

Customized Employment: A Strategy for Developing Inclusive Employment Opportunities

Robin Greenfield
Idaho Deaf-Blind Project

Emily is going on a cruise to Mexico with money she earned herself. When she was 19 years old, she used the process of customized employment to find a job. She had transitioned out of high school at age 18 and initially spent her days assembling flashlights in a production line at a local developmental disability agency. Her family wanted to help Emily find employment that allowed her to use more of her skills and was located in an inclusive setting in the community.

The concept of customized employment was introduced in 2001 by the US Department of Labor's Office of Disability Employment Policy. The strategy was designed to assist people with disabilities and other individuals who have potential barriers to employment, such as senior citizens, veterans, and people with complex health-related conditions. Customized employment is defined as,

... a means of individualizing the employment relationship between employees and employers in ways that meet the needs of both. It is based on an individualized determination of the strengths, needs, and interests of the person with the disability, and is also designed to meet the specific needs of the employer. It may include employment developed through job carving, self-employment, or entrepreneurial initiatives, or other job development or restructuring strategies that result in job responsibilities being customized and individually negotiated to fit the needs of the individuals with a disability. Customized employment assumes the provision of reasonable accommodations and supports necessary for the individual to perform the functions of a job that is individually negotiated and developed (U.S. Department of Labor, 2002, p. 43156).

For individuals with significant disabilities, the creation of a customized job increases "the opportunities for their participation and maximizes their competent performance" (Callahan, 2002). The principles and characteristics of customized employment are related to the concept of supported employment but are different in significant ways. A customized approach is initially guided by a job seeker's profile. Getting to know the job seeker at the beginning of the process is the key to developing a job that meets the needs of both the individual and the employer. In contrast, the typical supported employment approach is primarily driven by the jobs that are available in a community. Additionally, customized employment does not include group placements or subminimum wage positions as is often the case with supported employment (Inge, 2006). A customized employment approach leads to the development of a job based on the needs of the focus person rather than the labor market at large.

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The Customized Employment Process

The process of customizing a job starts with the development of an employment plan for a job seeker based on his or her strengths, interests, and complexities. Information gathered during this phase is more detailed than that obtained from a typical vocational assessment. One method of capturing the necessary detail is a process referred to as *discovery* (Callahan & Condon, 2007). Discovery seeks to answer the question "Who is this person?" by observing and talking to the individual in a variety of familiar and unfamiliar settings and by interviewing family members, friends, and service providers to get their perspectives on the strengths, contributions, performance, and needs of the job seeker.

The goal of the process is an understanding of the job seeker as an individual and the conditions that are necessary for the person to be successful in an employment setting. This includes not only the identification of an individual's preferences, interests, and contributions, but an understanding of "the complex issues that might emerge to compromise employment efforts" (Callahan and Condon, 2007, p. 23). Factors such as an individual's motivation to work and ways of learning a task are critical pieces of information in the discovery process. Conducting this kind of intensive investigation takes time but is well worth the effort to achieve effective employment outcomes.

Once the information is collected, it is written into a vocational profile that is used to develop an employment plan. The plan also includes a prioritized list of targeted employers, generated by the

job seeker's team and based on the information collected in discovery.

The information in the profile can subsequently be used to develop a portfolio that presents the job seeker to potential employers. This strategic marketing tool uses photographs and text to describe the skills and contributions of the individual. It can be presented to an employer by the job seeker, by a job developer, or by another employment professional who has been involved with the individual during the discovery process. For individuals who are interested in self-employment, the profile can be used to develop a business plan that outlines the skills the individual will bring to a business and describes his or her required resources and supports.

The discovery process can also be used in school-based settings to guide transition planning, career exploration, and vocational preparation for middle- and high-school students. Using the tools of discovery, team members can prepare students with significant disabilities for transition by exploring their preferences and interests and the conditions that allow the students to perform at their best. The process can enable students to make more informed choices and to advocate for themselves at IEP and transition meetings. Beginning the discovery process while students are still in school gives teams the time to really get to know them. The information they collect helps students build needed skills for the future. School is an opportunity for students to acquire work experiences in school-based jobs, participate in volunteer work in the community, or explore self-employment options.

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Customizing a Job for Emily

Idaho Deaf-Blind Project staff, together with a consultant from the University of Montana's Rural Institute on Disabilities and NCDB, facilitated an initial meeting to discuss customized employment with Emily's family and service providers. They explained the discovery process and how the information generated for the vocational profile would be used to find a job for Emily. The participants in the meeting included Emily, members of her family, staff from the developmental disabilities agency (DDA), her service coordinator, and a representative from the local vocational rehabilitation (VR) office. At the conclusion of the meeting, several members of the team volunteered to conduct interviews and observe Emily in a variety of settings.

The team members began collecting information by spending time with Emily in her home and in the community. They watched her make her favorite Mexican chicken soup and then ate dinner with the family later in the day. They observed her on the computer as she looked up the balance in her checking account. They went with her to an arts and crafts supply store and observed how she maneuvered through the aisles and the types of support she needed to find items and pay for them. They interviewed her parents, sisters, and other family members about chores she did on a daily basis and how she acted in unfamiliar settings. They asked if she ever initiated tasks on her own and discovered that she would automatically hang up people's coats when they came for a visit and sit down to play with their children without being prompted. They visited Emily at a DDA workshop and talked to the staff. They observed her at a bowling alley where she bowled on a weekly basis. They also talked to Emily and former teachers to find out how she learned new skills and how she had performed on vocational tasks in high school.

After conducting in-depth interviews and observations, the team compiled information and wrote it into a vocational profile. They included not only information learned from observations and interviews, but also details such as her family structure and social networks, transportation options in the community, her performance on formal and informal work done at home and at school, her favorite activities, her involvement in structured community activities, her preferred holidays and family traditions, her recreational likes and dislikes, her sensory challenges, and her academic, communication, and social skills.

Through this process the team began to understand who Emily was and the kinds of jobs that she might like and do well in. They learned that she performed best when there was a structured, predictable routine. She liked to use checklists and written instructions. She learned from modeling, verbal instructions, repetition, and repeated practice. She was described by her teachers as "thorough" and as someone who "likes to complete a task." She liked to be busy and to be around people, although the teachers did not think that it was necessary for them to continually engage her. She liked to do things with her hands (e.g., multipiece puzzles, pen drawings, cooking, crafts) and loved to buy cookbooks.

The team also learned more about the supports Emily might need in a work setting. They found out that she was uncomfortable in loud, echoing environments and would leave a setting if the sound was bothering her. They discovered that Emily had hearing aids but had chosen not to wear them, that she did not see out of her left eye, and that she had issues with depth perception. It was important to ensure that a worksite did not require her to go down steps on a regular basis, climb a ladder, or navigate over uneven terrain without assistance. When using a computer screen, she needed contrasting print with limited glare. She could read 12-point type, but it was easier and much less taxing on her vision if the print was larger. The team also discovered that Emily learned best when she initially had a one-to-one support person who provided systematic instruction and repeated practice on a task. Once she was familiar with an environment and knew the particulars of a task, she could do it on her own with intermittent support.

All of the information in the vocational profile was used to develop Emily's employment plan. It described her ideal working conditions and the terms for negotiation with an employer. The conditions included: (a) a steady pace of work that would keep her busy; (b) routine steps for a job (several tasks within a job would be all right); (c) clear rules and expectations; (d) a work schedule of 3 to 4 days a week of up to 8 hours a day; (e) avoidance of an extremely loud environment. The plan also listed Emily's specific job skills and a list of employers whose businesses might have a need for the tasks she could perform and match her conditions for employment.

At the conclusion of the meeting, the team decided that it would be beneficial for Emily to develop a portfolio for marketing herself to employers. She then designed one as a pictorial

and written representation of her contributions and capabilities. It included a variety of photographs of her playing the piano, making soup, using the computer, filing papers, working at a grocery store, and using public transportation. It also listed her areas of interest, the characteristics of her strong work ethic, and job tasks she could perform (e.g., delivering items, stocking, taking inventory, making snacks, sorting mail). The last slide of the portfolio asked the question “Could your business benefit from having any of these tasks performed?”

Emily obtained a job at a local fabric store. The manager was looking for a person who could work several hours a week and perform various tasks. She wanted someone who was reliable, had a strong work ethic, and a positive attitude. Emily, with the support of a job developer from the DDA, used her portfolio to present information about her skills and interests to the manager. She was subsequently hired to work four days a week for two hours a day, folding cloth on bolsters and making sure that the bolsters were in the proper order. Even though Emily had a number of marketable skills, she still required support to help her learn the steps of the job and complete the tasks in a timely manner. The funding for a job coach for Emily came from VR dollars and was coordinated with staff from that agency.

Emily is now 24 years old and is still working in her community. She no longer works at the fabric store, but she has used her portfolio to secure jobs at other places, including a daycare center and a television station. She now works at Kentucky Fried Chicken doing “lobby work.” She “loves it” and was, in fact, the “VR Client for the Year” for her region of the state. She works 12:00 to 2:00 p.m., Monday through Friday, and receives intermittent support from a job coach. The job coach was funded by a scholarship until recently but is now being paid with Medicaid funds.

Many customized employment services are supported by a blend of multiple funding sources. The Social Security Administration’s work incentive programs, such as PASS (Plan for Achieving Self-Support) have been one way to fund transition planning and career development activities for high school students. PASS plans have funded a variety of supports including assessments, job coaching, job development, transportation, and equipment for people who are eligible. Other sources of funding include Medicaid waivers, developmental disability council funds, state VR initiatives, and Medicaid infrastructure grants.

Customized employment is a strategy that strives to highlight an individual’s qualifications and interests in an effort to negotiate a job that satisfies both the employer and the job seeker. Although service providers and families who use the customized approach will likely encounter many of the same challenges that occur with the use of more traditional job development methods, those who decide to use it will discover a more innovative, person-centered assessment and planning process. They will discover that customized employment helps them to “think outside the box” as they work to develop a job for a specific person in the community or generally to expand inclusive employment opportunities.

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Seattle’s Deaf-Blind Service Center: A New Vision

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The Deaf-Blind Service Center (DBSC) is a community-based agency in Seattle committed to assisting Deaf-Blind people to reach and maintain their highest possible quality of life and degree of personal autonomy. The focus and vision of DBSC have evolved over its 20 years of existence, and today we are closer than ever to the community we serve.

The DBSC Board has always required a minimum deaf-blind representation of 50%, but I am the first Deaf-Blind executive director. This is a significant step forward. It provides a concrete model of deaf-blind leadership; it is not just an ideal or goal. It has become reality, and it means that the director experiences the same barriers and issues facing all deaf-blind people. The deaf-blind members of the staff, the clients who come to the agency, and members of the DB community can look to the director as a peer.

In this article I describe our services and the new vision of our agency—the DB Friendly Zone at DBSC and in the community. The agency’s services and activities are a response to current barriers and reflect our vision of the future.

Barriers

Most people use vision and hearing to know about the world, to gather information and communicate, and to travel from place to place. DB people do not have the same sensory means to achieve these goals, and they encounter barriers to a high quality of life, including:

- ◆ lack of access to communication and efficient transportation,
- ◆ stereotyping (stigmatizing) of deaf-blind people, resulting in inappropriately low expectations and rigid thinking, and
- ◆ the effects of years of neglect and isolation.

The barriers vary by context. For example, rural areas and cities present different combinations of barriers and resources related to transportation and communication. DB people need modifications in order to access their environment. When DB people gather for conferences, camps, or parties, everything is ready for them. The physical environment and the communication or social environments have been modified, car traffic has been eliminated, paths or trails are marked, the lighting is good, print materials are on buff paper in large print and in Braille, and everyone can communicate effectively. We have adopted this as our standard at DBSC, and we call it the DB Friendly Zone.

The second, and often the biggest, barrier that DB people face is the stereotype that many people have about what it means to be deaf-blind. There is a stigma to being DB. People often do not understand how to partner with us, be our allies, and share information with us. Instead, they try to “help” by telling us what to do and how to fit into the hearing-sighted world. We have adopted the

motto “DB to DB.” We want to partner with sighted and hearing allies, but first we look to each other for advice about how to live as DB persons. We want to raise expectations, and we want solutions to come from us and our community. Low expectations become a self-fulfilling prophecy.

The result of years of oppression is the third major barrier. When DB people are isolated or marginalized for years, the effects add up and can be huge. A DB adult who has been cut off for years will find it very difficult to catch up and may begin to doubt his or her abilities. We need to work to change the attitudes and systems that cause these problems. By observing DB senior citizens at gatherings held at DBSC every month, I have come to understand the damage that this oppression has done. Many of these adults had inadequate education as children and limited choices as young adults. For most of their lives they worked in sheltered jobs that provided a limited income. Their energy, time, and creativity were spent in the struggle to survive. Once retired, many became isolated and unaware of resources or potential hobbies that they might enjoy. Some have been abandoned by their children or grandchildren or have experienced the loss of a spouse.

The DB community is our foundation. DB people want and need access to information, to communication, and to transportation systems so that we can manage our own lives. DB adults do not want someone to do the shopping for them; they want to have access to information and transportation to do their own shopping. DB adults do not want someone to plan their employment; they want the education, information, and transportation to get their own job and to have the choice to make career changes as they go through life. DB people do not just want to talk about themselves and have someone solve their problems; they want to hear about you, your life, and your problems and successes too.

Creating Change

The change must begin with ourselves and our own sense of who we are and who we can be. DBSC can promote this change by increasing opportunities for DB people through:

- ◆ setting a clear example of a “can do” attitude as a model for professionals, educators, families, and DB individuals;
- ◆ setting a high standard for working together and sharing life experiences and information with which to make choices and decisions;

- ◆ developing DB leaders through education and training;
- ◆ providing role models for DB youth;
- ◆ educating the public;
- ◆ providing tools, systems, and strategies for access to information;
- ◆ establishing a DB Friendly Zone at DBSC.

In our new model, DBSC is continuing to offer case management and support service providers, with an emphasis on informed choices. It is our hope that professionals, family members, and DB people will be inspired by this perspective and will follow our lead.

Society is not yet accessible. The case manager/advocate at DBSC helps DB individuals to solve problems by providing them with information about their legal rights and available resources and teaching them techniques and strategies for communicating with members of the public such as landlords, hospital personnel, or Social Security representatives. This staff person also works with those same landlords, hospital personnel, and Social Security representatives to teach them about legal mandates, available resources, and techniques and strategies for communicating with DB people.

An important and even more popular DBSC service is the SSP (support service provider) program. An SSP is a communication facilitator and guide. With an SSP, a DB person can go shopping for food, clothes, gifts, and household items without relying on friends or family. SSPs relay visual information about what they see—what is new and changing in the city, what buildings are going up or coming down, what new products are being offered, and what is on sale. SSPs do not interpret, but they relay information. They provide incidental and informal information.

DBSC also provides a communication facilitator (CF) service. Deaf people have used video phones to make calls, and now DB people can take advantage of this opportunity. Communication facilitators are fluent in sign language, and they copy for a DB person the signs made by a Deaf person or interpreter at the other end of the video phone call. The Office of Deaf and Hard of Hearing (ODHH) has contracted with us to provide this service. It is one more way DB people can access information and be a part of the world.

Sharing Information in the DB Friendly Zone

Just like everyone else, DB people want to learn about things like the growing interest in organic

food and the reasons behind it, what is in the news, and where people are going on their vacations and why. These things are not learned by taking a class. This is the incidental learning that happens day-to-day while chatting with others. When DB people have access to these conversations, they come to understand the society in which they live. By learning about others' experiences, they are able to seek out new experiences for themselves.

Here at DBSC we start with touch and tactile communication. This is the foundation upon which our community is built whether an individual's first or primary language is English or ASL. Our doors have pads on the floor so that when someone walks through the door and steps on the pad, a signal is sent to our vibrating pagers. Our computers are ready with ZoomText® or Braille printers, and everyone who works in the office is fluent in tactile sign language. It is a comfortable place to be. The arrangement of the furniture, the type of equipment, and the color of the walls are all DB friendly. At DBSC, the DB way is the norm so that each DB person can feel respected and included.

We embrace our deaf-blind identity and look to each other for healthy role models. We look to sighted-hearing people to be our allies, not to provide advice on how to succeed as a DB person. The following are examples of how we apply this approach at DBSC.

DB to DB. We noticed that many DB people had started to rely on interpreters to communicate with other DB people. We adopted the mottos "Deaf-Blind to Deaf-Blind" and "Pro-Tactile" to emphasize that we can develop the skills to communicate effectively with one another for conversations or small meetings without the help of a sighted person. They also underscore the fact that we know best how to be deaf-blind.

Tactile Sign Class. We offered a tactile sign language class (taught by a DB staff person) that was open to all DB people regardless of their first or primary language. Having a deaf-blind teacher emphasizes our own expertise. Use of the tactile mode minimizes differences and emphasizes similarities. The combination of small class size (four students) and peer-teaching created a safe place to learn and build confidence. Students shared experiences and explored different methods of signing tactilely. Each student could explore and create his or her own method rather than conform to one method intended for all.

Working together. DBSC deaf-blind staff and clients encourage each other to use a white cane, tactile sign, and other tools and approaches that give us the most information. We help each other find creative solutions to problems. In this sense, we (agency and clients) are a team, working together towards a common goal.

In the DB Friendly Zone we are able to take a deep breath, gather information, and create solutions. Having good communication skills, access to visual and environmental information, knowledge of resources, and the skills to use different tools enables us to figure out together how to live. We are developing our own expertise and learning to trust our own perspectives. We are preparing for the future by involving DB youth in this process. Our goal is nothing less than universal access—access to information, transportation, and communication.

For more information about DBSC, go to <http://www.seattledbsc.org>.



Reaching out to the World

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Far from home, JennyLynn Dietrich experiences a familiar feeling when a crying child reminds her of her own frustrated childhood attempts to express herself and comprehend what others were communicating. Cross-cultural and language differences between the United States, where JennyLynn is from, and Guatemala, where she is now, drop away. She understands this child. JennyLynn and other American social work students from Gallaudet University have visited FUNDAL (Fundación Guatemalteca para Niños con Sordoceguera), an education center in Guatemala City for children who are deaf-blind or disabled. FUNDAL collaborates with the Hilton/Perkins International Program and other international organizations.

During her visit, JennyLynn, who is deaf-blind, learned that the tearful child had support from patient teachers to help her break through communication barriers. “I am overwhelmed by how nice the center is and how well the children are treated,” she says. “FUNDAL builds awareness in parents, showing how they can do more for their children. They have a group of people who teach

kids signing, so they can have a communication method. It’s incredible what they do.”

JennyLynn visited FUNDAL as part of a 2-week-study-abroad graduate course (<http://academic.gallaudet.edu/courses/spa/CREPBerw.nsf>). The visit to Guatemala was her first trip outside the United States. “I wanted to experience going beyond the borders of myself . . . being able to do more than I felt I could do,” she says. “[At FUNDAL] they are intrigued because I am deaf-blind, visiting their school from America and getting a master’s degree. They are impressed, and now they know that these kids can do it too.”

Over the course of history, deaf-blind leaders, such as Helen Keller and Father Cyril Axelrod, have reached out to deaf-blind communities in other countries, formed international organizations, and traveled abroad. Future leaders of today’s deaf-blind community are venturing overseas for similar reasons, and at younger ages.

“I stayed in Paris for an entire month mingling with kids my age from 11 other countries and visiting the Musée du Louvre, Eiffel Tower, Avenue des Champs-Élysées and more,” says Christine Roschaert, who traveled to France as a 12-year-old to participate in the Children’s International Summer Village (<http://www.cisv.org>). “That experience profoundly changed me for life; from there on I knew I wanted to explore more of the vast world.”

Now 29, she has done just that. “I found solace in discovering the world,” says Roschaert, who studied for a year at a school for students who are deaf and hard of hearing in Oldenburg, Germany, on a Rotary International high-school scholarship (http://www.rotary.org/programs/youth_ex). “After my stay in Germany, I became quite fluent in German and went to the top of my class when it came to speaking, reading, and writing German,” she says.

International experience exposes travelers to cultural and class differences and promotes awareness of global communities. Christine describes the ways she has been changed by her international exchanges as “more complex than the universe.” “I know that I have become a better person, more empathetic, and I have understood what it means to be privileged and underprivileged,” she says.

Many of these changes happened during an internship to the Philippines, when she was a student at Gallaudet University (<http://cge.gallaudet.edu/>). In the town of Jagna, Bohol, she taught at a primary school with 900 stu-

dents, 200 of whom were deaf or deaf-blind. Reflecting on this experience, she says, “I encountered many deaf and deaf-blind children [who] were denied proper education. I felt a surge of passion and I just knew that I was destined to do something on an international level.” Christine has dreams of working in other countries and eventually at the World Federation of the DeafBlind in Europe. “[I want to] change how others perceive DeafBlind people and empower others for independence,” she says.

Practical Traveling Issues

The practicalities of traveling overseas with a specific purpose require extensive planning. JennyLynn arranged for close-vision interpreters and SSPs to travel with her on her current study-abroad program to Guatemala. “I was very concerned about the possibility that I could get lost or trapped in certain areas where I couldn’t get help from the U.S. Embassy or my professors,” says JennyLynn. As it turned out, the only difficulties that she encountered were narrow, cobble roads and cars that wouldn’t stop.

Drew Hunthausen, a student at Golden West College, California, traveled abroad without his parents for the first time with sponsorship by the Westminster Lutheran Church to volunteer at a boys’ shelter in Jamaica. “When I first got there I was nervous because I am blind and also have a hearing impairment; I wasn’t sure what I was able to do or how I was going to fit in. But being there, just hanging out and spending time with the boys was all they really wanted,” he says. “They had quite a few questions about my disability. It was cool that after the first day the boys got to know me and they all wanted to lead me places.” The rocky terrain created a challenge in getting around, so Hunthausen brought his long cane and, depending on circumstances, asked other church volunteers to be his sighted guides.

Steven Frank, an avid traveler who is deaf-blind suggests preparing for a lack of accessibility when sight-seeing at historic ruins. “You may need two SSPs, one on each side, to tackle uneven or slippery steps,” he says. Steven also has suggestions for air travel. When he travels alone, he has an SSP go with him to check baggage and guide him to the airport gate. He informs the airline to put instructions in their computer system for an employee to meet him at the gate at the end of a flight and guide him to the baggage claim. He brings a photo of his luggage so that it can be identified.

Traveling without an assistant is permitted as long as the individual can “establish some means of communication with carrier personnel, adequate to permit transmission of the safety briefing,” as stated in the Air Carrier’s Access Act (ACAA). A 1997 lawsuit, which ruled against a U.S. airline in favor of a deaf-blind traveler, concluded that airlines cannot require personal assistants by substituting their own judgments about “safety” in place of the requirements imposed by the regulations. A later 2005 consent order ruled that international carriers must also comply with the ACAA when flying to and from the United States.

Steven suggests preparing in advance some communication notes on index cards. For example, anticipating the following situations, he might write cards saying:

- ◆ “To communicate, please trace block letters on palm of my hand.”
- ◆ “Please lead me to the closest exit.”
- ◆ “For a drink I would like cranberry juice, second choice is apple juice or cola.”
- ◆ “Please call a flight attendant.”
- ◆ “Please lead me to the restroom.”
- ◆ “Please lead me to the baggage claim area where my friend (or family) is waiting.”

He includes the same message in Braille on the cards so that he can identify them.

Steven also stresses the importance of becoming familiar with common safety precautions for traveling abroad, such as wearing a passport and money holder under one’s clothes or finding other spots to keep valuables safe. He always rests his foot against his luggage when waiting, to be able to feel if it has been removed, and keeps copies of his passport in a place separate from his actual passport.

With these preparations in place, the world becomes less intimidating. “I climbed to the top of the Mayan pyramids in Tikal [Guatemala], which was very cool although exhausting,” says JennyLynn. “The stairs were very steep, and I was crawling on hands and feet, but it was worth it.” Borders no longer limit JennyLynn. She knows that as she reaches across them, others like Christine, Drew, Steven, and the people she has met abroad will join hands with her, giving strength and leading the way.

Resources for Learning about International Opportunities

The National Clearinghouse on Disability and Exchange (NCDE) is sponsored by the U.S. Department of State and administered by Mobility International USA. The NCDE is a comprehensive resource that provides free information, tips, and referrals to people with disabilities about traveling overseas for the purpose of international study, internships, and volunteering. For information about learning a foreign language and Students with Learning, Hearing or Vision Disabilities," at <http://www.miusa.org/ncde/tipsheets/foreignlang>

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Explorers, Inc., is an international organization dedicated to providing travel and tourism experiences for people who are deaf-blind all over the world. It provides the unique experience of exploring destinations that may otherwise not be available to individuals who are deaf-blind. SSPs and interpreters accompany all trips. Explorers, Inc., strives to raise awareness of the needs of travelers, to remove barriers to access, and to expand travel opportunities everywhere in the world.

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Personal Perspectives: Angelyne Thorning

Peggy Malloy

The time for leaving high school and moving on to adulthood is an exciting stage of life for everyone, and this is certainly true for 19-year-old Angelyne Thorning. Angelyne lives in Florida where she is a senior in high school and currently making plans and gaining experiences that will help her make the important transition to adult life. In addition to the typical challenges faced by all teenagers, Angelyne has CHARGE Syndrome, which can cause hearing and vision loss as well as a number of medical problems. Angelyne has severe hearing loss, is blind in her left eye, and has low vision in her right eye.



When Angelyne was born, very little was known about CHARGE Syndrome. Her mother, Ruby, describes a time of trial and error as the family worked to get for Angelyne the medical and educational services that she needed. In addition to vision and hearing loss, Angelyne was born with a number of the medical problems associated with CHARGE. She spent the first 4 months of her life in a hospital and was in and out of the hospital frequently until age 6. As a teenager, she has had kidney problems that have required several operations. Ruby says that, "A lot of CHARGE children don't know anything but pain. Because of everything Angelyne has been through, it was hard for

her to make friends when she was growing up. She is very confident, but in some ways she had better relationships with adults than with kids her own age. She grew up fast, but slow at the same time.”

Angelyne uses oral speech, wears hearing aids, and uses an FM system at school. She has her own computer and e-mail account. In 2006, she had a poem published in *The International Who's Who in Poetry*. Outside of school, her interests include NASCAR and country music. Ruby believes that part of the reason that Angelyne has done so well is the influence of her sister Amber, who is 4 years older than Angelyne. When Angelyne was an infant, Amber watched Angelyne's therapists work with her and later did the same types of activities with Angelyne on her own. Angelyne had lots of practice and many opportunities to learn!

At 19, Angelyne is thinking about her future. Last year she attended a meeting for teenagers in Florida and Georgia who are deaf-blind. It was the first time that she met other teens with deaf-blindness. She even met another teen with CHARGE Syndrome. Angelyne has also been gaining work experience. When she was a junior in high school, she worked in the mail room and cafeteria of a local hospital for 3 hours a day, 4 days a week, and while attending a summer transition program for teens at the Lighthouse of Central Florida, she worked 2 days per week in the community. She learned how to use public transportation and acquired independent living skills such as cooking, cleaning, and washing clothes. The program also provided an opportunity to be with other teens who face similar challenges.

Last fall Angelyne participated in a 2-week vocational and independent-living skills evaluation at the Florida Lions Conklin Center for the Blind, where she learned that she has many qualities that will help her in the working world. She is focused, organized, a hard worker, and fun to be around. Angelyne says that her goals are to live independently, have meaningful work, and earn money. She is very interested in meteorology and is now trying to discover what type of education and training she will need to work in this field. After she graduates from high school, she plans to return to the Conklin Center for more assessment and training.



Worldwide Connections

Nancy O'Donnell
Helen Keller National Center

When I first told my colleagues about my plans to travel to Australia last September to attend the Deafblind International World Conference, several of them questioned whether the trip would be worth the cost, time away from family and work, and the physical toll of a trip halfway around the world. After all, with e-mail and the Internet, aren't worldwide connections just as convenient from one's office as they are in person? The answer is yes . . . and no.

Compared to the no-tech early days in the field of deaf-blindness, we all accomplish an incredible amount of quality work via e-mail, listservs, search engines like Google, and more recently, Internet-based video phone calls. And yet, there really is nothing like face-to-face communication and the energy generated in a room full of people who share a common interest. Perhaps that's what those who created the theme for this conference, "Worldwide Connections—Breaking the Isolation," had in mind. It's not just those who are deaf-blind who are isolated. Parents and professionals working in this tiny microcosm of a field feel the isolation too. A week of full-blown small- and large-group interactions was a great antidote for this.

My main purpose for attending this conference was to launch the newly formed Rubella Network. Although I later learned that network meetings would not play a major role in the agenda, we were able to squeeze this one in as a concurrent session. Those participants who had only met through online listservs finally had a chance to meet in person. Adults with Congenital Rubella Syndrome, parents of children with CRS, and the professionals who serve them all packed into a small meeting room for an enthusiastic and encouraging half hour. If there was one theme that emerged from that meeting, it was "Don't let rubella be forgotten." Although rubella has been eliminated in many parts of the world because of better immunization policies, it continues to wreak havoc in developing countries. Also, adults who are deaf-blind from CRS continue to be reported worldwide as having additional health concerns in later years. Questions about a link between rubella and mental health have surfaced, not only in those who are deaf-blind from CRS but in the deaf population as well. Degenerative processes leading to early death continue to be re-

ported. Fallout from the powerful and emotional MMR vaccine/autism debate continues. And a new study on maternal health is being piloted. There is plenty of work to keep us busy!

Presentations at the conference were quite diverse and filled with hope. In one, the incredible futurist Ray Kurzweil (projected on a “larger than life” screen via the Internet) explained how technological growth occurs exponentially rather than linearly. He predicted that incredible strides in technology will occur much more quickly than ever before. In another presentation, it was shown that developing countries are proudly creating some amazing new services through determination and ingenuity borne of necessity.

For one short week, those of us lucky enough to attend this conference were immersed in inspiration and affirmation. If Ray Kurzweil is right, we can only expect these positive experiences to grow exponentially.



Report from the 14th Deafblind International World Conference

Katrina Arndt
St. John Fisher College
Rochester, New York

I was fortunate to attend the Deafblind International World Conference in Perth, Australia, in September 2007. What a wonderful week! I knew it would be easy to feel overwhelmed by all the offerings, so I picked a focus area—transition from childhood to adulthood—to help me decide which sessions to attend. But the conference was so dynamic and the presentations so wonderful that, instead of staying with this theme, I attended a wide range of presentations and thought about how each related to transition issues. I came away with great respect for all of the presenters and a deep appreciation for the international community. In this article I review six sessions on a variety of topics.

Inclusion in Puerto Rico

Juanita Rodriguez of the University of Puerto Rico and her colleagues presented information about a systematic process used in Puerto Rico to include students who are deafblind in regular classrooms. To support the process, the National Technical Assistance Consortium on Children and Young Adults Who Are Deaf-Blind (NTAC) had

provided training in 2003 on deafblindness, authentic assessment, and best practices for inclusion.

To review how inclusive practices can and do occur, Rodriguez and her colleagues presented the case study of a young girl, J, and described how a systematic technical assistance model was used to successfully support her transition from a self-contained classroom to regular school for the first grade. The model used a person-centered process to explore J’s interests and communication, social, and academic skills and to revise her Individualized Education Program. Her peers were taught sign language, and cooperative learning was used to foster social interaction. J used accommodations in the classroom but underwent the same evaluation process as her peers. She participated in physical education and extracurricular activities and made friends with classmates.

This presentation highlighted the reality that for every child in a segregated setting there is a child somewhere with identical needs who is fully included. This “developmental twin” idea can be powerful in countering attitudinal barriers to inclusion in schools and in communities. It demonstrates that with supports and services, there need be no barriers to fully inclusive lives for people who are deafblind.

Accessing the Community in the UK

Jenny Fletcher of Sense UK discussed the background for legislation supporting access to community resources and activities by children who are deafblind. The legislation, which resulted in guidance for local authorities called “Social Care for Deafblind Children and Adults,” was due in part to lobbying efforts by older adults with deafblindness to Parliament and the House of Lords for rights to access their communities’ resources. The guidance includes processes for identifying people who are deafblind, followed by assessments to determine their needs and the provision of appropriate services. It also emphasizes the need for agencies to assign a member of senior management to be responsible for deafblind services and to provide information about services and activities in accessible formats.

The seniors’ lobbying efforts had a powerful effect on the lives of young people who are deafblind. Jenny presented four cases of children, ranging in age from 2 to 13, who participate in community activities such as swimming and playing in a park. This presentation was inspiring because it showed the direct, positive effect of advocacy efforts on the daily lives of young people.

Music and Movement Therapy in Sweden

Mea Nordenfelt from Stockholm, Sweden, discussed music therapy that she has used with two adults who are congenitally deafblind. She began by asserting some standard rules to ensure that “persons with disabilities are integrated into and can participate in cultural activities on an equal basis.” She showed video clips to demonstrate how she engaged with her clients through the use of songs, body movement, and props such as scarves and pillows, and she talked about the importance of body awareness and the interplay of touch, body movements, and emotions.

One of the individuals with deafblindness, T, had difficulty with balance, so the therapy took place on a floor covered wall-to-wall with thick mats. Mea worked with T by singing and moving in rhythm to a familiar tune. They sat back-to-back and swayed from side to side while Mea led T through a movement sequence. It was clear that he anticipated the movements and enjoyed moving through the sequence.

Mea stressed the importance of play and enjoyment in therapy, and she clearly practices what she preaches. It was absolutely clear that her clients benefited in significant ways from this therapy. I left the session with a strong sense of her passion for using movement and play not only as tools for communication, but for enjoying life! It renewed my commitment to understanding physical activity and body awareness as essential parts of any service plan and inspired me to think about including physical activity and movement as part of transition planning.

Young Adults in India

Dipti Karnad from Chennai, India, reviewed the cases of three young people preparing for transition to adulthood at the Clarke School for the Deaf, under the guidance of a vocational model designed to support the development of communication, mobility, academic, and social skills during participation in everyday activities. Karnad emphasized the important concept of partial participation, in which skill development and activities are individualized to meet each student’s needs. A focus on individual needs and interests is an essential component of all transition planning. Once interest areas have been determined, skill assessments guide transition teams in the development of supports and services.

Making Connections for People with Usher Syndrome in the UK

Marilyn Kilsby of Sense UK spoke about social connections for people with Usher Syndrome. She described two groups in England, a social group and an Internet-based e-group, and reviewed the challenges and characteristics of each. Challenges for social groups include arranging transportation, finding and paying communicator-guides and interpreters, locating suitable venues, and procuring technical support equipment. Hearing and Sight Impaired UK (HSI UK) has 337 people on its mailing list, 148 of whom live in London and South-east England. The group found a well-lit venue that was easily accessible by public transportation and contacted SENSE (a local organization for people who are deafblind), which organized volunteer communicator-guides and helpers.

Being part of a social group has benefited most of the participants. Many have become more confident, have developed leadership skills, or have lent their expertise to the group. Having a place where no explanations are needed is a welcome respite from the challenges of daily life, and one that most people enjoy.

The second type of group is an e-group, which takes place entirely in cyberspace. One such group, the Usher Life E-group, has 72 members from around the world. It grew out of the HIS UK social group and uses written English to share information and facilitate discussions about matters affecting those with Usher Syndrome.

Marilyn concluded her presentation by reminding us that while there are challenges to organizing a social group, the benefits are well worth the effort. She encouraged us to consider starting a social group in our own countries.

Person-Centered Planning in the US

Clara Berg and Arnie Mejia from the United States spoke about a wonderful way to think about person-centered planning: as a restaurant menu. First comes the appetizer, a process of finding out who a person is and what his or her likes, character, abilities, and preferences are. The appetizer ingredients appear throughout the meal and set the stage for the rest of the meeting. The second course is the entrée, which adds to the components of the appetizer a circle of support, opportunities, contact people, natural and paid supports, financial possibilities, and community settings. This part of the meal cannot be rushed. It takes time to make a good meal and a good per-

sonal plan for the future. For dessert, the plan is set in motion with responsibilities and due dates, charts to stay on track, and an open chart for new ideas. This way of thinking about planning reminds us that we can design the menu we want based on our individual needs. The same appetizers may not lead to the same entrée or dessert choices, and choice is what person-centered planning is all about.

Conclusion

This was an incredible conference, and it was great to be exposed to innovative ideas from around the world. After attending the conference, I was excited about what I had learned and determined to work to increase opportunities for people who are deafblind.



Research Update

Hearing loss due to auditory neuropathy is receiving increasing attention and research. The following list of materials provides information about this important topic. The first two items are overviews of the condition. The remaining items are research articles on the use of cochlear implants for auditory neuropathy.

Berlin, C. I., et al. (2007). Auditory neuropathy/dys-synchrony (AN/AD). In S. Schwartz (Ed.), *Choices in deafness: A parent's guide to communication options* (3rd ed.), pp. 49-77. Bethesda, MD: Woodbine House.

Thierry M. Differential diagnosis of auditory neuropathy/dys-synchrony and (central) auditory processing disorders. *Insights in Practice*, June 2007.
www.otometrics.com/insights_june_2007_print.pdf

Jeong, S. W. (2007). Cochlear implantation in children with auditory neuropathy: Outcomes and rationale. *Acta Oto-Laryngologica Supplement*, 558, 36-43

Miyamoto, R. T., et al. (1999). Cochlear implantation in auditory neuropathy. *Laryngoscope*, 109, 181-185.

Shallop, J. K., et al. (2001). Cochlear implants in five cases of auditory neuropathy: Postoperative findings and progress. *Laryngoscope* 111, 555-562.

Trautwein, P. G., Sininger, Y. S., & Nelson, R. (2000). Cochlear implantation of auditory neuropathy. *Journal of the American Academy of Audiology*, 11, 309-315.



For Your Library

Practice Perspectives: Children Who Are Deaf-Blind.

National Consortium on Deaf-Blindness, November 2007.

This publication provides details about the population of children who are identified as deaf-blind, including the classification of vision and hearing loss, the types of additional disabilities that may be present, and the causes of deafblindness. Vignettes and photos of four children who are deaf-blind illustrate the diversity of this unique group of children. Available on the web: <http://nationaldb.org/documents/products/population.pdf>. Print copies are available free of charge from NCDB (800-438-9376, 800-854-7013 TTY, or info@nationaldb.org).

Early Interactions: Parent-Professional Perspectives in Early Intervention.

Deborah Chen & Diane M. Klein. Paul H. Brookes Publishing Co., 2007.

This 45-minute-long DVD is designed to prepare current and future professionals to work effectively with young children with disabilities. It includes footage of two young children—Ryan an infant with visual impairment and cerebral palsy, and Michael, a toddler with visual impairment and hearing loss. Cost: \$89.95. Available from Paul H. Brookes, Publishing Co. (www.brookespublishing.co).

New articles

- ◆ Bruce, S. M., Mann, A., Jones, C., & Gavin, M. (2007). Gestures expressed by children who are congenitally deaf-blind: Topography, rate, and function. *Journal of Visual Impairment and Blindness*, 101(10), 637-652.
- ◆ Bruce, S. M., & Vargas, C. (2007). Intentional communication acts expressed by children with severe disabilities in high-rate contexts. *Augmentative and Alternative Communication*, 23(4), 300-311.
- ◆ Janssen, M. J., Riksen-Walraven, J. M., Van Dijk, J. P. M., Ruijsenaars, W. A. J. J. M., & Vlaskamp, C. (2007). Team interaction coach-

ing with educators of adolescents who are deaf-blind: Applying the diagnostic intervention model. *Journal of Visual Impairment and Blindness*, 101(11), 677-689.

- ◆ McKenzie, A. R., & Davidson, R. (2007). The emergent literacy of preschool students who are deaf-blind: A case study. *Journal of Visual Impairment and Blindness*, 101(11), 720-725.
- ◆ Parker, A.T., Davidson, R., & Banda, D. R. (2007). Emerging evidence from single-subject research in the field of deaf-blindness. *Journal of Visual Impairment and Blindness*, 101(11), 690-700.
- ◆ McKenzie, A. R. (2007). The use of learning media assessments with students who are deaf-blind. *Journal of Visual Impairment and Blindness*, 101(10), 587-600.



Announcements

New Personnel Preparation Project at Utah State University

A new personnel preparation program at Utah State University is recruiting students for fall 2008. SEIM, the Sensory Impaired Early Intervention Masters Program, has openings for individuals who wish to work with infants and young children with sensory loss. Student stipends are available that cover tuition and other expenses. Out-of-state students will receive in-state tuition rates. All students accepted into the program are eligible for financial support. For further information, contact Linda Alsop, SKI-HI Institute, Utah State University. Phone: 435-797-5598. E-mail: linda.alsop@usu.edu.

Paraprofessional/Intervener Online Training Program

A preservice online training program in deafblindness is now available through Utah State University. Based on the National Intervener Competencies, the courses are designed to prepare paraprofessionals to work as interveners with children and youth who are deafblind. It can also be useful to teachers, parents, administrators, and adult service providers. For further information, contact Linda Alsop, SKI-HI Institute, Utah State University. Phone: 435-797-5598. E-mail: linda.alsop@usu.edu.

SFSU and CDBS Teacher Training Program in Deaf-Blindness

San Francisco State University has been awarded a four-year personnel preparation grant from the U.S. Department of Education, Office of Special Education Programs. The new program—a partnership between SFSU's Moderate/ Severe Disabilities Credential Program and California Deaf-Blind Services—will prepare teachers to meet the needs of students who are deaf-blind and develop the next generation of leaders in the field of deaf-blindness. Students will be eligible to receive substantial stipends of approximately \$15,000. For more information, contact Dr. Pam Hunt, Professor and Coordinator of the Moderate/Severe Disabilities Credential Program, Department of Special Education, San Francisco State University. Phone: 415-338-7848. E-mail: hunt@sfsu.edu.

National Center on Severe & Sensory Disabilities

The National Center for Low-Incidence Disabilities has changed its name to the National Center on Severe & Sensory Disabilities (NCSSD). The new name emphasizes the needs of children with severe and/or sensory disabilities and the strategies to address those needs. NCSSD embraces the mission of improving the nation's capacity to teach children with severe and sensory disabilities so that these children can realize productive and fulfilling adult lives. Visit NCSSD's newly designed website or read the *Making Waves Newsletter* (www.unco.edu/ncssd/news/news.shtml) to learn more. NCSSD's *2008 Research in the Rockies Summit* is scheduled for the fall in Denver.

AADB Today: A New Electronic Newsletter

AADB Today is a monthly newsletter from the American Association for the Deaf-Blind. Each issue updates readers about AADB, highlights hot topics, and spotlights people in the deaf-blind community. Sign up for this free newsletter at the AADB web site: www.aadb.org.



Conferences and Events

The following list includes only a small number of events that will occur over the next six months. For a complete list, visit the National Consortium on Deaf-Blindness web site (www.nationaldb.org) or call 800-438-9376.

Secondary Transition State Planning Institute:
Building for the Future
May 7–8, 2008
Charlotte, North Carolina

The focus of this institute will be on needs identified through analysis of SPP/APR data, targeting transition-related indicators 1, 2, 13, and 14. It will address states' requests for technical assistance from the National Dropout Prevention Center for Students with Disabilities (NDPC-SD), the National Post-School Outcomes Center (NPSO), and the National Secondary Transition Technical Assistance Center (NSTTAC). Web: www.nsttac.org.

CHARGE Syndrome/Deaf-Blind Weekend
July 11–13, 2008
Kingsport, Tennessee

This conference is sponsored by the Tennessee and South Carolina Deafblind Projects, and presented by David Brown, an internationally recognized expert on CHARGE syndrome and deaf-blindness. David will focus on sensory systems, obsessive-compulsive behavior, self-stimulation, and intervention strategies, and he will be available to answer questions from parents and professionals. For information contact Jennifer Miller at 615-322-7194 or Jennifer.L.Miller@vanderbilt.edu.

Combined Summer Institute in Special
Education
July 14–17, 2008
Yakima, Washington

This conference, sponsored in part by Washington Sensory Disability Services, focuses on families and professionals working with children who are autistic, blind/visually impaired, deaf/hard of hearing, deaf-blind, or multiply disabled. The theme this year is *Communication and Language: Bridge to Success*. For more information contact Jackie Messer at 509-665-2630 or jackiem@ncesd.org. Web: www.ncesd.org/csi/default2008.htm.

Pathways to Possibilities
August 13–15, 2008
Virginia Beach, Virginia

This combined conference is for families and professionals who work with students who are deaf, hard-of-hearing, blind, low vision, deaf-blind, or multi-disabled. It is sponsored in part by the Virginia Project for Children and Youth with Dual Sensory Impairments/Deaf-Blindness. For more information, visit <http://www.vcu.edu/partnership/pathways>.

2008 Helen Keller National Center National
Training Team Seminars
Sands Point, New York

The Helen Keller National Center National Training Team was established to increase knowledge and support the development of skills specific to deaf-blindness. 2008 seminars include:

- ◆ May 19–23, Enhancing Services for Older Adults with Vision and Hearing Loss
- ◆ June 16–20, Professional Development for Employment Training Specialists
- ◆ July 21–25, Interpreting Techniques for the Deaf-Blind Population
- ◆ September 22–26, Person-Centered Approach to Habilitation
- ◆ November 17–21, Adaptive Technology Training

For more information contact the HKNC National Training Team. Phone: 516-944-8900, ext. 233/239. TTY: 516-944-8637. E-mail: ntthknc@aol.com. www.hknc.org/FieldServicesNTTSchedule.htm

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