, chauffeuring, on and on) it would not be a very pleasant home. Eventually she received the message that a lousy attitude would only be another handicap for her.

Do Your Best the First Time

This was probably one of the more difficult work ethics to instill. Her “best” did not always meet our standards of “best” and sometimes her vision prevented her from seeing details. When she was a teenager we assigned her a car to clean every Saturday. Because she knew that she was never going to drive a car she was not very interested in maintaining one and at first tried to do a minimal job. But she discovered that she had to do it over until she did it right. At first, we encountered a great deal of resistance but then she caught on: “Do it right the first time and then I’m finished.”

Work Equals Money and Money Means Power

Her two sisters learned this through baby-sitting but in Heidi’s early teenage years she was not baby-sitting material. However there were other jobs she could do for extra money and soon learned that doing jobs for money gave her spending power to buy some of the things she wanted.

Was it easy to teach her a work ethic? Not at all! She resisted much of the time. Other times she did such a lousy job that we wondered if it was worth it, but we knew that we had to give her the tools. Too many times we parents have a tendency to “baby” our children with special needs and allow them not to learn a work ethic.

My wife and I had many a “discussion” about this issue. She often felt I was too demanding and I would complain that she was too soft. Eventually we learned to compromise and both took more of a middle position. And eventually Heidi developed a work ethic which allowed her to enter the work-a-day-world and be successful.

“I Like Machines”

Deborah Roseborough
Parent & Family Specialist

As my son’s transition into the world of employment came near, I felt many different feelings. I felt frightened, curious, anxious and other feelings I can’t identify. All through our children’s lives we are preparing for the day they go out into the world. We teach our children to communicate, to be social, and to do skills that may be useful in the adult world. We transition through every level of school but the transition into the world of work is the most frightening thus far. However, with collaboration between the family and the agencies the vision can be exciting and fulfilling for all involved.

Danny is a 23 year old man with Congenital Rubella Syndrome. He has no vision and a profound bilateral sensorineural hearing loss. He uses three different means of communication: tactile signing, a communication board with voice output and communication cards with Braille labels (for Danny) and written labels and pictures (for co-workers). With recent technology, his hearing aids have provided enough amplification for awareness of his environment. He also has developed the ability to speak a 300 word vocabulary.

In the elementary school years, my son had opportunities to learn factory jobs such as counting parts and packaging them for a very small stipend. He learned that one receives money for working. He also had a chance to work on some machinery in class. This experience would become the key to his future. We discovered that Danny not only loved working with machinery but that he had a real knack for it. He was safe and meticulous as he worked.

In Danny’s vocational training in junior high and high school, he was given opportunities to work at off campus sites with machinery such as drill presses, sanders, and office machinery (such as thermoform machines, copy machines, book binding machines, etc.)

When it was time to do transition planning to adult services, Danny was asked his desires for work. He expressed over and over again that he loved to work on machines. Those involved in his transition planning were frightened at the thought of Danny working on machines due to his vision loss. They put him in a workshop setting, packaging and doing menial tasks contrary to his wishes. Danny quickly became bored and began to make up excuses as to why he did not want to go to work. Each day we would review his schedule for the next day. At this point he would tell me “Maybe tomorrow my head will hurt. Maybe my stomach will hurt. I may need to stay home.” The next morning he would request to stay home. When he was allowed to stay home, he had a big smile on his face and never mentioned sickness until the schedule for the next day was reviewed.

As I look back, it was quite a challenge to make my son’s dream a reality. After six months at the workshop, another meeting was called to convey the same message again. Danny said “I like to work with machines.” This time he was heard. We needed to develop strategies to convince employers that his placement would be safe and successful. A plan was set in motion to develop a video resume of Danny working with machines. The video also included footage of him

communicating and socializing with others at work. This project proved to be very helpful in getting his job. The video showed his abilities and personality rather than having the employer visualize his disabilities as overwhelming.

When our children are described on paper, they can get lost and the disabilities are highlighted. Although Danny is totally blind and profoundly deaf, he is a wonderful person first. We should respect his needs and desires in life and strive to help his dreams become a reality. Viewing life as a challenge instead of a problem would help us to overcome the barriers and achieve the dreams.

My son Danny is now working for a small engine repair shop. He is certified and repairs lawn mower engines, weed eaters, yard tools and rebuilds two and three cylinder engines. He needed to be oriented to his new work environment, just as we all need on a new job. He has a co-worker who is near if needed. Danny even manages to correct and assist his sighted friend and co-worker as needed. He has made many new friends on the job site and has joined them after hours for social activities. He has also enlightened others about hiring employees who are deaf-blind. When we weigh what it takes to provide our children with appropriate and desired employment the cost is very small compared to the benefits our children receive and give to their place of employment and our society as a whole.

The Journey to Employment

Rebecca Smethurst

Interpreter and Job Coach

My name is Rebecca (“Becky”). I have worked with Dan Tyce, who is deaf-blind, as his interpreter and job coach for the past eight years until his graduation from high school and completion of job training. I am a big believer of one-on-one interpreters/aides for children with deaf-blindness, beginning at an early age, and continuing through their school years and into job training.

Some of the greatest obstacles we initially faced were ignorance on the part of employers as to Dan’s abilities and also gaining access to the types of employment of which we, including Dan’s parents and teachers, felt he would be capable and deserving. Dan by nature is an easy going individual, with few expressed complaints, but often his expressions and communications in the beginning of his job search and training said it all, “I want more” and “I’m bored” and “I can do that if only given a chance” in response to employers’ rejections of “We don’t think he can or should try that”.

Dan has always liked working with his hands, being around people, and being in busy, noisy environments. His parents and educators tailored his job search to meet these likes, which is an important first step of the job search process. I began working diligently to bring his communication level up to speed; which I knew would be the first hurdle to cross over in gaining the respect and confidence of employers. I introduced him to the Tadoma Method of communication which is a form of communication for persons who are deaf-blind. After several years Dan’s communication skills have soared.

Dan also worked hard with his mobility instructor while in school. We went on weekly trips into the community to work on social skills. I often “acted out” situations with him which might encounter from time to time, and we repetitiously reviewed day-to-day situations such as asking for directions, buying items, riding the bus and the like. We fashioned Brailled, laminated hard back cards with simple pictures and statements for use with the public. These would be categorized and bound in a pocket book or held together with a ring. Dan could simply choose the card he desired, present it to a person and that person could read the simple phrase, see the picture and then respond as the card instructed. These cards are used today in his workplace to communicate with his boss and co-workers. As we were in the community, we physically introduced him to various workplaces or explained to him the industry in a given area. This allowed him to become familiar with a variety of job fields and allowed potential employers to become familiar with Dan. Even as we did these things, we ran into obstacles. Many people are simply unaware that deaf-blind does not mean unable. When Dan began pre-graduation job training his opportunities were limited to tasks such as simple sorting and packing. These tasks were not a challenge for Dan. It is important for individuals to be challenged with their work so it does not become boring, one needs find the level of challenge for each individual, because personalities and abilities vary from person to person. Dan loves machines and working with his hands and tools. Most of the employers we encountered and with whom we worked believed that since he couldn’t see or hear that working with machines was simply out of the question. I found that to get employers warmed up to him, I had to convince them that he could work as fast and safe as the other employees. I would have the employers teach me the skills and as I learned the job, I would let Dan feel the machines, and explained them to him. It worked! They slowly gained faith and confidence that he could perform more challenging tasks in working with the machines. We constantly had to review everything about the machines so Dan could become familiar with them. This process was repeated as he was introduced to new machines. We developed ways to make his work faster, such as moving bins closer to drop in the finished product, having parts ready to go and lined up, etc...

Over the course of his training, Dan has worked on copy machines, book binders, assembly lines, drill presses, shrink wrap machines, heat sealers, power drills and small engines. Today Dan has realized the type of work he likes the most: working with tools and machines in a busy environment. Today he works in a lawn mower and small engine repair shop. He has taught others about acceptance and patience. His co-workers respect him and his work. His boss is in awe of his diligence and hard work. I know his employment opportunities will not stop here. A person with deaf-blindness, no matter how severe, can meet the opportunities and experience to make their choice for employment.

In conclusion, I feel it is extremely important for the deaf-blind to start preparing for careers and employment early and incorporate the following ingredients:

- Full-time interpreters for school, social/community skills and job searching
- Weekly experiences in the community with new, concrete opportunities
- Exposure to noises/feel of workplaces with hands on feeling of tools, machinery and the like
- Trying new communication methods (card systems, pictures, voice communication devices, Braille, etc.

Mobility training whether basic or complex.

Advocates to help (explore government and school based programs work assistance and volunteer training)

I am very grateful, and I know Dan is even more grateful to the many teachers, assistants, his mobility instructor, community, employers, friends and family who have journeyed with Dan and me on his road to employment. It is more than being an aide or job coach or interpreter. It is being a friend whom Dan can trust and voice through. This is true of all who work with the deaf-blind. I feel very privileged to have traveled the journey to employment that we have traveled the past eight years.

Special, And Yet . . .

Ian Pumpian, Doug Fisher and Caren Sax
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We were asked by the editors of reSources to respond to a growing number of requests from parent concerning how to optimize their children's future employment opportunities. We were immediately reminded of similar questions posed to Dr. Barbara Wilcox ten years ago. She responded in a TASH 1987 newsletter in an article entitled "What Should Parents Expect?" Her response provided a perspective and a framework for answering this question ten years later. What was clear in her response, and should be clear in ours, is that there are factors that are fundamental to any individual transitioning into adulthood and employment. These factors are not different for individuals with disabilities including those who are deaf-blind. Rather, we must attend to these factors aggressively and creatively, if employment is to become a reality for more people who are deaf-blind. Make no mistake, the biological abilities and limitations of people who are deaf-blind should not limit their employment potential. Instead those individuals will magnify our achievements or deficiencies in responding to the factors mentioned below and originally offered by Barbara Wilcox.

Develop Social Skills and a Social Network

Throughout the history of special education, the teaching of social skills has been an area of concern and attention. Wilcox was astute enough to also delineate the importance of developing a social network. Too many programs are founded on the assumption that building social skills will lead to a student's ability to develop a social network or that developing social skills is a prerequisite to establishing a social network. Nothing could be further from the truth. We are now understanding that it is our social network, i.e., our relationships with friends, family, peers, and others, that leads to the development and refinement of our social skills, and it is our social network that tolerates our lack of social skills. As a result, educational programs which systematically exclude students who are deaf-blind from opportunities to develop relationships with neighbors, peers and other members of our community have become less and less defensible. Such exclusion denies these students the opportunity to adequately develop a supportive and extensive social network; a network that is critical to discovering opportunities, discovering effective support strategies and establishing a means of determining each student's interests, preferences and developing abilities.

Conclusion #1: Well-supported, inclusive educational programs are an investment in future employment opportunities.

Skills Related to the Demands and Opportunities of the Local Community

Employment opportunities and success depend on the development of social supports and relationships. Similarly, these relationships are a means to provide the future employee with regular involvement and interaction in his/her community. Familiarity with the environments and routines of the community, and good orientation and mobility within it, are basic skills of any prospective employee and are critical factors for those with disabilities. We would like to stress that community involvement must be developed and established within the typical routines, times of day and interactions shared by same age peers. To provide a community based instruction program within a context that separates students from these normal times, routines and interactions, that is, to teach skills out of context, is proving to be less effective and not warranted. As a student reaches the age where the focus of transition is no longer within the context of the public school (i.e., 18 - 22), the instructional day can and should logically be in the environments frequented by other young adults. For younger children their comprehensive school site represents a significant community environment in which orientation, mobility, skill development and interactions can be taught and enhanced. These experiences, coupled with involvement in extracurricular activities, non-school time with peers, and active family membership are keys to future success.

Conclusion #2: A history of active involvement as an included member of one's school and community is an investment in work force membership.

Occupational History

The natural, normal development of accepting and assuming responsibilities is an important part of building attitudes and skills that will later lead to job experience and employment. For young children, accepting responsibilities begins with simple chores at home and in the classroom. As students become older, they must assume more responsibilities for the family and at school. In addition, wonderful opportunities exist to become involved in community causes through, for example, religious organizations, environmental campaigns, and the like. These experiences can establish new skills, attitudes and interests. High school opportunities for career exploration and job experience are an important part of building an occupational history. Opportunities for after-school or weekend jobs and job experiences within the school building (e.g., attendance clerk) can build career experiences. We have been arguing for the coordination of special education job training and high school work study programs for some time. Job exploration during high school must continue to be an opportunity for peer integration rather than segregation. It should occur during the times and in the places where other high school students work. Wage earning is one important consideration at this age but so is exploring interests, building social/support networks and developing skills. Certainly these experiences provide the individual and his family with important insights into job modifications; interests that are developed; and opportunities to be further explored. For the high school student, notions of career should also be well-

supported through the schools academic program and his/her participation in extracurricular activities. At age 18, the IEP should include job experience located in real businesses and involve apprenticeships and mentorships sponsored by the employers and employees of that business. Transition services provided in these job experiences should document ways specialized support can compliment, rather than replace, the natural support and supervision of the business. These work experiences are fundamental to further determine student interests and the types of accommodations and supports that are necessary for success. In addition, the employers and employees involved in these experiences should become a valuable part of the network of people that the student can rely on for securing job opportunities.

Conclusion #3: Assuming and learning to accept responsibilities as an active member of one's family, school and community, and having real job experiences as a young adult are an investment in making future employment a reality.

Involvement of Family, Siblings and Peers in the Design of the Educational Program

Ten years ago, Barb Wilcox emphasized the importance of parents as participants in implementing their children's educational program. Now we appreciate the importance of parent's involvement but we must also include the individual student, his/her siblings, peers, and mentors in the educational process. We assume that as an individual establishes a more comprehensive social and support network that members of this network will have significant insight into what works and what doesn't work; the work interests that have been expressed; and what possibilities need to be explored and how to explore them. At a younger age, these discussions naturally focus on the student's academic program and extracurricular involvement. As the student reaches the point of his or her transition from school to adulthood, the self-advocate, peers, employers and family members play a critical role in beginning to explore new living, social, additional education and employment opportunities. Members of this network must be appreciated for their knowledge, resources and advocacy. To exclude them from the planning process would be a terrible mistake. Our continued failure to involve such important people is either a result of our failure to develop such a network or a failure to use processes to secure their input. If job development, placement and support continues to be the sole responsibility of a transition teacher and case manager, who also have responsibilities for many other unemployed transitioning students, then post-school options will continue to remain bleak.

Conclusion #4: Getting to know people who are well-connected through their community and who become interested in you and your child is a significant investment to opening the door to future employment.

We could have easily written an article focusing on the need for areas you already know are a part of finding employment for an individual who is deaf and blind. You would have expected a focus on good practitioners with well-developed and specialized skills to work with this population. Why say the obvious? Hopefully, we have stressed that it should be equally obvious that an enriched school experience and a child growing up as an active, respected and well-supported member of his home, school and community will contribute to one's adult successes. The trick will be to use the skills and expertise that we all know are effective with people who

are deaf and blind as a means of building the capacity of the community to support a person's employment. Such skills and expertise are not enough to replace the resources in the community or the logic to support one's inclusion in it.

Transition Services

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In 1990, law was passed that mandated "a statement of needed transition services in the Individual Education Plan (IEP), for students beginning no later than age 16 and annually thereafter....."

WorkAbility I, an employment development program administered through the California Department of Education, has been providing transition services in the form of paid specialized work experience and training since 1981. There are approximately 32,000 secondary, students (age 14 and up) . Program components include, but are not limited to: recruitment, assessment, counseling, pre-employment skills training, vocational training, student wages, placement in unsubsidized employment, assistance with transition planning, and follow-up for one and two years after leaving school. Data shows that 69% of the students who participated in the WorkAbility I program are still employed two years after exiting the educational system. This is almost a direct reversal of national employment data of persons with disabilities: "a full 66% of all Americans with disabilities between the age of 16 and 64 are not working (Harris and Associates, 1994). If you would like more information on this program, please call the WorkAbility I office at (916)323-3309.

Additional transition programs are available for persons with disabilities who may not currently be enrolled in the public school system. These programs are co-funded by the Departments of Rehabilitation and Education, therefore, participant requirements include eligibility for Department of Rehabilitation services.

The Transition Partnership Program begins while the youth is in school but can continue to provide services after they exit school. WorkAbility II provides services to persons who may be enrolled in Regional Occupational Programs/Centers or adult education programs. WorkAbility III serves clients through the community college system. While WorkAbility IV provides services through the state colleges. Although these programs offer similar services, specific services may vary program to program. For more information, please contact your local Department of Rehabilitation office or the Department of Rehabilitation Transition Unit at (916) 323-0336