Transition Planning for Students who are Deafblind

Coaching from Students, Parents and Professionals

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Foreword

It is with great pleasure that we offer this publication, *Transition Planning for Students who are DeafBlind*. Its purpose is to provide information and resources for deafblind students as they plan for or participate in postsecondary education and training. We hope that the use of this publication won't be limited to students and their parents; high school teachers, transition specialists, postsecondary services professionals, rehabilitation counselors, and other related staff also may use this as a tool when working with students as they transition from secondary to postsecondary education and training programs.

We view transition as a collaborative effort among several groups of people who can provide resources and support. Students and their families may find it helpful to work closely with high school faculty and staff, transition specialists, vocational rehabilitation counselors, educational audiologists, orientation and mobility specialists, and other related professionals. We strongly encourage students to visit colleges, universities, and vocational training programs to see where the best "fit" is for them. Meeting with students or consumers at these institutions can provide additional information that can be valuable when making decisions about the future. Other online resources can be very helpful throughout the process as well.

A valuable resource for students who are deafblind is the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC), whose mission it is to **enable each person who is deaf-blind to live and work in his or her community of choice.** Many of the contributors to this publication have provided services for or received services from HKNC staff; this publication would not have been possible without their involvement with HKNC. Authorized by an Act of Congress in 1967, HKNC is a national rehabilitation program serving youth and adults who are deaf-blind. Support services for youth and adults who are deaf-blind, their families, and the professionals who serve them across the country are provided through a system of field services, including regional offices, affiliate programs, and national training programs. The regional center representatives are responsible for assessing the needs of individuals, communities, and states within their regions; developing strategies of collaboration, coordination, and cooperation to help meet those needs; and advocating for those who are deaf-blind in local, state, national, and international forums. Through the affiliate programs, HKNC is able to develop and expand a nationwide network of state and local programs to meet the needs of individuals who are deaf-blind. The

National Training Team (NTT) was established to increase knowledge and support the development of skills specific to deaf-blindness in those working with consumers who are deaf-blind across the country. Additional information about the Helen Keller National Center and its services can be found at www.hknc.org.

As students consider postsecondary options and opportunities, another resource may provide additional information for students, their families, and the professionals who interact with them. In 1996, the U.S. Department of Education, Office of Special Education and Rehabilitative Services funded four regional postsecondary education centers across the United States to serve as a collaborative organization to provide technical assistance to post-secondary educational institutions that enroll individuals who are deaf, hard of hearing, late-deafened, and deafblind. These centers comprise the Postsecondary Education Programs Network (PEPNet). Technical assistance comes in the form of workshops, written materials, conferences, informational guides, and consultations to help such institutions initiate or enhance the accessibility of their programs to this student population. PEPNet works closely with two-and four-year colleges, secondary education programs, vocational training and rehabilitation programs, adult education programs, private and public community service agencies, individuals with hearing loss, consumer and professional organizations, state and national organizations, and clearinghouses. Providing resources and training related to successful transition from secondary to postsecondary education and training is an important goal of this project. Readers are encouraged to contact the nearest PEPNet regional center for assistance. Additional information about PEPNet and the four regional centers can be found at www.pepnet.org.

We are proud of the effort that has gone into developing this publication. The contributors worked in a very creative and collaborative manner to provide as much information as possible. It is our hope that it will be a practical and helpful tool for you.

Marcia Kolvitz, Ph.D., Director; PEPNet-South

The Purpose of This Monograph

Cynthia L. Ingraham

It has been more than half a century since Robert Smithdas became the first deafblind person to obtain a Master's degree. He attended college with the support of a 1:1 attendant and a host of classmates and volunteers who made certain that all his textbooks, many of his assignments and exams were available to him in braille. This accomplishment was thought to be rare and unlikely even though some 50 years prior, Helen Keller had obtained an undergraduate degree with the assistance of Anne Sullivan serving as her 1:1 attendant.

Today, there are a number of deafblind students who are forging their own way through secondary and post-secondary education programs without the support of a 1:1 attendant or seemingly any accommodations beyond preferential seating, materials in alternate format and the occasional interpreter. Unlike Helen Keller and Robert Smithdas, many of these students are often not given a chance to live up to high expectations. Too often, today's deafblind students are misplaced in programs that do not meet their individual support needs and do not challenge them academically. For the very few who are placed within integrated classrooms and provided with access to the same scholarly material as their peers who are not disabled, their access to other areas of the curriculum that focus on developing social skills, independent living and travel skills, and vocational exploration opportunities are limited at best.

This monograph has assembled together student and parent biblioesssays, position papers and reflective commentary from professionals who work with deafblind students. For the students profiled in this monograph, like many deafblind students, access to academic achievement was often met with obstacles due to low expectations, inadequate support services and misgivings concerning the ambiguous characterization of deafblind individuals. The goal of this monograph is to open a dialogue among students, family members and professionals regarding the attested state of education for deafblind students whose academic potential is predicated on how they are viewed within the education system especially and society in general. This sample grouping of bright deafblind students offers a

foundation for evidence based research in the area of curriculum design which recognizes academic potential in all students irrespective of severity of disability or level of support required.

Advances in technology, understanding of cognitive development in children, and civil rights legislation for persons with disabilities have created an environment that is rich with potential for the millions of deafblind children and adults who face academic, vocational and social obstacles on a daily basis. However, legislation can only go so far to address the unconscious bigotries that are held by many in society toward those who think, speak or look differently.

The expectation of this monograph is that just as Helen Keller and Robert Smithdas demonstrated that when given appropriate educational opportunities deafblind students can excel; educators and parents will see that today's deafblind students have the capacity to realize similar success which can in turn have a positive impact on future academic and employment outcomes for the deafblind students of tomorrow. As more stories of intellectually gifted, artistically talented and self-determined deafblind students are revealed, the greater the likelihood that societal attitudes will collimate civil rights legislation resulting in successful academic and employment outcomes for the large majority of deafblind students and not merely a select few.

Chapter One

History of DeafBlindness

"Labels

Are often misleading

They have negative meanings

That makes one

Feel out of the circle

Called Life"

~ Marcia McDermott

(On Being Disabled, 2006)

A Brief History of Services for Deafblind People in the United States

Jerome D. Schein[i]

Enid G. Wolf-Schein[ii]

The history of services for deafblind people in the United States divides sharply between the years before and after the 1964-65 rubella epidemic. Before the epidemic, there were few services; after, many services came into being or existing services were expanded.

This article covers the nineteenth and twentieth centuries, omitting the most recent two or three decades. It does so out of respect for historians' well-supported contention that events' meanings only become clear after the passage of time. Its purview is limited to the United States, even though much information of value to the rehabilitation and education of deafblind people comes from outside this country. These limitations, it is hoped, will sharpen this account's focus.[iii]

Prevalence

As noted, a major factor in the history of services for the deafblind population is its size. From 1870 through 1930, the U. S. Bureau of the Census estimated the deafblind population per 1,000,000 to range from 10, in 1900, to 160, in 1930 (see Table 1). This extreme variability probably arises, in part, from differences in methods used by census takers rather than reflecting actual population characteristics. However, as the 1964-65 rubella epidemic demonstrated, epidemics can radically alter the prevalence of deafblindness, as can migration and changes in population composition, though less dramatically. At least some of the variation in rates, then, may be accounted for by actual fluctuations in prevalence.

Table 1.

Deaf and Deafblind Persons per Million General Population:

Decennial Years 1870 to 1930

Year	Deaf Persons	Deafblind Persons [a]
1870	4200	30
1880	6750	50
1890	6480	40
1900	4920	60
1910	4860	10
1920	4250	20
1930	4650	160

Source: Adapted from data in Best, 1943.
[a] Entries rounded

Even at its highest—with a rate of about 160 per 1,000,000, in 1930—deafblindness in the U. S. was a rare condition. It did not attract much notice until the 1964-65 epidemic added a large number of deafblind children to the population in a brief span of time—an estimated incidence between 1,500 and 2,500. That relatively great increase captured government attention, prompted by parents who demanded assistance for their deafblind children.

The study by Wolf et al. (1982) provided 1980 estimates of the deafblind population. The study divided its estimates into four categories[iv] (Table 2). Defined in broadest terms, the deafblind population in that year was 346 per 100,000. Although this is much greater than 160 per 1,000,000 for 1930, it still represents a small fraction of the general population.[v] For the narrowest definition, the estimate of 20 per 100,000 is 25% larger than the 1930 estimate. However, because of the methodological disparities already noted, direct comparisons of the rates in the two tables should not be over-interpreted.[vi]

Table 2.

Prevalence and Rate per 100,000 of Deafblindness in the Noninstitutionalized,

Civilian Population, by Four Definitions: 1980

Definition	Prevalence	Rate/100,000
All Definitions Combined	743,275	346
Deaf and Blind	41,859	20
Deaf and Severely Visually Impaired	25,481	12
Blind and Severely Hearing Impaired	357,818	169
Severely Visually and Hearing Impaired	309,117	146

Source: Wolf, Delk, & Schein, 1982.

Definitions

Always problematic, definitions of deafblind persons have fluctuated over the years. In 1972, Congress defined a deafblind child as:

> one who has auditory and visual handicaps, the combination of which causes such severe communication and other problems that he cannot properly be accommodated in special education programs for the hearing impaired or for the visually handicapped child (Federal Register, 1972).

Subsequent federal legislation has adopted this definition or a variation of it when addressing education for deafblind children.

The Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) determined eligibility for its services according to the more detailed and, with respect to vision, precise definition:

> Central visual acuity of 20/200 or less in the better eye with corrective lenses or central acuity of 20/20 if there is a field defect such that peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, and a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, and the combination of the

two causes such extreme difficulty for the person to attain independence in activities of daily living, psycho-social adjustment or in the pursuit of a vocational objective (cited in Wolf, 1986).

In determining the size of the deafblind population, Wolf, et al. (1982) recognized the diversity in definitions of deafblindness. Rather than choosing amongst them, they developed four categories of deafblindness that attempted to encapsulate those actually followed in the delivery of services:

Deafblind Narrowly Defined - No usable hearing for speech and no usable vision.

Deaf and Severely Visually Impaired - No usable hearing for speech and defective vision in both eyes or blindness in one eye with the other defective.

Blind and Severely Hard of Hearing - No useful vision and severe hearing loss in both ears.

Severely Vision and Hearing Impaired - Vision as defined in the second category above and hearing as defined in the third category (Wolf-Schein, 1989, paraphrased).

The broader definitions recognized the value of identifying persons who, at one time, might not meet the most rigid definition but who were at risk of losing more vision or hearing and, therefore, would then meet the most extreme criteria. For those planning services and providing their funding, those data can be useful.

Rubella epidemic of 1964-65

Until the 1964-65 rubella epidemic, deafblindness received little public attention. At that time, the American Foundation for the Blind's register of deafblind school children listed a total of 564, only 177 of whom were enrolled in educational programs (Wolf, 1987). That epidemic affected about 30,000 neonates, of which an estimated 2,500 were deafblind (Thompson & Freeman, 1995). Salmon & Rusalem (1966, p. 15) wrote, "It has been conservatively estimated … that there are three thousand deafblind adults in the United States". With a pending influx of nearly three times the in-school population and more than half the total of deafblind adults as a result of the rubella epidemic, it was apparent that heroic measures would be needed to accommodate the sizable increase in the demands for educational and rehabilitation services.

Education[vii]

The first deafblind student cited in the professional literature appeared in 1849 (Woodruff, 1849). For the remainder of that and the following century, no special educational facilities were established specifically for deafblind children. Those who gained an education were accommodated in schools, many of which had no special arrangements for their loss of both hearing and sight.

From 1800 to 1930, what education was available to deafblind children could usually be found in schools for deaf or blind students—if it could be found at all (Best, 1943). Perkins School for the Blind was one of the first to provide education for a deafblind child, and it was the first to establish a special department for the instruction of deafblind children. Occasionally, states provided some education for deafblind students, but most did not.[viii] Even as late as the 1960s, few opportunities were provided for deafblind students, and practically none for those with below-average estimates of their intelligence. As Thompson and Freeman (1995) wrote,

> School-age children with deaf-blindness who functioned below-average intellectually were most often placed in residential schools or 'asylums' where they were typically provided only custodial and life--sustaining services. During this period [1950-1969], personnel trained to instruct children with deaf-blindness were few in number, and opportunities for personnel inservice training and acquaintance with new methodology and teaching materials were very limited (p. 20).

Preparation for teachers of deafblind students was virtually non-existent until the American Foundation for the Blind sponsored programs in 1949, 1950 and 1951. These early efforts, however, did not stimulate continued interest among established programs preparing teachers of deaf and of blind children (Salmon & Rusalem, 1966).

The federal government became involved in special education when Congress passed the Elementary and Secondary Education Act of 1965. This law, however, did not expressly provide for deafblind students. The Congress initiated its first legislation specifically for deafblind students in 1967, when P. L. 90-247 established the Centers and Services for Deaf-Blind Children Program.

Congress expanded the program to provide research and personnel by passage of P.L. 91-230, in 1970. It established regional centers to identify deafblind students and to create programs, design curriculums, and prepare personnel to educate them.

In 1975, Congress enacted The Education for All Handicapped Children Act (P. L. 94-142). This remarkable law recognized states' primacy in education but required them to

provide it for all children with disabilities. In so doing, it made education a civil right, putting into effect what the courts had been ruling; e.g., that as long as states provided free education for some of their citizens, they must provide it for all. Congress subsequently enacted amendments clarifying and expanding existing legislation, but none so far-reaching as the provisions of 94-142. Congress's subsequent actions have given assurance that its positive attitude toward services for deafblind people will continue, at least in the near future.

Rehabilitation

Federal legislation establishing vocational rehabilitation was first passed in 1916. Called The National Defense Act, it recognized for the first time the nation's obligation to disabled veterans. It was a tentative venture, providing training only for wounded soldiers. This small first step was followed, in 1920, with an expansion of services to include nonmilitary persons. Although successive legislation slowly increased the range of persons covered, the services remained limited to job training and placement. In 1954, the amendments grew to address the need for qualified personnel by offering training grants.

State and local rehabilitation programs, like educational ones, were few and scattered throughout the country before 1964. One of the most outstanding was the Industrial Home for the Blind (IHB), in Brooklyn, New York. In 1917, IHB undertook the rehabilitation of deafblind adults (Salmon & Rusalem, 1966). In the next years, IHB obtained grants from the then-Vocational Rehabilitation Administration (VRA) to serve the increasing numbers of deafblind adults seeking its services.[ix]

Plans to expand regionally the model exemplified by IHB were put forward in 1958, but even with VRA' s encouragement they failed:
"Consequently, when 1962 dawned, the IHB remained the only agency for the blind in the United States with formally organized services for deaf-blind adults" (Salmon & Rusalem, 1966, p. 24).

The 1967 Vocational Rehabilitation Act Amendments authorized establishment of the National Center for Deaf-Blind Youth and Adults (HKNC)—a much-needed rehabilitation facility. This marked the first recognition of deafblindness by the federal government. Previously, deafblind people were considered infeasible for vocational rehabilitation.

This giant step forward was followed, in 1973 and 1978, with further shifts in the federal government's attitude toward persons with disabilities. First, the title of the legislation changed by dropping 'vocational' from its name. The Rehabilitation Services Administration, which replaced VRA, received a mandate from Congress to shift from

economic to social considerations. The legislation provided for independent living services, lifted age restrictions, and broadened to encompass telecommunications and recreation. However, these advances were marred by Congress's failure to appropriate sufficient funds to cover all these services, leading to the observation that "these laws show that congressional attitudes had advanced, even if its fiscal policies had not caught up with its social ambitions" (Schein, 1985, p. 352).

Personages

People make history, so an account that does not highlight at least some of those who were prominent in their days would miss much. For the roles played by deafblind persons, the early days might better be referred to as *her*story than history. Three young ladies are prominent in the Nineteenth Century accounts of education.

One of the first deafblind students cited in the literature was Julia Brace, a pupil at the American Asylum for the Deaf (subsequently the American School for the Deaf) who enrolled in 1824. Her biographer wrote:

She is the earliest case of any note in our own country, being now 41 years of age; and having resided in the institution for a period of twenty-seven years, is now as she has always been, an object of great interest to those who visit it (Woodruff, 1849, p. 65).

Ms. Brace did not receive the attention that Laura Bridgman did a few years later. Ms. Bridgman's fame is largely due to Charles Dickens, who immortalized her in his account of his tour of the United States (Dickens, 1868). He met her when he visited the Perkins Institute for the Blind and was charmed by her and by the potential that she demonstrated for educating persons who lacked vision and hearing. Perkins' superintendent, Samuel Gridley Howe, had accepted her in order to test his theories about education. He deemed her education a success. Though Howe's assessment was probably valid at the time, Ms. Bridgman, like Ms. Brace, remained at her school her entire life. Neither achieved more than a modicum of independence, so their educations would not be regarded as successful today (Schein, 1983).

By contrast, Helen Keller achieved substantial independence, despite her deafblindness. Born in 1880, she lost her vision and hearing as a result of illnesses suffered in her nineteenth month. Her education by Annie Sullivan has been immortalized in books, movies, and a stage play. Ms. Keller attended Perkins, where she met Laura Bridgman. Ms. Keller attended two other schools, one in New York and the other in Cambridge, to prepare herself for college. She graduated from Radcliffe, in 1904, *cum laude* (Schein 1988).

After college, Ms Keller authored several books, scripted a movie and played herself in it,[x] performed in vaudeville, and became a fund-raiser for the American Foundation for the Blind. She was, undoubtedly, the most famous deafblind person in the world, earning awards from a number of countries including her own. Her highly successful education and her magnificent career improved public attitudes toward deafblind persons. They may also have aroused some unjustified expectations for other deafblind children—something for which she cannot be blamed. It should also be noted that hers was not a completely fairy-tale life; she suffered frustrations and occasional loneliness. Nonetheless, "Without exception, those who knew her found most impressive her unfailing enthusiasm for life" (Schein, 1988, p.318).

A history of services to deafblind persons in the United States, no matter how brief, cannot overlook two men: Peter J. Salmon and Robert Smithdas. Both were associated with the IHB. Salmon began his career there in 1917. Not deafblind himself, he took several positions in the agency, eventually becoming its director. His lobbying on behalf of deafblind people is legendary (Hunt, 1966). The founding of HKNC crowned his six-decade efforts.

Dr. Smithdas replaced Helen Keller as the United States' most famous and, certainly, most accomplished deafblind person. He earned a bachelor's and a master's degree, directed educational services—first at IHB and later at HKNC—and wrote several books, while leading an active social life. He is a worthy successor to Ms. Keller.[xi]

Most of the biographies and autobiographies of deafblind persons emphasize their accomplishments. Implicitly, these accounts mean to counter professional and the public attitudes of hopelessness. Their authors have strongly supported education and rehabilitation of deafblind persons, mostly with pragmatic rationales.

If History Predicts the Future

Historians wisely eschew attempts to characterize the present and never to predict the future. They recognize the need to gain the perspective from elapsed time. So we close this account in full recognition that the education and rehabilitation of deafblind persons will continue to change. Innovations in diagnosis and treatment, devices like cochlear implants, developments like the Internet, and the actions by state and federal legislatures will doubtless positively influence the future for deafblind persons.

However, attitudes toward persons with disabilities, generally, and deafblind persons, in particular, may shift. Discussing dissatisfaction with legislation extending benefits to disabled people, an editorial in the influential New York Times wrote:

The problem is that our resources are finite and therefore limited. But the needs and desires for 'free' social services—that is, Government-financed education, health care, welfare aid to the handicapped and all the rest—are potentially infinite. They cannot all be met and therefore we must work out principles on how to spread our inadequate resources as best we can, to ration them among the many and diverse claimants (Schwartz, 1982, p. A21).

To counter this argument one need not disagree that society's resources are limited. Rather, one can argue that the relatively tiny amount of the federal budget allocated to services for persons with disabilities pales in comparison to expenditures for military hardware. Attacks on services for persons with disabilities obviously reflect a distorted view of priorities. When these attacks arise, some history should aid those who wish to counter them.

In 1864, in the midst of the Civil War and with the opposing forces battling within sight of the Capitol, Congress founded Gallaudet College, an institution of higher education for deaf students. The very idea of educating deaf children had not been completely accepted let alone providing them with higher education. Yet the Congress did just that: it put into place a service for a group with disabilities alongside of provisions for the survival of the republic. That gesture did not imperil the nation; to the contrary, it increased its strength. Gallaudet University today stands as a vibrant symbol of a nation's enduring values.

Summary

The history of services for deafblind persons in the United States prior to 1964-65 was dominated by two facts: deafblind people were rare and providing for their education and rehabilitation strained most service providers' capabilities. The former fact often made them nearly invisible to government and nongovernmental agencies and the latter frustrated well-intentioned efforts to serve them. The deafblind population grew dramatically after 1964--65, but its relative size and the difficulties in serving them have not abated. Service providers and deafblind people can look forward to advances in devices and techniques to ease the service burdens, but they need to remain vigilant to views that disparage attempts to educate and rehabilitate them.

Before 1964-65, state and local governments provided services only sporadically. Two nongovernmental agencies—Perkins Institute for the Blind and IHB—stand out among the handful that did offer services to deafblind persons. Aside from the paucity of services was the lack of qualified service providers.

Following the 1964-65 rubella epidemics, Congress enacted legislation greatly expanding services for deafblind people. Through 1974, when it passed the Education of All Handicapped Children Act, Congress increasingly directed educational services meaningful to deafblind students. It also gave more attention to deafblind adults with programs that sought to improve their economic and social lives. Subsequent actions by the state and federal governments suggest that, in the near future, governments will not abandon its support for the education and rehabilitation of deafblind persons.

Endnotes

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[ii] Dr. Wolf-Schein is Adjunct Professor of Education, University of Alberta, Canada. She is also a Fellow of the American Speech-Language Hearing Association.

[iii] A further narrowing of scope is lack of concentration on specific problems associated with deafblindness: communication, mobility, social relations, recreation, etc. These matters will be covered in other sections of this volume, so their presence here would be redundant.

[iv] For the detailed explanations of the four categories into which Wolf et al. divided their estimates, see "Definitions" below or refer to the original study.

[v] The 1870-1930 data were derived from general-population enumerations, and the instructions given to the census takers in classifying individuals as deaf and deafblind are unavailable. The 1930 estimates derived from general-population censuses, in which identifying deafblind persons was not emphasized, while the 1980 study was a part of a special National Health Survey on hearing loss. As a consequence, more instances of deafblindness were likely missed and population sizes underestimated in 1930 than in1980.

[vi] The 1980 estimates are for the noninstitutionalized population. For information about the numbers of deafblind persons in institutions, see Wolf-Schein, 1989.

[vii] Readers desiring more detail about the education of deafblind children should refer to Farrell (1956) and Wolf (1987).

[viii] Among those states that enrolled deafblind students were Alabama, California, Massachusetts, Michigan, and Connecticut.

[ix] Of interest to feminists, not until 1958 did IHB expand services to include deafblind women (Salmon & Rusalem, 1966, p. 24).

[x] The movie won critical acclaim, but was not financially successful.

[xi] For more early biographies, see Rocheleau and Mack (1930) and Tabak (2006). For later accounts, see Salmon and Rusalem (1966).

Chapter Two
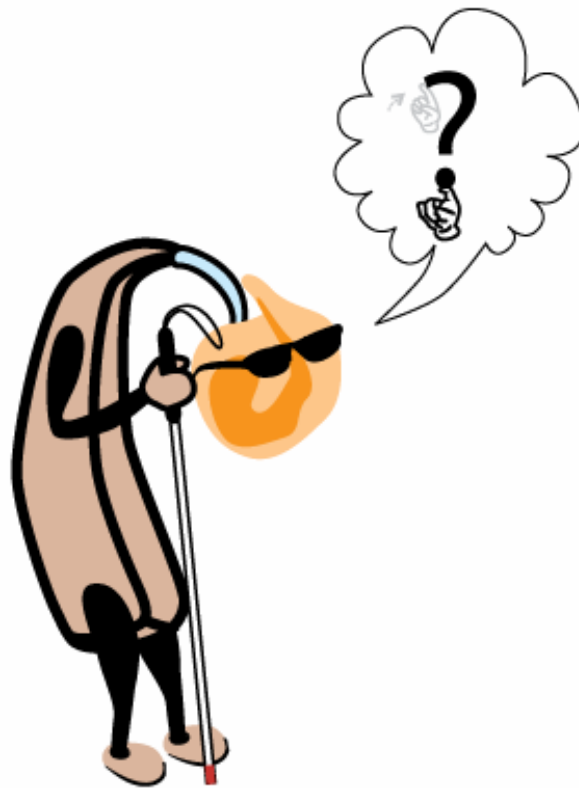
What Does It Mean to be DeafBlind – Really?

Cynthia L. Ingraham

Much has already been said about the diverse makeup of the population of consumers who are deafblind; however, what remains unclear for many service providers, educators, family members, and VR counselors specifically is who are the people that meet the criteria to be included amongst the ranks of the deafblind population (Ingraham, Carey, Vernon, & Berry, 1994). The recent change to the coding system for deafblindness used within the Rehabilitation Services Administration (RSA) has created some confusion regarding the specific *identity* of the average deafblind consumer. This brief chapter will attempt to clarify the term "deafblind" and aid professionals, family members and students in understanding its use and benefit.

As was noted in the first chapter of this monograph, the term deafblind is comprised of four different categories of individuals.(See Table I) Many professionals may operate with the misconception that an individual with whom a verbal dialogue is possible or who utilizes his/her vision for reading and traversing the community could not possibly be considered deafblind. On the contrary, according to the federal definition, many individuals who are recognized as deafblind retain very usable vision and hearing; and to the average person may **appear** to have no obvious limitations. It is for this reason that a more functional explanation of the term "deafblind" will be discussed here.

Notwithstanding, the four categories of deafblindness have greatly helped to more succinctly define the population; however, these categories might seem, to the untrained professional, to be too inclusive and broad. If one keeps in the mind the basic definition of the term there would be less opportunity for confusion and mislabeling of students. Simply defined, deafblind means the co-existence of a significant vision and hearing loss which impacts an individual's ability to function in areas of daily life including, but not limited to: communication, education, employment and ability to access basic community resources (Adler, 1987).

The individual who is born without any usable vision or hearing is often who comes to mind when we think of persons who are deafblind. While rare, it is not uncommon for a person, as a result of maternal illness, gestational trauma or birthing complications, to be born without the ability to see or hear anything at all. With early and proper education, these individuals can grow up to lead very satisfying and productive lives. Specialized training, adaptive equipment, and personal motivation have enabled many such individuals

to not only thrive, but to fall in love, marry and raise their own families as well. While functioning with total independence may be a challenge for this group of students, as would be for any person, support services from community based service programs, religious institutions, volunteer organizations, friends, families, and even paid staff can afford these students full access to the community. Like Helen Keller, many deafblind students find attending academic programs more achievable with the support of a *companion* or *Intervenor* (a term that has become more widely recognized in education). This refers to an individual who essentially functions as the eyes and ears for the deafblind student. More specifically, the Intervenor provides the deafblind student with access to information which he is unable to hear, see, or otherwise gather on his own (Olson, 2004).

Some of the stories profiled in this monograph will resemble the stereotypical image that comes to mind when the term deafblind is used.

Table 1

Categories of DeafBlindness	Common Etiologies	Personal Adjustment Support	Orientation and Mobility Needs	Independent Living Skills Training	Communication Needs
Congenitally DeafBlind	Congenital Rubella Syndrome, CMV, Premature Births, etc.	Early intervention services for student and family members.	Early intervention services for student and family members.	Early intervention services for student and family members.	Early intervention services for student and family members. Touch cues, object cues and manual communication.
Congenital Deafness and Acquired Blindness	Heredity, Usher Syndrome, Alstrom Syndrome, Alport Syndrome, Trauma, illness, accident, advanced	Personal and vocational adjustment to blindness training.	Orientation and mobility training using techniques, devices and specialized transportation services.	Training in cooking, cleaning, labeling, eating and grooming skills required for independence.	Alternative forms of receptive and expressive communication including, English, braille, tactile sign language, tactile fingerspelling, Print on Palm, adaptive face to face,

	age, etc.				telecommunication and Internet access technology.
Congenital Blindness and Acquired Deafness	Illness, trauma, accident, heredity, medical complications, advanced age, etc.	Personal and vocational adjustment to deafness training.	Adaptive technology devices to compensate for hearing loss, including: assistive listening devices, digital hearing aids, Cochlear Implants, adaptive mobility aids and specialized training by O&M instructor familiar with the unique mobility needs of deafblind students.	Adaptive technology and techniques for food shopping, safe food preparation, cooking, clean-up, home repairs and labeling food containers.	Alternative communication systems, devices, techniques for receptive and possibly expressive communication, including tactile sign language, tactile fingerspelling and finger braille.
Acquired Deafness and Blindness		Personal, vocational and mental health counseling to	Adaptive technology devices to compensate for hearing		Alternative forms of expressive and receptive communication, including tactile

| | | address adjustment to deafblindness. | and vision loss, including: assistive listening devices, digital hearing aids, Cochlear Implants, adaptive mobility aids and specialized training by O&M instructor familiar with the unique mobility needs of deafblind students; braille instruction, | | sign language or tactile fingerspelling, braille, Print on Palm, adaptive communication devices and software for magnification, speech output and print translation. |

However, there are additional stories of successful students that may change the opinions of those who have previously believed/thought that deafblindness was a rarity or a phenomenon.

The scenarios below are meant to provoke thought and to give a more clear understanding of the wide-ranging degrees of deafblindness.

Scenario A

Any deaf or hard of hearing person preparing a meal which required fresh onions has experienced the effects that dicing an onion can have on one's ability to see. The deaf

person may tell you that he has experienced what it's like to be temporarily deafblind. Once the fumes from the onion make contact with the tear fluid of the eyes, excessive secretions will follow, resulting in temporary loss of visual acuity. For a person who is deaf, this loss of visual acuity has instantaneously impeded any ability to receive information through the modality normally preferred by deaf individuals. Even though the individual may still have the ability to see some things, images are so distorted and blurred that the result is what is medically termed *legal blindness*. The individual can see well enough to maneuver to the sink to wash out his eyes; however, functioning with this degree of vision loss on a daily basis would require a great deal of "personal adjustment" training. Personal adjustment training not only includes learning how to accept this change in vision and possibly fluctuating vision, but also include training in adaptations or modifications to daily activities. For example, locating the vegetables from the refrigerator would not only require knowledge of the kitchen's layout, but the person would have to know where the vegetables were stored inside the refrigerator. If the vegetables require peeling, more training would be needed to know which utensil is the safest for the chore. How will the person know if all the skin has been removed from the vegetable? What is the least messy way to mix dry or wet ingredients? If cooking is required, will the microwave or stove top be used? How will the person know to set the cook time for the microwave? How can he cook on the stove without getting burned? What about setting the table and cleaning up afterwards? How will the individual store the leftovers? Who will clean the dishes and the prep area? As the person prepares for the next day, how will he know which clothes to select and if the selected items are color-coordinated? If the person wanted to chat with a friend on-line, how would he connect to the Internet?

From this simple scenario of an individual who is already deaf experiencing extremely blurry vision, you have witnessed a type of deafblindness. The individual retained some useable vision; however, the vision which remained was so impaired that personal adjustment to blindness training would be required to perform very basic daily activities.

Scenario B

Likewise, if a person who is already blind attends a loud rock concert and is seated close to the speakers, he/she may experience temporary hearing loss during the concert and for some time following. The buzzing and ringing in the ears may impede the ability to have normal conversations with friends and loved ones. This individual may be required to use braille or the less appropriate shouting for receptive communication until such time that the

hearing becomes more reliable. If the ringing in the ear stops and the person discovers that it is no longer possible to hear speech spoken at a normal conversational level, the use of some type of assistive listening device may be required. Also as a result of this newly acquired hearing loss, when this person with congenital blindness and acquired deafness leaves home to attend school, it may be observed that his previous ability to accurately locate traffic sounds and other environmental noises is no longer reliable. Once in the classroom, the individual may be unable to hear the instructor even after having his seat moved closer to the front of the classroom. Talking on a cell phone may also become difficult as a result of this newly-acquired hearing loss. Dining out with friends may be nearly impossible due to the loud voices of the other restaurant patrons and wait staff. How would this person address these new impediments to independence? What other types of reliable and more efficient means of receptive communication should the individual consider? What types of adaptive technologies are available to help a student in a situation such as this to get around in the community? How will the student be able to continue with education? As was seen in the previous example, personal adjustment training will be needed. This specialized training will include exposure to alternative forms of receptive communication and possible training in the use of assistive listening devices.

Scenario C

Another type of functional limitation to consider would be associated with a person who is the unfortunate victim of a traumatic event (i.e., explosion, gun shot, or serious illness). To be more specific, let's say the individual is involved in an automobile accident. The person who is a passenger in the front seat of the automobile is thrown into the windshield when the driver loses control of the vehicle on an icy surface. The lacerations and head trauma result in damage to the seventh and eighth cranial nerves. The person becomes deafblind in an instant. Once a vibrant and curious student, the individual is now unable to hear or see anything. As the wounds and lacerations are attended to in the hospital emergency room, the individual can sense the presence of others. However, he is unable to hear what is being said and can not see what activities are taking place. How will this person know what comes next? How will the individual locate the restroom? How will this person feed himself? How will the hospital staff communicate with this person? Will this individual be able to return to a life of independence? What type of work will this individual be able to perform now? Again, personal adjustment training will be required to enable the student to regain his independence and ability to access his community.

Each of these brief scenarios describe individuals who once may or may not have been considered deafblind – but are now faced with the reality of combined vision and hearing loss and the need for personal adjustment training to deafblindness to identify and introduce any viable alternate forms of receptive and possibly expressive communication to address their individual needs. Normal activities of preparing a meal, accessing the community, and working, interacting with friends, or attending school have been greatly affected by the inability to see or hear clearly. These scenarios *are* examples of a few realities of deafblindness.

In addition, deafblind students include individuals who are born deaf and slowly lose their vision due to Usher Syndrome, as well as individuals who were born during the Rubella epidemic of the 1960s with complete loss of both vision and hearing. Even students with neurofibromatosis have been identified within the deafblind population. Using the term deafblind in the first two scenarios implies that the individual, after acquiring a secondary sensory loss, will require some degree of personal adjustment training. Access to adaptive communication methods, assistive technology, specialized employment adaptations, education and maybe even mental health counseling are invaluable tools to help the individual identify coping strategies that can aid him with his personal adjustment (Miner, 1996; Vernon and Annala, 1982). Also, it will be essential for this person to learn how to cope with frustrations, depression, and isolation often encountered when trying to function independently within a society that is not readily accessible. Any professional who has experience working with a student facing a similar reality of acquired deafblindness should immediately consider the student's training needs relative to personal adjustment training and possible therapeutic counseling.

Although this monograph targets the needs of students and young adults of transition age, in actuality the fastest growing segment of the deafblind population are individuals who make up the Baby Boomer generation and children of the Great Depression. The risk of age-related vision and hearing loss is increased in these two groups of consumers. In the year 2006, it was estimated that every day 8,000 individuals reached the age of 60 (US Department of the Census). Every new day brought another 8,000 potential members to the population of the deafblind who may require personal adjustment training as well. This is due in part to Baby Boomer's history of spending long hours over many decades sun-bathing, which has now been linked to macular degeneration later in life (Macular Degeneration Association). This fact coupled with prolonged exposure to loud music at rock concerts and the use of headphones for personal stereos, have resulted in

auditory nerve damage and permanent hearing loss for many Boomers. It is ironic that this group of aging consumers who, as they transition to retirement or continue working beyond the age of 70, will be in great need of the identical support services, adaptive communication methods, and assistive technology used by transition-aged high school students profiled in this monograph.

Nonetheless, the particular area of transition that will be focused upon in this monograph *is* specific to persons who are young adults; yet the relevance for younger school age children and aging Baby Boomers will become obvious as you read through the various chapters and student biographical essays. Personal adjustment training including self identification, self awareness, specialized support services, and early preparation have been proven to appreciably enhance the quality of life outcomes for students and individuals of all ages who are coping with the reality of impaired vision and hearing.

Chapter Three

Aids and Accommodations for DeafBlind Students: Recommendations for High School Students Who Are Preparing for College and Work

Anindya Bhattacharyya
Aaron Spears

Introduction

The steadily increasing numbers of students who are deafblind in regular secondary and college classrooms have always created an accommodation challenge for the education system. Students who are deafblind, while few in number compared to their "non-disabled" peers, represent one of the more tricky populations for educators when providing classroom accommodations. However, in this new are of technology, deafblind students have access to a whole array of assistive technology and wireless mechanisms that can improve their access to educational materials and enhance their ability to communicate with school personnel and their peers.

For deafblind students attending high school or college, the need for access to a large volume of printed material is a definite reality. One clear difference between high school and post-secondary education is not so much the volume, but the complexity of information that must be comprehended. For bright students who may have been able to survive high school programs receiving only a fraction of the information presented by the classroom teacher, receiving the same quantity of complex information at the post-secondary level can be catastrophic. Effectively utilizing today's technology can increase a student's ability to receive, in a timely manner, all of the information presented or made available to other students. This eliminates the possibility of merely getting by, and provides the student with the opportunity to truly excel. Systems of communication that may have been effective with teachers and students at the secondary level may have to be adapted through the use of assistive technology once the student moves to the post-secondary level.

Where to Begin?

The population of deafblind students is so diverse, with each student possessing individual abilities and experiences. The magnitude of sensory loss differs from one person to the next, ranging from complete loss to mild functional disabilities. Also, some deafblind students may have additional physical limitations (i.e., decreased tactile sensitivity or poor

muscular coordination) that require special adjustments in order to use assistive technology efficiently.

Before any equipment can be provided it is important that the deafblind student have an awareness of their personal needs, preferences, and skills. Any opportunity to work with and obtain assessments on a variety of equipment while in high school is ideal for deafblind students who are considering post-secondary education or employment. For the evaluator, the focus should be on the skills and abilities that the student possesses. With regard to accessing technology, the three major abilities that an evaluator would need to consider are: 1) residual vision; 2) aural speech discrimination; and 3) the ability to read Braille. Depending on the skills that the student has, a particular device may or may not be practical. Many of the adaptive technology devices used by deafblind students can be quite expensive. As a result, numerous education programs and service agencies are hesitant about purchasing a specific piece of equipment for students who have progressive losses until such time that the equipment becomes an absolute necessity. However, it is highly recommended that students use any abilities they have while preparing for any anticipated losses related to a doctor's prognosis.

Using multiple sensory inputs to access technology can reduce potentially frustrating situations. In the area of assistive technology, "redundancy" is a term that best describes using multiple means of access. An example of redundancy related to this chapter would be when a student simultaneously uses limited hearing ability to listen to computer-generated

Anindya "Bapin" Bhattacharyya works with a student on computer access using braille at the Helen Keller National Center.

speech output, while also using his/her vision to read the same text (in Special Education this process is known as multi-sensory input). When the educational material, assignments, or class notes that the student can access with one sense is unclear, another sense can be used to clarify the message. Historically, the refusal by administrators and service providers to purchase equipment that enable students to exercise redundancy in the learning environment has resulted in otherwise bright and capable students entering secondary and post-secondary programs with a number of educational gaps. Once equipment is identified, the student should be kept apprised of any updates in technology and given a chance to see if updated models would work more effectively. The student should always be consulted to determine what specific tech support he currently requires or has received in the past.

Self-identifying as a deafblind person with precise needs is probably the single most critical factor of success if the student wishes to obtain support from an educational or community service program. However, it is not uncommon for students to lack complete knowledge of the plethora of support services and devices available. Notwithstanding, speaking with the student directly should be the first step when deciding upon any communication or accessibility equipment. And by all means, contact with local and national technology resource personnel is highly recommended.

Types of Equipment

[Because there is a wide variety of equipment available, and given that technology is always advancing and manufacturers are continuously updating their products, please refer to the resource section of this monograph to obtain specific product information and manufacturers.]

The equipment listed will be categorized in order of its primary use. However, many devices can be used in a multitude of ways. Users of assistive technology are always devising creative ways to use their devices.

Telephone Access

The telephone was one of the first forms of technology to be adapted for students with communication needs. For a student who is unable to discriminate speech over the telephone, a TTY can be used to converse with others. Many college campuses have TTY units available for all students to access. However, if a deafblind student requires a special attachment for the TTY that enlarges the font, a separate unit called the TTY with Low Vision Display (TTY-LV) should be made available for use in the dorm room or Office for Students with Disabilities should be requested. During a TTY-LV conversation, both communicators must have a TTY, and each person alternates typing messages back-and-forth to one another. For some deafblind students, the speed at which a person types can affect whether information is received clearly. For deafblind students who have restricted visual fields or whose visual acuity is poor, rapid TTY conversations are of no use. However, it is the responsibility of the student to request that the individual with whom they are speaking type slowly and pause in between words. Some students may also want to limit the volume of text received during a single exchange. For example, a student may begin a TTY conversation by stating, "I have limited vision and need you to type each word slowly and pause for two seconds after each word. Please only type four short sentences at a time. Thank you." Since some TTY users may want to communicate with non-TTY users,

the relay service can also be used. Again, it is the deafblind student's responsibility to alert the communication assistant (operator) that, due to vision loss, typing should be slow and exchanges brief. When the non-TTY user speaks, the communication assistant will type what is said to the TTY user and may have to remind the speaker to slow down so that information can be delivered at the pace and in the manner the student has requested. For deafblind students who are unable to see the TTY screen, another modification can be to add a Braille display so that a person using the TTY can also access what the other person has typed. The TTY with an interfacing Braille display allows a person who is unable to reliably access either visual or auditory information to use the telephone. A few relay services, including AT&T, have special numbers designated for deafblind users who cannot read incoming messages at normal typing speed. These operators are trained to type slower and make any necessary accommodations to meet the needs of deafblind callers.

Internet Protocol (IP) Phone Access

Fortunately, deafblind students can use computers and Braille notetakers to make phone calls via the Internet. There are three ways to accomplish this: 1) via a website; 2) via an instant messaging program; and 3) via stand-alone software programs called NexTalk Text Service (NTS) and MyTTY.

These programs take a matter of seconds to install onto the computer and, once installed, the student can launch the program and get started in no time. An information screen with three options (text call, relay call, and send a message) will be displayed. The "text call" option allows the student to make a direct TTY call to another person with a TTY device. The "relay call" option allows the student to connect to a relay service communication assistant (operator) and the system will then work the same way as when using a regular TTY. Finally, "send a message" enables the student to send a message to another NTS user who is either online or offline.

Aside from these two software programs, the second option is via an instant messaging program. At this time, America Online (AOL) Instant Messenger (AIM) serves as a telecommunications mechanism for placing relay calls to any standard phone in the United States. Unlike traditional phone communications, AIM does not enable the student to make direct calls to other parties with TTY devices nor to manipulate real-time data transmissions via relay calls.

Aaron Spears works on his PacMate (Freedom Scientific) notetaker at his home.

Currently, four relay service providers offer a text-based AIM Relay Service. For each provider, the user adds a screen name to the AIM buddy list; after clicking on it, a help screen will appear and give instructions about how to place a relay call. The AIM screen name for MCI's IP-Relay is MyIPRelay; ThatsHamilton is the screen name for Hamilton Relay Service; SprintIP is the screen name for Sprint Relay Service; and SIPRelay is the screen name for Sorenson Relay Service. DeafBlind students can simply add the screen names to their buddy list and then make TTY relay calls over the Internet.

Lastly, while not very accessible, a student can opt to conduct TTY and relay calls via the NTS website (www.nextalk.net), as well as on all websites for the providers mentioned above. For deafblind students who use Braille displays, this method is not recommended because these websites use either Flash or Java web-based technologies, or both, to enable real-time data transmissions. These web-based technologies are not compatible with Braille displays.

Video Relay Service (VRS) and Video Phone (VP)

Throughout the years, sign language interpreters have been a vital link in terms of facilitating

Laptop computer with web cam.

communication between deaf, hard of hearing, and deafblind individuals and the general public. Today, sign language interpreters at telecommunication relay services (TRS) are available to users who have enough usable vision such that the interpreter can be seen via the television or monitor screens. In 2000, the Federal Communications Commission (FCC) adapted the definition of relay to include video relay services (VRS). Users of VRS must have equipment, known as a video phone (VP), which allows them to send their image to the relay center. Once connected, a deafblind caller can simply sign a message to the sign language interpreter, who then conveys the message to the person receiving the call. That person, in turn, can reply and the interpreter will then transmit the message in sign language back to the deafblind caller. It is imperative for interpreters and persons communicating with a deafblind person via VP to make sure signs are not made so large that the student with restricted visual fields is unable to receive the full message. Staying within the video frame and using a signing plane that offers contrast with the interpreter's skin tone is very important. Also, the overall background lighting and clutter should be assessed to ensure the deafblind student has access to a communication environment that offers few distractions.

It is important to note the difference between VRI (video remote interpreting) and VRS (video relay service). Video remote interpreting uses video–conferencing equipment to provide sign language interpreting services. In a typical VRI environment, both deafblind and hearing individuals are in the same room but the interpreter is in a remote location. By contrast, Video relay service provides sign language interpretation for voice telephone calls. With VRS, the deafblind and hearing individuals are in different locations and are linked through an interpreter provided through the TRS.

While both VRI and VRS depend upon a telecommunications link, VRS is used

Video phone camera.

specifically to indicate the service provided through TRS and therefore should not be confused with VRI.

DeafBlind students with usable vision can use video phones for direct communication with one another without going through a VRS interpreter. However, for students who are fully deafblind, there are several options using an Internet-based chat program with a webcam which will enable the student to use sign language to converse expressively with the other party and then receive responses on a computer with a Braille display. While MSN Messenger and AOL Instant Messenger are used with webcams, incoming responses come in after the other party has

BrailleSense braille notetaker from GW Micro, Inc.

finished typing rather than in a real time manner. Sorenson VRS' Ensemble SL software allows a deafblind student to see incoming responses in real-time, and the video quality is clearer than that which appears on a video phone when the deafblind student signs back to the other party. Ensemble SL is free to download; however, the student will need to purchase a specific webcam listed on Sorenson's list of supported webcams.

Face-to-Face Communication

Screen Braille Communicator II (SBC II).

In addition to facilitating long distance communication, technology can help a deafblind student to communicate face-to-face with another person with whom they do not share a common mode of communication. For example, a deafblind person who relies on tactile sign language may attempt to communicate with a person who does not know sign language. The face-to-face communication device would serve as a link between the two individuals.

If the deafblind student's preferred modes of communication are Braille and tactile sign language, and the other person does not know Braille or sign language, the two have incompatible communication modes. However, this does not mean that these two individuals cannot communicate with one another. Face-to-face communication aids can act as interpreters, or communication translators, enabling these two people to communicate directly with one another.

There are several different types of equipment that can serve as the link between these two individuals. These include print-Braille, Braille-voice, and print-voice. In addition, the use of enlarged or magnified text also allows individuals with poor visual acuity to use this form of communication. Presently, there is research in the area of tactile sign-print conversion, but as of now there are no commercially-available models.

With the extensive use of wireless products today, a deafblind person can now use a Braille notetaker with Bluetooth capability and basically use any Bluetooth-enabled personal digital assistant (PDA) to launch a face-to-face communication system. There is no need to worry about having to use a cable to connect the Braille notetaker to the PDA. Using Bluetooth-enabled technology, the two devices can communicate together wirelessly up to a distance of 30 feet. When accessing this type of wireless communication, the Bluetooth technology allows the deafblind student and another party to sit anywhere in the same

classroom and have a conversation. In addition, the deafblind student can also converse with another deafblind or blind student running their own notetaker units wirelessly within the required 30 feet radius.

Print Access

DeafBlind students can also use technology to access printed information. Two devices are available that enable a deafblind student to access printed information. For students with residual vision, there is the video magnifier (formerly called CCTV or closed-circuit television); a second method would be a scanner with optical character recognition (OCR) capabilities.

The video magnifier consists of a video camera which points down toward a piece of paper, or whatever the student wants to view. The image from the video camera is then enlarged and displayed on a TV screen. A typical video

Portable video magnifier

magnifier unit packages the video camera and the TV monitor all in one case. Some variations of typical video magnifiers include portable models and video magnifiers that can interface with a computer monitor. The image from a video magnifier can usually be modified by inverting the screen colors or changing the level of contrast.

A scanner that has OCR equipped with voice or Braille output is another effective way to access printed material. The scanner takes a digitized picture of a printed page; then from the digital image, the OCR software identifies every letter of print based on its shape. The software then converts the information into a computerized format which can either be accessed through a computer or presented in the student's preferred format (voice, Braille, enlarged text).

Global Positioning System (GPS)

In the past, deafblind students were accustomed to accessing the community using a cane or a dog guide and not always having knowledge of their surroundings, i.e., what businesses, municipal buildings, or other establishments were along the route. This was even more troubling when the deafblind student arrived on a college campus and was required to travel in a new environment far away from his or her home. The same was true when a deafblind student traveled via taxi and the driver was unable to inform the student about their surroundings. Additionally, audio or video information shared with sighted or hearing passengers on buses/trains that is not accessible to the deafblind student, has also

been cited as impediments to independent travel. Using the GPS, the deafblind student can obtain a list of all bus and train stops within a designated area, much the same way Internet maps work for sighted drivers. The device works by having the deafblind student say, "I'm going to such-and-such a place," and the GPS unit will respond by saying which bus to take and how to get to a designated stop. This method is more reliable and fosters greater independence for the deafblind student than relying on the bus driver to remember to inform the student when their requested stop has been reached. And unlike many Internet maps, the student does not have to travel all around a community before learning that a street no longer exists. Because the student is using the device in the community, the directional information supplied is more reliable than that found on many Internet sites.

It goes without saying that the GPS device is extremely useful in potentially dangerous or emergency situations when detours or alternate routes must be accessed due to unexpected safety precautions or accidents.

Presently, two Braille notetakers, Braille Note from Humanware and Pac Mate from Freedom Scientific, have support for GPS. In order to use GPS successfully, a deafblind student will require adequate training in how to simultaneously utilize and travel with the equipment. It is important to note that the GPS does not replace the use of a cane or a dog guide, or any other sensor devices. For best results, a deafblind student should consult with his or her technology and orientation and mobility (O&M) instructors to obtain recommendations for how to properly and safely use the GPS device.

BrailleNote QT can accommodate GPS technology.

Computers

Computers have been integrated into the daily lives of nearly everyone. DeafBlind students are also incorporating computers into their personal lives, workplaces, educational settings, and recreational activities. Because one of the fastest growing uses of computers for deafblind students is to access the Internet, there will be a section on Internet access following this description of computer access equipment available for deafblind students.

Computers have become a means of removing many societal barriers for deafblind individuals. For example, to avoid having to manipulate printed information as mentioned in the previous section, the

Desktop computer with braille display.

deafblind student can receive information in a computerized format. Instead of using a video magnifier, OCR, or an interpreter to access a newspaper, a deafblind student can access the same newspaper over the Internet using a computer with their preferred method of access. The following is a brief overview of some methods commonly used by deafblind students to access computers.

Screen magnification. Information that appears on a computer screen can be magnified by either installing a screen magnification program or by changing the settings on the computer. With screen magnification, everything that appears on a computer screen can be magnified. Of special note to keep in mind when information is magnified on the computer is that far less information will actually appear on the screen at any one time. Subsequently, the student must possess the proper skills to manipulate the screen image efficiently to see everything that is available. Another important feature of screen magnification programs is the ability to modify the screen colors. By changing the colors of the background or font, a deafblind student can make the screen easier to read.

Braille displays. For Braille users to access the computer, a form of Braille called "refreshable Braille" is used. The Braille display consists of a row of Braille characters. Each character consists of either 0-8 pins that raise or drop to represent all possible Braille letters, punctuation marks, and symbols. With a refreshable Braille display, a user can access all information that is text. The one limitation of Braille displays is the unit's inability to display graphics. This can create a problem for applications that rely heavily upon graphics. However, most icons are now labeled with text so they can be identified when using a refreshable Braille display.

Voice output. If a deafblind student has sufficient residual hearing to discriminate speech, a voice output system may prove useful. A voice output system converts text from the computer screen to spoken voice. The computer produces the speech by piecing together small bits of sound called phonemes. The computer uses a combination of phonemes to produce each word. Because the computer is limited in how one phoneme blends into the next, computer generated voice may sound robotic. For this reason, some students with a mild hearing loss, who are still able to discriminate speech when talking with another person may find it difficult to understand the speech generated by a computer. If the student demonstrates inconsistent speech discrimination ability, it is recommended that he or she use a redundant system by combining speech output with either refreshable Braille or screen magnification.

Accessing the Internet

Historically, communication across great distances for deafblind people has been difficult. In many instances, deafblind students required the assistance of a sighted person to place a telephone call or were limited to direct face-to-face communication. With advancements in technology, this is no longer the case. Using the Internet, deafblind students can now independently interact with friends, family, and colleagues around the world. For the deafblind student, the two most popular components of the Internet are e-mail and the World Wide Web.

Student using the PacMate braille notetaker to access the Internet.

E-mail. With e-mail, a text message is typed on one computer with access to the Internet and then sent to a storage site until such time that it is accessed by the recipient. The primary advantage of e-mail over conventional mail is that e-mail can travel from one side of the world to the other in a matter of seconds.

For deafblind students, e-mail is easily accessible because it is text. One tremendous advantage of sending e-mail as opposed to a regular printed letter is the receiver of the e-mail can read the document in their preferred mode. A deafblind student who uses a Braille display to access the computer can read the e-mail in Braille, regardless of how the sender wrote the e-mail. So with e-mail, the sender of a correspondence no longer needs to have the ability to write Braille to converse with a deafblind student who is a Braille reader. This electronic means of sending and receiving information has opened the door for increased communication options and has reduced isolation for thousands of deafblind students.

By far, the specialized form of e-mail called a "listserv" has had the greatest impact on deafblind students' ability to connect with and mentor one another. With a listserv, e-mail is sent to an address which distributes that message to all subscribers of the listserv. For example, a very popular listserv called "deafblind" has subscribers, who are deafblind, family members of deafblind people, and professionals in the field of deafblindness. This specialized listserv has subscribers from virtually all around the world. A person posts a message on the listserv, which is then sent to all subscribers. This allows every subscriber to learn about the experience of deafblind people from all around the world.

World Wide Web. The World Wide Web consists of millions of web sites with each web site containing information and hyperlinks to other web sites. These hyperlinks allow a

user to seamlessly jump from one site to a linked site. For example, if a person reading the PEPNet website (which is stored in Minnesota) presses the hyperlink for Regional Centers, the web surfer can jump to all the web sites for all the PEPNet Regional Centers across the country. From there the person can jump to different state agency web sites and just keep going. This allows a deafblind student to locate vast amounts of information rather quickly. Some of the most common uses of the World Wide Web can, with proper equipment and training, be accessed by deafblind students.

Another important aspect of the World Wide Web is the use of search engines. These are web sites that enable the deafblind student to find other web sites containing information on topics of interest. Using search engines effectively permits a deafblind student to quickly find research information for term papers and to conduct job searches. Through the web, deafblind students can also access news, the weather, and other endless forms of data.

For a deafblind student, getting out to a store can be a major challenge at times. It is for this reason that a growing number of deafblind students shop on-line. In the past, typical shopping scenarios for a deafblind student would begin with the student placing a call to a friend or volunteer to request a ride to a particular store when adequate transportation did not exist in the community. Next, the deafblind student may have required sighted guide assistance to get around the store and/or needed to request assistance to read the labels of every item desired. Today however; just about anything can be purchased over the Internet, including clothing, food, computers, furniture, and even airline tickets. Now with the Internet, all that is required of the deafblind student is a visit to a particular store's web site. After quickly browsing through a description of the merchandise and placing selected items into an online shopping cart, the purchase can be made with a credit card. The purchased items are then delivered directly to the deafblind student's dorm or home. All of this can be accomplished by the deafblind student independently in the security of his dorm room or apartment.

With the rapidly growing trend of distance learning occurring in education, classes are now taught via the Internet. Instead of going to a classroom and accessing a sign language interpreter or a note-taker, a deafblind student taking a class on the web can receive text lectures and submit assignments as email attachments. The information available in an on-line class is far more accessible than that found in conventional classroom setting because the deafblind student can access course information in their preferred mode at times he feels are most convenient.

Banking is another essential service that is accessible using the web. This allows a deafblind student to independently pay bills and perform other banking tasks. The bank will write checks and forward them to utility companies, credit card companies, or whomever payment is due. Many universities are now providing students with personal debit cards that can be used to pay for books, meals, and other school essentials. These debit card accounts can be reviewed on line and give the student access to personal records, tuition payments and other financial aid concerns. Without question, the opportunity to make use of the Internet for corresponding with the financial aid office, where it is typically next to impossible to find interpreters, is a more desirable way to apply for scholarships, grants or work study assignments without all the hassles involved with in person visits.

The web also provides deafblind students with a means of communicating. There are two web applications that allow deafblind people to easily communicate with other people: chat rooms and instant messaging (IM).

A chat room is place on the Internet where people log-on at the same time. Anyone who is logged-on to the same chat room can type messages which are simultaneously viewed by all those who are logged-on to that same chat room. There are a few chat rooms that are specific to deafblindness; one such chat room is available through DB-Link.

As previously stated, another means for communicating over the web is instant messaging (IM). With IM, one person types a brief message to another person who is also on-line at the same time. The two people can continue their conversation by typing messages back and forth. This back and forth typing of messages is similar to having a TTY conversation, with the exception that the deafblind student can be engaged in other activities on-line while having the IM conversation. It is also possible to IM more then one person at a time. This feature has become a great vehicle for affording deafblind students the same immediate access to information that hearing-sighted, sighted-deaf, and hearing-blind students cherish. Also, there are programs (e.g., ICQ) available to allow a deafblind student to establish a live conversation with another party in the same manner that one would on a TTY.

Summary

This chapter provided a brief overview of assistive technology used by and available to deafblind students. Students who are deafblind are a heterogeneous population with a wide range of vision and hearing losses. Each deafblind student also possesses a broad range of skills, abilities, and preferences. This fact should be kept in mind when trying to

locate the right assistive device. What is best for one person is not always best for everyone. It is recommended that when trying to determine the most appropriate equipment for a deafblind student, that the individual's uniqueness be taken into consideration and addressed. Also, because new devices are constantly being developed, staying up to date on progress in technology is vital.

Assistive technology can make a substantial impact on a student who is deafblind. It can open doors and allow deafblind students to overcome obstacles that once seemed overwhelming. Using technology to close the digital divide will offer the deafblind student more options for training and future employment. Most importantly, the proper technology and training can help decrease feelings of and/or actual isolation and loss of relationship experienced by many students who are deafblind.

Resources

Helen Keller National Center
for Deaf-Blind Youths and Adults
141 Middle Neck Road
Sands Point, New York 11050
(516) 944-8900 voice
(516) 944-8637 TTY

Anindya Bhattacharyya, Technology Center
anindya.bhattacharyya@hkc.org

Resource List as of May 11, 2007

ABLEDATA
8630 Fenton Street, Suite 930
Silver Spring, MD 20910
phone: (800) 227-0216
TTY: (301) 608-8912
Fax: (301) 608-8958
email: abledata@orcmacro.com
website: www.abledata.com
(Clearinghouse: Database of products for people with all disabilities, including deaf-blindness. Note: they do not sell items.)

Ai Squared
P.O. Box 669

Manchester Center, VT 05255
phone: (802) 362-3612
fax: (802) 362-1670
email: sales@aisquared.com
website: www.aisquared.com
(Manufacturer: ZoomText screen magnification program/screen reader)

American Thermoform Corporation
1758 Brackett Street
La Verne, CA 91750
phone: (800) 331-3676 or (909) 593-6711
fax: (909) 593-8001
email: sales@americanthermoform.com
website: www.americanthermoform.com
(Manufacturer/distributor: braille embossers and a broad range of assistive technology)

American Time and Signal Co.
140 Third Street, South
P.O. Box 707
Dassel, MN 55325
phone: (800) 328-8996
fax: (612) 275-2603
email: atsclock@hutchtel.net
website: www.atsclock.com
(Manufacturer: James Remindo tactual alarm clocks with vibrators)

Atlanta Brailler Repair and Service
3830 South Cobb Drive, Suite 125
Smyrna, GA 30080
phone: (800) 726-7406 or (770) 432-7280
fax: (770) 432-5457
email: franklevine@atlantabraillerrepair.com
website: www.atlantabraillerrepair.com
(Service center: repairs manual and electric braillers)

Apple/MAC Computers
website: www.apple.com/macosx/features/voiceover
(Manufacturer: Screen reader/Spoken Interface for blind MAC OS X users)

Audio Visual Mart, Inc.
603 Williams Blvd.
Kenner, LA 70183-0020
phone: (800) 737-6278 or (504) 712-0400
fax: (504) 712-0032

email: info@av-mart.com
website: www.av-mart.com
(Manufacturer/distributor: BraillePhone TTY and a broad range of assistive technology)

Beyond Sight, Inc.
5650 South Windermere Street
Littleton, CO 80120
phone: (303) 795-6455
fax: (303) 795-6425
sales email: jim@beyondsight.com
tech support email: support@beyondsight.com
website: www.beyondsight.com
(Manufacturer/distributor: LapTalk LT laptop computer, Braillino braille display/notetaker with a Nokia personal digital assistant (PDA), and a broad range of assistive technology)

Brytech, Inc.
600 Peter Morand Crescent
Ottawa, ON
K1G 5Z3
Canada
phone: (800) 263-4095 or (613) 731-5800
fax: (613) 731-5812
email: inquiries@brytech.com
website: www.brytech.com
(Manufacturer: Enhanced Note Teller)

Chris Lagarde
Schotenhof 4
NL 4841 RN
Prinsenbeek
The Netherlands
phone/fax: +31 (0) 76-5420463
email: clagarde@xs4all.nl
(Manufacturer: Screen Braille Communicator)
Clarity, a Division of Plantronics, Inc.
4289 Bonny Oaks Drive, Suite 106
Chattanooga, TN 37406
phone: (800) 426-3738 or (800) 552-3368
fax: (800) 325-8871
email: claritysales@plantronics.com
websites: www.plantronics.com and www.clarityproducts.com
(Manufacturer/distributor: TTY's, alert system for phone signals, doorbell, and fire drill, bluetooth handsets, and amplified telephones)

Compu-TTY and KROWN MFG., INC.
3408 Indale Road
Fort Worth, TX 76116
TTY: (800) 366-9950 or (817) 738-8993
phone: (817) 738-2485
fax: (817) 738-1970
email: sales@krowntty.com
website: www.computty.com
(Manufacturer: KROWN TTY)

Dolphin Computer Access
60 East 3rd Ave., Suite 130
San Mateo, CA 94401
phone: (866) 797-5921 or (650) 348-7401
fax: (650) 348-7403
email: info@dolphinusa.com
website: www.dolphinusa.com
(Manufacturer: Supernova screen reader, Luna Plus with magnification and speech support, and
Luna magnification)

Duxbury Systems, Inc.
270 Littleton Road, Unit 6
Westford, MA 01886⋏3523
phone: (978) 692-3000
fax: (978) 692-7912
email: info@duxsys.com
Duxbury support email: support@duxsys.com
MegaDots support email: caryn@duxsys.com
website: www.duxburysystems.com
(Manufacturer: Windows-based Duxbury and DOS-based MegaDots contracted braille
translation software)

Electronic Vision Access Solutions and Dell
P.O. Box 371
39 Canal Street
Westerly, RI 02891
TTY: (401) 596-3500
phone: (800) USA-EVAS (800-872-3827) or (401) 596-3155
fax: (401) 596-3979
email: inforequest@evas.com
website: www.evas.com
(Manufacturer/distributor: access technology and turn-key computer systems)

EnableMart

4210 East 4th Plain Blvd.
Vancouver, WA 98661
phone: (888) 640-1999 or (360) 695-4155
fax: (360) 695-4133
email: sales@enablemart.com
tech support email: support@enablemart.com
website: www.enablemart.com
(Manufacturer/distributor: braille displays, braille notetakers, screen readers and speech synthesizers, screen magnification software and CCTVs/VGA readers, braille embossers, handheld organizers and phone accessibility software, and a broad range of assistive technology)

Enabling Technologies Company
1601 Northeast Braille Place
Jensen Beach, FL 34957
phone: (800) 777-3687 or (561) 225-3687
fax: (561) 225-3299
email: enabling@brailler.com
website: www.brailler.com
(Manufacturer/distributor: braille embossers and a broad range of assistive technology)

euroBRAILLE
34, rue du General Brunet
75019 Paris
France
phone: (011) 331-53728510
fax: (011) 331-42019840
email: developpement@eurobraille.fr
website: www.eurobraille.fr
(Manufacturer: DRACULAwin and DRACULAvox braille and voice synthesis screen reader)

Freedom Scientific Blind/Low Vision Group
11800 31st Court North
St. Petersburg, FL 33716
phone: (800) 444-4443 or (727) 803-8000
tech support: (727) 803-8600
fax: (727) 803-8001
email: info@freedomscientific.com
website: www.freedomscientific.com
(Manufacturer/distributor: Focus/PowerBraille braille displays, Braille Lite/Type Lite/Pac Mate notetakers, braille embossers, JAWS for Windows screen reader, Magic screen magnification program, OpenBook optical character recognition (OCR) software and a broad range of assistive technology)

GW Micro

725 Airport North Office Park
Fort Wayne, IN 46825
phone: (260) 489-3671
fax: (260) 489-2608
email: support@gwmicro.com
website: www.gwmicro.com
(Manufacturer/distributor: Window-Eyes screen reader, Braille Sense braille notetaker, and a broad range of assistive technology)

Handy Tech Elektronik GmbH
Brunnenstr 10
D-72160 Horb
Germany
phone: ++49 / 7451 / 5546-0
fax: ++49 / 7451 / 5546-67
email: info@handytech.de
website: www.handytech.com
(Manufacturer: Braillino, Braille Star, Easy Braille, and Tablet Braille displays, and a broad range of assistive technology)

Harris Communications
15155 Technology Drive
Eden Praire, MN 55344
TTY: (800) 825-9187 or (952) 906-1198
phone: (800) 825-6758 or (952) 906-1180
fax: (952) 906-1099
email: mail@harriscomm.com
website: www.harriscomm.com
(Distributor: a broad range of assistive technology)

HITEC Group International, Inc.
8160 Madison Avenue
Burr Ridge, IL 60521
TTY: (800) 536-8890
phone: (800) 288-8303 or (708) 654-9200
fax: (888) 654-9219
email: info@hitec.com
website: www.hitec.com
(Distributor: a broad range of assistive technology)

Hooleon Corporation
417 Building A South 6th Street
Cottonwood, AZ 86326
phone: (800) 937-1337 or (928) 634-7515

fax: (928) 634-4620
email: sales@hooleon.com
website: www.hooleon.com
(Distributor: large/braille keyboard labels and a broad range of assistive technology)

Howe Press
Perkins school for the Blind
175 North Beacon Street
Watertown, MA 02172-2790
phone: (617) 924-3490
fax: (617) 926-2027
email: howepress@perkins.org
website: www.perkins.org
(Manufacturer: Perkins Brailler, Tell-a-Touch, and a broad range of assistive technology)

HumanWare
175 Mason Circle
Concord, CA 94520
phone: (800) 722-3393 or (925) 680-7100
service department: (925) 521-3629
tech support: (925) 681-4636
fax: (925) 681-4630
email: info@humanware.com
website: www.humanware.com
(Manufacturer/distributor: talking laptop computers, Braille Star/Brailliant/Easy Braille braille displays, Braille Note MPower and PK notetakers, video magnification systems, and a broad range of assistive technology)

Independent Living Aids, Inc.
P.O. Box 9022
Hicksville, NY 11802-9022
phone: (800) 537-2118 or (516) 937-1848
fax: (516) 937-3906
email: service@independentliving.com
websites: www.independentliving.com and www.annmorris.com
(Distributor: a broad range of independent living aids including light detector, Vibe watch, and computer-related adaptive technology products)

InSiPhil US, LLC (formerly Telesensory Corporation)
650 Vaqueros Avenue, Suite F
Sunnyvale, CA 94085
phone: (800) 804-8004 or (408) 616-8700 or (408) 616-4701
fax: (408) 616-8720
email: info@insiphil.com

tech support email: techsupport@insiphil.com
website: www.insiphil.com
(Manufacturer/distributor: CCTV's and a broad range of assistive technology)

Kurzweil Educational Systems Inc.
100 Crosby Drive
Bedford, MA 01730
phone: (800) 894-5374
fax: (781) 276-0650
email: info@kurzweiledu.com
website: www.kurzweiledu.com
(Manufacturer/distributor: Kurzweil 1000 optical character recognition (OCR) software and reading machines)

Lighthouse International
111 East 59th Street
New York, NY 10022-1202
TTY: (212) 821-9713
phone: (800) 829-0500 or (212) 821-9200
fax: (212) 821-9707
website: www.lighthouse.org
(Information resources and manufacturer/distributor: blindness-related products)

LS&S Group
P.O. Box 673
Northbrook, IL 60065
TTY/v: (800) 317-8533
phone: (800) 468-4789
fax: (847) 492-1482
email: sales@lssonline.net
website: www.lssgroup.com
(Distributor: a broad range of assistive technology)

NXI Communications, Inc.
4505 South Wasatch Boulevard, Suite 120
Salt Lake City, UT 84124
TTY: (801) 274-6004
phone: (801) 274-6001
fax: (801) 274-6002
BBS: (801) 274-6005
email: info@nxicom.com
website: www.nxicom.com
(Manufacturer/distributor: text-based communication technology - Nextalk TTY software)

Optelec US, Inc.
32D Billerica Rd.
Chelmsford, MA 01824
phone: (800) 828-1056 or (978) 392-0707
fax: (800) 929-2444
email: optelec@optelec.com
website: www.optelec.com
(Manufacturer/distributor: Clearview CCTV's, magnifiers, Easylink, and a broad range of
assistive technology)

Performance Systems, Inc.
3050 Post Oak Bolevard, Suite 1710
Houston, TX 77056
phone: (888) 737-7978 or (713) 723-6000
fax: (713) 723-6221
email: info@performancesystems.com
website: www.performancesystems.com
(Distributor: Virtual Touch System (VTS) - a mouse with a tactile display to show graphics, text,
art, photography and tactile games)

Phone-TTY, Inc.
1246 Route 46 West
Parsippany, NJ 07054-2121
TTY: (973) 299-6626
phone: (973) 299-6627
fax: (973) 299-7768
email: phonetty@aol.com
link: www.tdi-online.org/tdi/fs_ttymanufacturers.asp
(Manufacturer: Phone-TTY modems and Futura TTY software)

REIZEN Inc.
P.O. Box 3312
Farmingdale, NY 11735
website: www.reizenusa.com
(Manufacturer: Reizen braille alarm clock and vibrator and watches, talking weight scales, alarm
clocks, and watches, large print alarm clocks, and telephone amplifiers)

Repro-Tronics, Inc.
75 Carver Avenue
Westwood, NJ 07675
phone (201) 722-1800
fax: (201) 722-1881
email: davisrepro@aol.com
website: www.repro-tronics.com

(Manufacturer/distributor: Tactile Image Enhancement
machine and Thermo pen)

Sendero Group, LLC
1118 Maple Lane
Davis, CA 95616-1723
phone: (888) 757-6810 or (530) 757-6800
fax: (530) 757-6830
email: gps@senderogroup.com
Website: www.senderogroup.com
(Manufacturer/distributor: GPS system for the Braille Note, Id Mate bar code scanner, and a
broad range of assistive technology)

Serotek Corp.
1128 Harmon Place, Suite 310
Minneapolis, MN 55403
phone: (877) 661-3785
fax: (612) 659-0760
email: mcalvo@freedombox.cc
Website: www.freedombox.cc
(Manufacturer/distributor: a software- or hardware-based voice-enabled system to access
e-mail/Internet)

Sighted Electronics, Inc.
69 Woodland Avenue
Westwood, NJ 07675
phone: (800) 666-4883 or (201) 666-0159
fax: (201) 666-2221
email: sales@sighted.com
website: www.sighted.com
(Manufacturer/distributor: BrailleX braille displays, ELBA notetaker, braille embossers, a full
range of CCTV's, and a broad range of assistive technology)

Silent Call Communications Corporation
5095 Williams Lake Road
Waterford, MI 48329
TTY/v: (800) 572-5227 or (248) 673-7353
fax: (248) 673-7360
email: silentcall@silentcall.com
website: www.silentcall.com
(Manufacturer/distributor: Vibra Call alert system)

The American Printing House for the Blind, Inc.
P.O. Box 6085

1839 Frankfort Avenue
Louisville, KY 40206-0085
phone: (800) 223-1839 or (502) 895-2405
fax: (502) 899-2274
email: sales@aph.org or catalogs@aph.org
website: www.aph.org
(Manufacturer/distributor: braille books and a broad range of assistive technology)

Teltex, Inc.
404 East 13th Avenue
North Kansas City, MO 64116
TTY/v: (888) 515-8120 or (816) 221-6316
fax: (816) 221-6830
e-mail: andrew@teltexinc.com
website: www.teltexinc.com
(Distributor/service center: TTY, amplified telephone, signalers
or assistive devices, as well as repairs on old TeleBraille Is, IIs, and IIIs, VersaPoint embossers,
and Navigator braille displays)

Triumph Technology
1349 Pike Lake Drive
New Brighton, MN 55112
phone: (651) 636-5184
fax: (866) 347-8249
email: info@triumphonic.com
website: www.triumphonic.com
(Distributor: Braillino braille display/notetaker with a Nokia personal digital assistant (PDA),
Tabli visual display, and a broad range of assistive technology)

Ultratec, Inc.
450 Science Drive
Madison, WI 53711
TTY/v: (800) 482-2424 or (608) 238-5400
fax: (608) 238-3008
email: service@ultratec.com
website: www.ultratec.com
(Manufacturer/distributor: TTY's)

VirTouch Ltd.
P.O. Box 45125
8 HaMarpeh Street
Har Hotzvim, Jerusalem 91450
Israel
phone: (011) 972-2-587-0340

fax: (011) 972-2-587-0205
email: info@virtouch.co.il
website: www.virtouch.co.il
(Manufacturer: Virtual Touch System (VTS) - a mouse with a tactile display to show graphics, text, art, photography and tactile games)

Vision Cue
4858-A S.W. Scholls Ferry Road
Portland, OR 97221
phone: (888) 318-2582 and (503) 297-1510
fax: (503) 459-4003
email: info@visioncue.com
website: www.visioncue.com
(Manufacturer/distributor: Alva braille displays and Mobile Phone Organizer notetakers, screen readers and speech synthesizers, Turnkey Systems, screen magnification software and CCTVs/VGA readers, braille embossers, handheld organizers and phone accessibility software, and a broad range of assistive technology)

Visual Aids Electronics
7625 Hayvenhurst Avenue, Unit 11
Van Nuys, CA 91406
phone: (818) 909-9453
fax: (818) 909-7578
email: vae2000@aol.com
(Service center: repairs Navigator 40 and 80 braille displays, TeleBrailles, and VersaPoint braille embossers)

Information Resources

American Association of the Deaf-Blind
8630 Fenton Street, Suite 121
Silver Spring, MD 20910-4500
TTY: (301) 495-4402
fax: (301) 495-4404
email: info@aadb.org
website: www.aad.org

American Foundation for the Blind
11 Pennsylvania Plaza, Suite 300
New York, NY 10001
phone: (800) AFB-line (800-232-5463) or (212) 502-7600
fax: (212) 502-7777
email: afbinfo@afb.net
website: www.afb.org

DB-Link: Information Clearinghouse
Teaching Research Division of Western Oregon University
345 North Monmouth Avenue
Monmouth, OR 97361
TTY: (800) 854-7013
phone: (800) 438-9376 or (503) 838-8776

fax: (503) 838-8150
email: dblink@tr.wou.edu
website: www.tr.wou.edu/dblink

Helen Keller National Center
141 Middle Neck Road
Sands Point, NY 11050
TTY: (516) 944-8637
phone: (516) 944-8900
fax: (516) 944-7302
email: hkncinfo@hknc.org
website: www.hknc.org

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910-4500
TTY: (301) 587-1789
phone: (301) 587-1788
fax: (301) 587-1791
email: nadinfo@nad.org
website: www.nad.org

National Federation of the Blind
Technology Center for the Blind
1800 Johnson Street
Baltimore, MD 21230
phone: (410) 659-9314
fax: (410) 685-5653
website: www.nfb.org

Deaf-blind Listservs

1. CHARGE Syndrome Mailing List
The topic of this listserv is CHARGE Syndrome. To subscribe, use the online form at

groups.yahoo.com/subscribe.cgi/CHARGE

or contact Casey Fisher at charge@neti.saber.net for assistance.

2. Deaf-Blind Action Mailing List
This listserv is used as a forum for people who wish to learn and discuss political issues
and advocacy affecting all deaf-blind people. This list is open to professionals, deafblind people,
and to their families and friends. To subscribe, leave the subject line blank and send the
following to dbaction-subscribe-request@home.ease.lsoft.com.

3. Usher Syndrome Mailing List
This listserv is an Internet forum for people with Usher Syndrome, their parents, friends, spouses, and service providers. To subscribe to this list, send a blank e-mail to ushers-subscribe-request@tr.wou.edu or contact Randy Pope at Ushers-owner-request@tr.wou.edu for assistance.

4. Deaf-Blind Techies Mailing List
The topic of this listserv is adaptive technology. The purpose of this list is to discuss all types of adaptive technologies related to deafblindness, to exchange information, inquiries, ideas, and opinions about how adaptive technology helps deafblind people. This list is open to deafblind people, professionals, families/friends, and manufacturers. To subscribe to this list, leave the subject line blank and send the following to: dbtechies subscribe request@tr.wou.edu

5. Paperless Braille Displays Mailing List
The topic of this listserv pertains to paperless or refreshable braille displays. The purpose of this list is to discuss all types of refreshable braille displays including notetakers with braille displays, to exchange information, inquiries, ideas, and opinions about all the features offered by each brand of braille display. This list is open to those who use braille displays or those who want to learn to use them, professionals, families/friends, and manufacturers. To subscribe to this list, leave the subject line blank and send the following to: listserv@icors.org and in the body of a blank message write "sub pbd-l"

Chapter Four

Mental Health Counseling

"I've seen many harsh winter storms

Icicles on my heart

Then spring with its beauty in color changing

With blooming flowers in my heart

With summer and it's heat

I find beauty in the summer

Sunrise and Sunset

Then fall with its crispy windy days

With darkening colors...."

Marcia McDermott

(Reflections From A Recycled Heart, 2006)

Mental Health Counseling with DeafBlind Students: Recommendations for Families and Professionals

Cynthia L. Ingraham
McCay Vernon

Students who are deafblind represent a uniquely heterogeneous group of consumers. Factors such as age at onset of sensory loss, the degrees of the loss, the etiologies, and the progressive versus the static nature of hearing and visual disabilities are among the reasons for this huge variability. These are specific conditions not faced by the general population of adolescents. More importantly, these added factors can have profound effects on deafblind students' language development, opportunities for human interaction (marriage, friendships, family ties), mobility, psychological adjustment, employment, and education (Salmon, 1970).

It is common for fear to be a student's primary reaction upon hearing the diagnosis of a disorder which can potentially lead to deafblindness. Students have reported feeling completely helpless and without control. The desire to stop time and rearrange the stars leaves the student feeling as though death has come; but the heartbeat, breathing, eating, and sleeping continues as he awaits the actual death of his body (Sculthorpe, 1966). This anguish is magnified for students who have already adjusted to life with the single disability of deafness or blindness. For these students, getting through elementary school and then entering adolescence only to learn that the sense upon which they had established their connection to the world has been or soon will be purged can be quite devastating.

Christian Markovic communicating with student using tactile sign language at community art festival.

This change, coupled with the typical crises and stresses which result from living in a world that can not be seen or heard, and the lack of mental health specialists who possess the multiple counseling skills and experiences needed to effectively serve deafblind students, creates a demand for services far in excess of supply. It is the purpose of this chapter to describe some of the mental health issues raised by deafblind students and to provide practical ways and valuable resources to address these challenges.

Factors Related to the Onset of DeafBlindness Which Impact Mental Health and Overall Psychological and Educational Functioning

The conditions affecting adjustment to deafblindness vary tremendously in terms of the age at the onset of the loss of hearing and of vision, respectively. For example, was the student born deaf and then later became blind? Did the blindness precede the deafness, or did both occur together? The reason age at onset is of such profound psychological importance is that it determines in large part the coping skills and other assets, and the overall life experience the student may potentially bring to his new life as a deafblind individual (Adler, 1987; Stiefel,1991). Age at onset determines, in part, some of the personal resources a student can call upon in coping with isolation from peers and comprehending what is involved with being deafblind. The age at onset of the preexisting blindness or deafness also impacts the amount of grief already experienced (Duncan, Prickett, Finkelstein, Vernon, & Hollingsworth, 1988). Having not dealt with severe grief and acceptance issues, the newly diagnosed deafblind student will be faced with mammoth issues related to identity, self-worth, sense of belonging, and attaining independence (Adler, 1987).

Blindness Followed by Deafness

Most students who become blind before losing their hearing have been blind from birth, or for many years. Whether blind resulting from neonatal or postnatal complications, blind students who experience deafness later in life are likely to have become accustomed to traversing through the environment relying on their four remaining senses. Thus, they are already on their way or have made the adjustment to blindness. For example, most blind students will already possess orientation and mobility and self-help skills used by the blind. Often, many of these individuals can read braille. These students also tend to have a good command of English and have retained usable speech. For these blind students, deafness symbolizes the absence of the one key sense believed to be most important, i.e., hearing. Such a major loss involves intense grief, mourning, and possibly denial, anger, and other emotions that are understandable reactions to a major life tragedy. In terms of function, the major psychological loss faced by blind students with late onset hearing loss is related to

Student using the PacMate braille notetaker to access the Internet.

receptive communication. Although these students may still possess intelligible speech and

the ability to verbally *express* themselves to others, it may be difficult for them to understand what others say in response. Most do not know sign language. Fingerspelling is slow, and few people know it. Other means of receptive communication such as print-on-palm are also slow and laborious. In addition, the student may not have previous experience with reading and writing print letters from which to draw. Thus, these students find themselves tremendously isolated from other people, an isolation caused primarily by an inability to *receive* communication.

However, blind students who become deaf still have reasonable access to information through reading braille. They may have lost auditory input through radio and television; however, streamlined programs can still be accessed via the Internet by using a Braille display. The increase in web-based information outlets that are accessible to persons with vision loss has enabled many deafblind students to remain up-to-date with local and world events. Thus, isolation from people is primarily physical, but not necessarily in the sharing of ideas.

Among these students, those who need psychological services may find that assistive devices such as the TeleBraille (this device is no longer manufactured in the US; however, thousands of units still remain in use) or Screen Braille Communicator (SBC), can be used to communicate directly with a mental health specialist. The deafblind student can receive, via Braille output, information that the practitioner types via a qwerty keyboard attached to a Braille display. The student can then respond orally or by using the Braille keys to type out his or her response. The words typed by the student will appear in regular print on the LCD screen that faces the practitioner. Another option for deafblind students who possess knowledge and comfort with a computer keyboard or Braille keyboard is to utilize the computer screen (practitioner access) and braille display (student access) to type out and receive responses on a desktop or laptop computer. The student can then access the practitioner's typed remarks using the Braille display connected to the computer, and the practitioner can in turn read the student's responses that appear on the computer screen. This method, while neither smooth nor ideal, can enable the blind student with acquired deafness to have direct access to experienced practitioners who may have valuable strategies and input which can help the student cope with his new limitations.

Deafness Followed by Blindness

By far, one of the largest numbers of deafblind teenagers and adults are those who are born deaf or who lose their hearing early in life, and then later lose their sight. For many years, research suggested that nearly half of all identified deafblind adults had a genetic disorder called Usher Syndrome. This disorder typically involves a progressive loss of vision

due to Retinitis Pigmentosa (RP), and an early onset of hearing loss, which may or may not be progressive depending on the particular form of Usher that is present (Table).

Table: Three Types of Usher

Symptom	Type I	Type II	Type III
Hearing loss	Born deaf with profound hearing loss and have a "corner audiogram" with responses only to very loud low tones	Born hard of hearing with a sloping sensorineural loss from mild loss in low frequencies to severe-profound loss in high frequencies	Born with good hearing or mild hearing loss which gets worse over a decade or more. Sloping sensorineural pattern on audiogram
Balance	Absent inner ear balance	Normal inner ear balance	Some balance disturbance progressive
Vision loss from RP	Night blindness in infancy or early childhood. Blind spots by late childhood or teens. Legally blind by early adulthood	Night blindness in childhood or teens. Blind spots by late teens or early childhood. Legally blind in early to mid adulthood	Timing of progression may vary, but night blindness precedes daytime loss

Reprinted from: Davenport, S.L.H. (1995). Usher Syndrome Fact Sheet. National Institute on Deafness and Other Communication Disorders. Hereditary Hearing Impairment Resource Registry, Boys Town National Research Hospital, 555 N. 30th St., Omaha, NE 68131.

Usher Syndrome

Students with Usher Type I and some with Usher Type II usually learn to cope effectively with their deafness or partial hearing early in life. Most attend or have attended some type of education program for deaf youth, have primarily deaf friends, and are becoming skilled in sign language and fingerspelling. When these individuals become legally blind, they are able to communicate expressively and receptively with deaf people, hearing people who sign, and deafblind people who use tactile sign language. This means that these students have a major psychological advantage over deafblind people who grew up blind, because there are three (aforementioned) groups of people with whom they can readily communicate expressively and receptively. Thus, students with Usher Syndrome have a realistic chance to reduce the major psychological impairment of deafblindness, which is isolation from other people. However, if most deafblind

Two deafblind consumers using tactile sign language to catch up on the latest gossip.

students are to escape isolation, society has to structure environments that will make this possible. Access to residential living facilities with other deafblind and deaf people must be available. There is need for reliable transportation to helping with accessing a community center where other persons can be found with whom the deafblind student can communicate regularly. However, such arrangements can be rare. On-line chat rooms, listservs, instant messaging, and video phones are other high tech means by which deafblind students can use to remain connected to their peers and others.

Another major *advantage* students with Usher Syndrome, or other such acquired forms of deafblindness, have is that the loss of vision may be gradual, spanning a period of 20 to 60 or more years. Thus, psychological adjustments can be made gradually. When such students have matured, married and had children, or when they have been able to maintain close contact with the deaf community, this existing support system may be used to help with adjustment to deafblindness. Students who remain uncoupled, or who withdraw from the deaf community face greater barriers in coping with isolation.

Students with Usher Type I can typically receive adequate mental health services from facilities or specialists who know sign language and understand deafness. By contrast, students with Usher Type II and Type III can often hear and see adequately enough to combine residual hearing with speechreading and assistive listening devices in order to make use of regular mental health practitioners and programs. However, it is preferred that practitioners with knowledge of and experience with adolescent students and adults who are deafblind render these essential services.

Other Etiologies

Most other deafblind students are those who were first deaf, and then lost their sight from diseases such as diabetes, glaucoma, macular degeneration, cataracts, or other conditions that usually do not cause blindness until the student is well into adulthood. Certain conditions, such as diabetic retinopathy or cataracts, may involve loss of vision with partial return of vision and a lot of uncertainty about prognosis. This is extremely traumatic and, understandably, can precipitate depression, anxiety, and suicidal feelings. The relatively sudden or uncertain onset of blindness in most deafblind students who first lose their hearing *generally* makes adjustment more difficult than for those with Usher Syndrome.

Individuals in this other etiology category can generally have their mental health needs met at facilities serving deaf people, because such clinics have practitioners who know sign language. However, for students who have no sign language skills and have relied extensively on their vision for speechreading or other visual cues during

communication, sudden vision loss can be demoralizing. Feelings of complete abandonment and rejection are common for this group of adolescents. Many of these students report feeling as though they had been abducted and taken to an isolation room, which permits only a blurred semblance of their previous existence.

<u>Sudden-Onset Post Lingual DeafBlindness</u>

A tiny percentage of deafblind students were born with normal hearing and vision, and then lose both senses simultaneously over a brief period of time. Usher Syndrome Type III, meningitis, severe accidents, or war injuries are the usual causes. For these students, the initial psychological trauma is emotionally unsettling

However, these students bring to deafblindness a wealth of knowledge gained from their years as hearing-sighted individuals by using a technique called visualization (Alexander, 1994). This knowledge aids in mobility, in self-help, and, most importantly, in human communication. These students with acquired vision and hearing loss have the potential to overcome some of the isolation from ideas, people, and knowledge that most prelingually deafblind students face.

Generally, students with late onset deafblindness retain intelligible speech, which enables them to communicate expressively in a treatment or education setting. The mode of receptive communication that they generally rely on varies depending on the degree of vision and hearing loss. Braille, writing large print messages, and close vision or tactile sign language represents just a few of the communication modes used by this group of students. However, because onset is often later in life, these students frequently lack proficiency in using many of these modalities. This makes obtaining psychotherapy an especially tedious and difficult process. The concept of living in a world with diminished vision and hearing may be so foreign to these students that personal adjustment is often very slow and not easy.

Peer Interactions and Mental Health

One of the best actions that can be taken to help a deafblind student cope is to provide opportunities for meeting and interacting with other deafblind individuals. While not always easy to arrange, it is possible in many cases. If the student is an older teenager or an adult, several options are available.

One option is state-sponsored learning weekends or camping activities for deafblind consumers. Here, students have the opportunity to interact with peers and are given the chance to meet deafblind adults from whom they can gain a better understanding of the independent living and employment potential of persons with the same disability. The

Helen Keller National Center for Deaf Blind Youths and Adults (HKNC: 141 Middle Neck Road, Sands Point, NY 11050; PH: 516-944-8900) is another program which can provide deafblind students with an opportunity to gather together with their peers in a structured and supportive environment. The HKNC program is a federally-supported, and offers residentially based training curriculum and regional services. With its more than 50 affiliated programs across the nation, HKNC provides comprehensive rehabilitation services for eligible deafblind persons 16 years of age and older (Ferrell, Carlson, and Friend, 1995). The Center offers pre-employment and job training, education (e.g., braille, tactile sign language or adaptive technology), basic life skills such as independent living skills, mobility, use of assistive devices, and other skills needed by deafblind persons. Also, the many colleges and universities that offer quality support services for deaf and hard of hearing students are now attracting more deafblind students. Such academic and social environments are another excellent place for the deafblind student to receive peer support while adjusting to life with limited hearing and vision.

Another helpful organization is the **American Association of the DeafBlind (AADB)**, a national consumer group for deafblind people and professionals (8630 Fenton Street; Suite 121, Silver Spring, MD 20910). The AADB holds week-long conferences every two years where deafblind people and their families attend from all over the United States. It has several local chapters in some large cities; and has recently begun pairing young deafblind students with older deafblind mentors. The AADB conferences are ideal settings for acquainting deafblind individuals and their families with the deafblind community nationwide, and for establishing friendships with professional workers who are deafblind and/or involved in the deafblind field. Some other facilities are listed in the Available Services section of this chapter.

The key point to make is that for students facing life with vision and hearing loss, contact with others who share this dual disability is a major enrichment to their lives and a huge aid in their ability to cope with life. The students learn about services, assistive devices, and ways to handle situations, but most of all, students receive support and a realization that they are not alone. Parents also obtain corresponding benefits by witnessing how other families with a deafblind member interact successfully.

Because peer interaction is so critical, if a young, deafblind person is to avoid isolation, the selection of an appropriate school program is essential. Usually, a school district may have, at most, one or a very few deafblind students. If this is the case, the deafblind student is usually placed in a class with children who have different disabilities and/or vary widely in educational and age levels. Sometimes, an interpreter is provided, but not always. Often, the teacher has had little or no experience or training in the area of

deafblindness. Due to a lack of training, the support staff (psychologists, audiologists, administrators, counselors, aides, consultants, etc.) generally lacks the qualifications to meet the special needs of the deafblind student. Additionally, in these settings there are often issues related to limited or no opportunity for interaction with other students who are deafblind. This imposes upon the deafblind student severe isolation, which can have life-long, damaging impact. Funding, ego-driven needs of school administrators whose ignorance of deafblindness can lock a student into this type of educational placement indefinitely unless strong, articulate parents and advocates take a stand for students and demand the rights to which they are entitled under Section 504 of the Rehab Act, the Individuals with Disabilities Education Act (IDEA) and other related legislation.

The most effective approach for deafblind youth up to 16 or 18 years of age is to have a psychological/educational evaluation completed. Community-based adult service agencies may have more resources from which to choose than the school system. The **Helen Keller National Center** has a list of affiliated agencies from across the country that can provide information on existing mental health and peer support services for deafblind students (www.hknc.org). The **Perkins School for the Blind** (175 N. Beacon Street, Watertown, MA 02172; PH: 617-972-7220) is another excellent resource from which to obtain psychological and educational assessments for students with cognitive disabilities, in addition to vision and hearing loss. Under existing laws such as IDEA, Section 504 of the Rehabilitation Act, the 1998 Amendments to the Rehabilitation Act, No Child Left Behind and other legislation, deafblind students have a legal right to demand proper assessment services. As indicated earlier, few school districts have a multi-disciplinary team available, which is needed to conduct a comprehensive, multi-disciplinary, educational evaluation. Under IDEA the local school district is responsible for paying the full cost of a student's evaluation, including travel and meals for the deafblind student and a parent or guardian.

One value of obtaining this type of evaluation is that a part of it provides detailed educational recommendations. These recommendations can then be used as documented expert opinion regarding what is an appropriate program for the student. Such legal leverage can be critical for parents in obtaining the educational program that a deafblind student needs, and to which he or she is entitled.

Other resources for psychological and educational evaluations exist in the eleven states, which have what are called "dual schools." These institutions, which serve both deaf and blind students on a single campus, are located in Alabama, Arizona, Colorado, Florida, Hawaii, Idaho, Montana, Nevada, South Carolina, Virginia, and West Virginia. These schools usually have programs and evaluation services for children and youth who are deafblind. Other states have facilities for deafblind youth at either the state residential school for deaf

students, or for blind students. A listing of additional programs for deafblind youth can be found in the annual April edition of the <u>American Annals of the Deaf</u>. This publication is available in many large libraries or can be purchased for $27 from the <u>American Annals of the Deaf</u> (KDES PAS-6, 800 Florida Avenue, NE, Washington, DC, 20002-3695).

Psychological Aspects of the Diagnosis of Progressive Visual Disorders

As indicated earlier, a great majority of the population of deafblind adults have Usher Syndrome. This disorder poses some unique psychological issues. Even though the condition of Retinitis Pigmentosa (RP) in Usher Syndrome can be diagnosed at or near birth, it is usually not discovered until between the early teens and mid-to-late twenties (Minor, 1996). By this time, most students with Usher Syndrome and their families have adjusted to their deafness or hard of hearing status. To most deaf people, including those with Usher, blindness is perceived as the worst possible additional disability that could occur. Thus, for a student to be told that blindness is a possibility in addition to their existing deafness presents a severe psychological trauma, the full emotional impact of which few can understand.

The question ophthalmologists, parents, psychologists, and other mental health workers face is how to communicate the diagnosis of RP. How best to provide emotional and psychological support to the student who must ultimately cope with the reality of facing the future as a deafblind person, should be approached with compassion and patience.

In order to understand how to be helpful to persons in this situation, it is important to understand the individual's psychological status at the time of diagnosis. Usually, the student is in his teens or twenties, which means he has already started to cope with the loss of night vision; which is an early manifestation of the disorder. Forms of coping usually involve not going out at night, especially to dark places such as the settings for many social events, nighttime sports competitions, and other similar activities. This type of coping can be self isolating, and the beginning of withdrawal and loneliness, which frequently accompanies deafblindness. The individual has also begun to experience narrowing visual fields due to the RP. Thus, the student may have stopped playing some sports, yet another factor that leads to reduced human contact and a sense of belonging.

As already noted, by the time these young people learn that they have RP, adjustment to deafness or partial hearing has already been made. For example, most will have learned sign language. Those students who have not should begin classes immediately; as such skills can become a major asset. As the RP progresses, the use of sign language will enable these students to communicate with other deaf people, thus providing social outlets. As vision loss increases, a switch to a tactile form of sign language will occur.

During this critical time, it is also important that students learning sign language, who are still of school age, consider entering an academic program with other deaf students who also use sign language. Another option would be for the student to connect with other sign language users in both academic and social settings if they have not already done so. This can provide the student with awareness of the Deaf community, which is of great value because as his vision loss progresses. Signing deaf people or hearing individuals who learn sign language can help the student to establish a relatively easy two-way communication system and to avoid feelings of isolation. Increasingly more students are undergoing cochlear implant surgery at earlier ages so the urgent need to acquire sign language skills for a select group of deafblind students may not be as great.

With these considerations in mind, what is the best way to handle the actual communication of the diagnosis of vision loss to the student whose condition has just been identified? A lot depends on such factors as the age of the student, the type of disorder he or she may have, the degree of the hearing loss, and the resources available. However, some general suggestions can be made.

First, the student needs to be told that he has condition that affects his vision in specific ways. For most deaf students who have just been diagnosed with a condition that can lead to potential blindness, this can be helpful information. For years, the deafblind student may have questioned the reason he was bumping into things, especially at night, or in crowded situations. He may wonder why he felt awkward playing certain games or did not see a ball when thrown to him. Also, curiosity for why people said he was ignoring them when he passed by. To realize these behaviors have been due to poor visual acuity, reduced peripheral vision and night blindness can be a relief. If the particular condition is accompanied by a balance problem, loss of sensation in the extremities or other physical disabilities, these additional limitations need to be explained as well.

Once the student has been told he has an eye disorder and its symptoms have been explained, it is important to let him know whether the vision loss is progressive and if he will need to be re-evaluated every year.

Some doctors, parents, or mental health professionals stop at this point and do not explain any further, until the student asks, "Will I be blind?" If or when this or other questions are asked each should be answered honestly. The reality of most disorders is that, even if the condition is progressive, total deafblindness is not necessarily the ultimate outcome. Many people with progressive disorders such as Usher Syndrome retain some useful vision well into their 50's or 60's. It is important not to flatly state, "You will become blind," because to most people, especially young people, the word "blindness" denotes a total loss of vision. Scientifically, blindness is defined legally and medically as a visual loss

of 20/200 or greater in the better eye with correction, or else a visual field of 20 degrees or less. Furthermore, no one can predict with specific accuracy how rapidly vision will be lost in a student with a progressive disorder because there is such great variability. However, as many have discovered, most persons diagnosed with conditions such as Glaucoma, Diabetic Retinopathy or Usher Syndrome wish their condition had been fully explained to them early on, so as to enable them to properly plan for the future as it related to careers, marriage, family planning, and choice of where to live (Minor, 1995; Vernon, Boughman, & Annala, 1982).

Becoming a of a support group or other group with individuals who are also coping with vision loss is one of the best possible therapeutic activities for students who have just learned of their diagnosis (Vernon & Hicks, 1983). This same kind of interaction with other deafblind people can be equally valuable to students experiencing a sudden onset of deafblindness, or blind people who later lose their hearing. However, depending on the severity of the loss, these latter students must first master sign language or use an interpreter. As stated earlier, this is a problem not faced by most students who have grown up deaf and already know sign language by the time vision loss begins.

It bears repeating that the Helen Keller National Center for Deaf-Blind Youths and Adults and the American Association of the Deaf-Blind Conferences are ideal settings for a student who is becoming, or has become deafblind, where supportive interactions with others sharing the same disability can occur.

Issues in the Assessment of Students who are DeafBlind

Psychological assessment of students who are both deaf and blind is a challenging task for three major reasons: 1) the problem of communication, 2) a lack of adequate psychological tests designed specifically for these individuals, and 3) a lack of psychologists qualified to work with the population. A few tests have been developed for persons who are blind or deaf, and for deafblind children (Mar, 1996; Vernon & Hammer, 1996). Also, certain tests for non-disabled people are sometimes modified for use with students who are either deaf or blind. However, no comprehensive psychological or personality tests have been developed for and standardized on older deafblind persons. At best, testing involves the adaptation of existing instruments used with the general population, which is far less than satisfactory.

Because tests for blind people usually emphasize sound or language, they are obviously inappropriate for deaf people (Vernon & Green, 1980). Similarly, tests for deaf clients inevitably require vision and are unsuitable for blind clients. In a test such as the Wechsler Intelligence Scale for Children (WISC), the verbal scales are applicable to blind

persons, and the performance scales to deaf persons who have sufficient vision (Vernon & Green, 1980). Thus, students who are both deaf and blind are inadequately tested. In addition to the absence of appropriate tests, there is a lack of qualified psychologists. To work effectively with deaf students, a psychologist should know sign language and have experience socializing and working with deaf people (Vernon & Hammer, 1996). To be effective with blind students, a psychologist should be able to administer the appropriate tests for persons with vision loss, have some understanding of Braille, and be familiar with blindness (Vernon, Bair, & Lotz, 1979). Professionals with either background are extremely rare, and only a handful of psychologists in the United States are familiar with both deafness and blindness.

As a result of these limitations, extreme injustices are inevitably imposed upon deafblind students in the form of gross misdiagnoses and hospitalization for mental illness, or a diagnosis of intellectual disability, when students experience neither (Vernon & Green, 1980; Miles & Riggio, 1999). Such errors are commonplace. Many practitioners who have worked with deafblind students and adults have encountered individuals who spent decades in mental institutions because of incorrect diagnoses.

One important way of avoiding injustices is to obtain an extensive case history. Whenever possible, the case history should include information about the student's early development and complete school records. If available, family members should be asked to describe, in operational terms, important details of the student's behavior. Finally, it is vitally important to obtain a complete medical history that includes the etiology and time of onset of both the auditory and visual losses.

To locate a psychologist or psychiatrist capable of evaluating deafblind students, refer to the "Available Services" section of this chapter.

Available Services for Students Who Are DeafBlind

It is impossible, within the scope of a monograph chapter, to address fully the many complex issues involved in mental health for deafblind students. For this reason, a section on available services and resources is provided below:

- Locating Psychologists

  The American Psychological Association has a special interest section on deafness, which is part of its Division 22, Rehabilitation Psychology. By contacting the American Psychological Association, one may obtain the names and addresses of psychologists in the United States who are members of this special section and knowledgeable about deafness and deafblindness. Most of these individuals know sign language and have

experience working with deaf people and, in some cases, deafblind students. (750 First Street, Washington, DC 20002-4242)

- Locating Psychiatrists

  The American Psychiatric Association has a special caucus of psychiatrists working with deaf and deafblind people in the United States. A list with addresses of its members can be requested. Most caucus members know sign language. (1400 K Street, NW, Washington, DC 20005)

- Vocational Rehabilitation

  Every state provides vocational rehabilitation for disabled individuals, including those who are deafblind. This includes job training, medical services related to job training, independent living, psychological evaluations, and a multitude of other services that are available to eligible applicants (Ingraham et al, 1994). Vocational Rehabilitation is a state agency that is sometimes listed as a "Division" or a "Department," but is always available in the phone book in the "State Government" section. Vocational Rehabilitation usually has trained counselors who work with deafblind students and who would know of local mental health services that are available and can accommodate deafblind students. These specialists can also provide access to vocational rehabilitation services for deafblind clients.

- Helen Keller National Center for Deaf-Blind Youths and Adults

  This agency should be contacted by every deafblind student age 16 or older (141 Middle Neck Road, Sands Point, NY 11050; PH: 516-944-8900). The Center offers a number of evaluation and training programs for students, professionals and family members. Resource information on available mental health professionals trained to work with deafblind students can be obtained by contacting the HKNC Regional Representatives or Affiliates. (www.hknc.org)

- American Association of the Deafblind

  Also described earlier in this paper, with address and phone number, this organization can provide some socialization options for deafblind students (8630 Fenton Street, Suite 121, Silver Spring, MD 20910).

- Hilton/Perkins Program Perkins School for the Blind

  Also described earlier in this paper with address and phone number, this school should be contacted by every parent of a deafblind youth aged three to 18, to discuss the possibility of having their child evaluated there (175 N. Beacon Street, Watertown, MA 02172; PH: 617-972-7220).

- Boys Town Research Hospital

This hospital provides comprehensive educational, psychological, medical, and communication evaluations for deafblind youth, and has special services for sexually abused children and their families, including those who are deafblind. The Boys Town Research Hospital is also conducting extensive research on genetics related to Usher Syndrome. (Institute for Communication Disorders, 555 N. 30th St., Omaha, NE 68131)

- DB-LINK: National Information Clearinghouse on Children Who are Deafblind

  DB-LINK is a federally funded information clearinghouse that identifies, coordinates, and disseminates information related to children (0-21) who are deafblind. DB-LINK provides free, individualized information and referral services across many topics, including effective early intervention, special education and general education practices, medical, health, social, recreational services, legal issues, employment and independent living, post-secondary educational services, and information on the nature of deafblindness. In addition, fact sheets are developed on selected topics. These, too, are available at no cost. Parents, professionals, employers, and other members of the public are encouraged to contact DB-LINK (Jacobs, 1999-2000). (Teaching Research, 345 N. Monmouth Ave., Monmouth, OR 97361 [PH: 800-854-9376; TTY: 800-854-8150; FAX: 503-838-8150; www.dblink.org)

- National Family Association for Deafblind (NFADB)

  NFADB is a national network of families who focus on issues surrounding deafblindness. As a national organization, NFADB advocates for all persons who are deafblind, supports national policies to benefit people who are deafblind, encourages the founding and strengthening of family organizations in each state, provides information and referrals, and collaborates with professionals who work with persons who are deafblind. The organization has representatives in each of its 10 regional districts throughout the country. It also publishes a quarterly newsletter (Jacobs, 1999-2000). (141 Middle Neck Road, Sands Point, NY 11050 [PH: 800-255-0411 ext. 275])

- The Directory of Mental Health Programs and Resources for Hearing Impaired Persons

  This book lists mental health programs for deaf people, which means the agencies presented have professionals on their staff who can use sign language, understand deafness, and will probably have some experience with deafblind clients. It also lists available inpatient services for severely mentally ill deaf and deafblind individuals. (Available for $15.00 from the Gallaudet University Bookstore, Washington, DC 20002 [PH: 202-651-5380]).

- Foundation Fighting Blindness

  This is primarily a research foundation studying RP and other retinal disorders and causes of blindness. It has a human services division which will provide up-to-date

literature on Usher Syndrome and general information on services and current research on this disorder. (Executive Plaza I, Suite 800, 11350 McCormick Road, Hunt Valley, MD 21031 [PH: 800-683-5555]).

Summary

The major psychological problem faced by students who are deafblind is isolation. By learning sign language or some other reliable mode of communication, appropriately using available public services, and by maximizing peer interactions with other deafblind students, deaf signers, and hearing signers, the isolation of deafblindness can be significantly reduced. Developing computer literacy skills which afford access to chat rooms, listservs, instant messaging, and video phone technologies are also critical skills to acquire.

Although psychologists, social workers, and psychiatrists able to provide competent, helpful evaluations or treatment of students who are deafblind and need these services are in short supply, methods and places to locate such individuals are suggested for both deafblind youths and adults. Any appropriate or available resources should be thoroughly explored and contacted to improve the mental health outlook for deafblind students.

Chapter Five

Orientation and Mobility
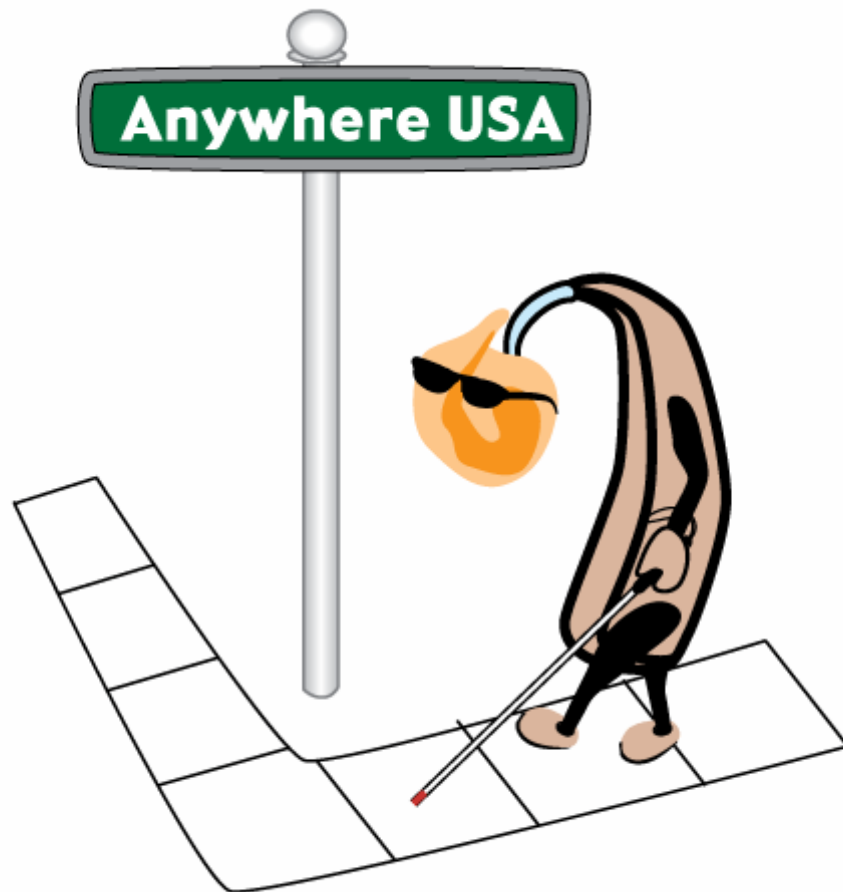
Orientation and Mobility Issues for DeafBlind Students: Considerations for High School, College, and Community Life

Penni Telleck

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Orientation and mobility (O&M) skills for deafblind students involve far more than just walking from one place to another. Teaching good O&M skills involves understanding and determining the area in which the individual will travel. Also, it is very important to identify the safest and most appropriate routes of travel, and the most practical mode of transportation the student should use. Beginning early in the education program for some deafblind students is not always possible and often services that are provided are offered on a limited basis. It is for this reason that all deafblind students, who are planning to attend college or a university away from home, should receive extensive O&M training while still in high school. This training should involve, in addition to cane travel and the proper use of a sighted guide and tactile maps, the use of mass transit and accessible transportation services for persons with disabilities. Training on how to access potentially complex transportation services and how to successfully utilize these services can not only ensure the security of the deafblind student, but can also give the student a boost of confidence and self assurance. If a deafblind student is also coping with a physical disability and is not able to walk long distances, an early visit to the college campus is imperative. Furthermore, it is critical that all deafblind students receive training from a certified O&M instructor to enable comfortable and confident travel on the college campus and any areas within the community that will be visited frequently.

Many college campuses are large and very complicated, with classrooms several yards or even miles apart. Once the student has decided to pursue post-secondary education, and has decided on the specific program of study, identifying which campus to attend is the next step.

The deafblind student may opt for a two-year program versus a four-year program, based solely on the size of the college campus. Community colleges offer students a glimpse of college life and the rigorous demands of a large four year program. The community

DeafBlind students who receive mobility training are often transported out into the community for lessons.

college may have fewer students on campus, along with fewer buildings to negotiate compared to a larger, university campus. For some students, changing classes while in high school may have consisted of walking down several hallways, a few flights of stairs, or even walking to trailers located on school grounds. The community college experience expands this concept of increased distances when changing classes. For many students who are deafblind, learning how to navigate a large crowd and a larger environment may be overwhelming, especially if the student has never received orientation and mobility training or any one-to-one support services. Moving independently from one location to another may present an entirely new and frightening learning experience for the deafblind student. Conveniently, many community colleges are limited to one or two buildings. Additionally, it is possible that many of the classes on the student's schedule will be held in a section of the campus where several buildings are located and limited travel by foot is required. In this way, the community college may present an attractive post-secondary option for the deafblind student.

Some deafblind students, however, may be required to negotiate a large college campus; in such cases, some form of transportation should be considered. If the student has definite plans to attend college on a large campus, discussing mobility needs with the Office for Students with Disabilities will enable the student to receive transportation support or preferential consideration for class location. Knowing how to use co-workers and classmates as sighted guides may also be necessary during emergency situations or when unscheduled events arise. However, the O&M instructor should make certain to provide the deafblind student with alternate routes to consider should an actual emergency occur. These alternate and emergency evacuation routes should be taught during early visits to the college campus, but after the initial orientation lessons related to dorm, cafeteria and classroom

Understanding bus routes or other types of public transportation is essential for any college student or individual who desires to live independently.

locations have taken place. Each semester, deafblind students will likely require O&M training from a certified instructor to map out routes to and from newly scheduled classes. Even if the student is familiar with a particular building, it is advisable that an O&M instructor orient the student each semester.

When considering participation in civic organizations and places of worship located in the community, consistency is the key to the student's ability to safely and effectively utilize

these facilities. It is not realistic to think that a deafblind student, who has significant vision loss and hearing loss, will be able to master an entire college campus, office building, or place of worship after a single visit. While there may be deafblind students who are capable of such a feat, it should not be considered the norm nor expected. Ample time should be allotted with multiple visits scheduled to the site in order to provide the student with proper instruction. Time for students to take notes in their preferred media should also be provided.

Receiving orientation to special and necessary locations on campus and at the work or internship sites are a few of the areas that should be mapped out for the deafblind student. For example, a large print or tactile map of the campus that identifies and plots locations and safe routes for the cafeteria, library, computer lab, and health facilities can be essential for the deafblind student when navigating the grounds. Any housing accommodations must take into consideration the location of students' dorm in relation to the majority of scheduled classes and the cafeteria. Also, safety issues regarding emergency alerting devices, door and telephone signaling systems should be in place before any housing accommodations are finalized.

Also, prior to the beginning of the semester, the deafblind student should receive orientation to individual classrooms and other important offices, preferably during times when the campus is less populated. The student should receive orientation to the front versus the back of the classroom, especially when more than one entrance for a classroom exists. Orienting a deafblind student to a classroom will include pinpointing the location of the area where the instructor tends to stand, the nearest exit, and any break areas. Lighting fixtures, waste baskets and windows should also be identified. Explanations of this nature will be of great benefit to the deafblind student when classes begin and participation in group discussions take place. Again,

Using the long white cane not only helps the deafblind student to understand his/her surrounding; the cane is also a way to let others (especially motorists) know that the student has vision loss.

optimum times for this initial orientation can occur during holiday and summer breaks when most college students are away.

The route the student should access for getting to and from the restrooms should be worked out upon arrival to the classroom. This will reduce the likelihood of any unnecessary complications or disruptions during the class lecture. Such support may be provided as a courtesy by classmates or the interpreter assigned to that location; however, it is critical

that a certified O&M instructor provide the initial mapping out of the most efficient and safest routes the student should travel. Once the student is comfortable with the layout of the campus, follow-up may be done after the actual semester begins. Since courses are offered throughout the day and into the evening, a deafblind student who may be quite capable of traveling during the day without much difficulty may require assistance during the hours between dusk and nightfall. Orientation and mobility training with a long cane using a flashlight or night vision goggles may be beneficial on campuses that are not well lit or when students require additional lighting.

It is highly recommended that the O&M instructor obtain a copy of the student's class schedule as soon as possible and begin orienting the student to the sequence of that schedule. It is helpful to arrange several practice runs starting from the student's dorm room, the cafeteria or the campus entrance for students who commute, until students are comfortable traveling selected routes. In addition, alternate routes may be incorporated along with other buildings that not specifically pertain to the student's current class schedule. For example, if the student learns that a class has been cancelled and decides to study at the library, or go to the bookstore, or even visit an advisor's office, awareness of alternate routes to negotiate the campus will be useful. The more knowledgeable the deafblind student is about the campus, the less likely supplementary orientation training will be required for future semesters.

Knowing the type and degree of hearing and vision loss the deafblind student experiences is very important when mapping out travel routes. Depending on the severity of

Mobility lessons for students who use motorized scooters or wheelchairs should take place on the college campus before the semester begins.

the student's hearing loss, echolocation can be emphasized to help students detect when they are passing by a large open space, entering an area with a large cluster of buildings or significant obstacles. If the student is able to localize sound, the O&M instructor can help identify auditory landmarks which may be helpful later when trying to master a particular route.

For deafblind students with a unilateral hearing loss, sound localization may require very good sound tracking skills. For deafblind students, there are important implications for sound localization when a unilateral hearing loss is present. For some deafblind student's hearing sensitivity may only be in one ear or the audiogram may show different thresholds of hearing. For other deafblind students who have different thresholds, sound

must be loud enough to stimulate both ears for good sound localization. It's important to note that, some deafblind students will be capable of localizing sound with one ear if the sound source is persistent and the student is able to tilt/move his head from side to side.

Another important skill for the deafblind student to master involves sound shadow. The process of sound shadow occurs when an area has reduced sound power due to reflected and/or absorbed energy. This phenomena known as sound shadows are created when objects are located between the student and the sound source. As sound bounces of soft or moveable surfaces, energy is dissipated into or around that object. When the sound energy strikes a rigid object, like a classroom wall, the energy is then reflected. In both cases, the quality of sound being received by the deafblind student will be changed from how it appeared originally. Lastly, incorporating the use of olfactory skills may greatly enhance a deafblind student's ability to master a particular travel route. However, seasonal smells from gardens, trees, restaurants or street traffic can offer valuable clues for deafblind students traveling alone or when using sighted guide (Tucker, 1997 and Howard Hughes Medical Institute, 1995).

When teaching a deafblind student to use a long cane in an unfamiliar environment,

Proper cane techniques include scanning (turning the head from side to side) and cane placement. The cane should touch the surface area just before the student places his/her foot on that spot. This will enable the student to be aware of and maneuver around any obstacles.

it is best to emphasize the importance of the constant contact technique to maximize the amount of information received. As the cane moves along the ground, the deafblind person is able to detect cracks in the sidewalk, smooth versus brick surfaces, curbs, and whether veering from the concrete pathway into the grass has occurred. During inclement weather the cane is a very important tool that can help the deafblind student know when an icy or snow-covered surface is up ahead. Navigating around mounds of snow removed from the roadway may cause additional hazards when traveling on sidewalks. Climbing over the mounds or walking in the street or roadway is very dangerous and is not recommended. Alternate forms of transportation should be identified when weather conditions make travel my foot dangerous. Also, the cane is a very good way for other pedestrians and motorists to identify the deafblind student as an individual with vision loss. This acknowledgement of vision loss may help keep the deafblind student out of harm's way. Because college campuses and community neighborhoods are uncontrolled environments, use of the cane is imperative. Also, it is important for the deafblind student to remain attentive at all times whenever

traveling in the community. Even when using sighted guide or a dog guide, the cane can be used to detect any surface changes that may not be identified by the dog guide or sighted guide.

For indoor travel, the deafblind student will want to request that any changes in the physical layout of a building are shared ahead of time. If living in a residence hall with a common area, it is recommended that the deafblind student share information or specific limitations regarding vision and hearing loss with dorm mates, so that furniture is not randomly moved and items that can be a potential hazard are not left in the middle of the floor.

Summary

Starting college can be a very anxious time for any student. For the deafblind student, the new college environment not only offers opportunities to meet new friends and to participate in new academic challenges, the size and layout of new college campus can also serve as a deterrent to the student's ability to fully enjoy their post secondary education experience. Planning ahead while in high school will help the deafblind student to be better prepared for their new academic life whether on a small manageable commuter campus or at a large four year university program. A better understanding of the college campus can help the deafblind student with orientation. Visit the campus early so that the student has a mental image of the campus layout and other essential landmarks.

Some important concepts that any O&M instructor will need to keep in mind when working with deafblind students include: Not all deafblind students who use hearing aids possess strong speech-reading skills or use American Sign Language (ASL). In many cases, written English skills of a student who is culturally deaf may be limited. Generally, the language skills of students who are hard-of-hearing will be developed through an auditory base while those students who are deaf will be developed through sign language. This will have great implications for the way in which students are able to process the verbal and written instructions provided by the O&M instructor. DeafBlind students for whom English is a second language may benefit from the use of tactual models, or ASL concepts may be required so that instructions are fully understood.

Helpful Tips for Mobility Instructors
- Not all deafblind students are totally deaf.
- A hearing aid does not correct a hearing loss like glasses correct refraction problems. Most deafblind students have sensorineural hearing losses and the clarity of speech

remains affected, even with a hearing aid. As a result, many hearing aids do not make speech more clear, instead some devices merely amplify the sound.

- Not all deafblind students use ASL. Not all deafblind students use interpreters. Some deafblind students may prefer to communicate through speech-reading while others may prefer sign language.
- DeafBlind students who are culturally Deaf will vary in their communication skills. It is important to note that a deafblind student's language skills may not be related to intelligence, but are often times more representative of someone learning English as a second language.
- Remember: Interpreters will sign comments and everything that is spoken. Try to refrain from making off-color remarks as the interpreter is obligated to pass the information along to the student.
- Interpreters are not there to answer the deafblind student's questions. If the student has a question, he/she needs to direct it to the O&M instructor. The interpreter will voice the student's question if the instructor does not understand.
- If a deafblind student is using an interpreter, speak directly to the student, NOT the interpreter.
- Assure that you have the deafblind student's attention before speaking.
- Look directly at the deafblind student when you speak.
- Not all people with hearing impairments are good speech-readers. Good speech- reading skills have no correlation to a deafblind student's intelligence. Only 26-30% of spoken English is visible on the lips.
- Speak naturally and clearly. Slowing down slightly may help, but please DO NOT exaggerate lip movements or shout.
- Short sentences are easier to understand than longer sentences.
- Frequently, the deafblind student who is speech-reading has to mentally "fill in the gaps" during communication. An extremely valuable technique for the O&M instructor is to use a bold dark marker to write out key words related to the topic under discussion. This technique can also be used when it is time to change the topic.
- Do not smoke, chew gum, or otherwise block the area around your mouth when communicating with the deafblind student, as this makes speech-reading more difficult.
- Try to avoid standing in front of windows or other light sources. The glare will make it difficult for the deafblind student to read lips and see facial expressions.
- If you do not understand the deafblind student, ask him to repeat. If that doesn't work, use a black marker and paper. Good communication is a crucial goal; the specific

method that works best for both the instructor and the deafblind student is what becomes important.

- Students with hearing loss may need to sit near the sound source, i.e. close to the instructor or speaker.

- Most hearing aid users are now fitted with digital programmable hearing aid(s) that allow for greater flexibility in different environments. Also, the increased use of the cochlear implant (CI) has also improved the auditory skills of many deafblind students. However, hearing is still impaired and clear, smooth communication will require effort.

No two deafblind students are the same. When working with a student stamina should be taken into consideration. Also, it is important to remember that working with deafblind students will require a greater amount of time – especially when using an interpreter or tactile sign language. For this reason, the O&M instructor should schedule extra time when introducing new routes or new concepts. In some cases, taking frequent breaks may be necessary to review vocabulary, new concepts and to permit the student time to take notes. Like the student, an interpreter may need additional time to become familiar with vocabulary, concepts and may need to discuss appropriate signs to use in order to convey a technique or concept. Finally, depending on the student's type and degree of vision loss, clothing should be worn that provides a contrasting background color for the hands and face of interpreters and O&M instructors. When working with hard of hearing students the use of matte lipstick can help with lip reading. Always, it is important to remember that excessive amounts of makeup, fingernail polish and shiny jewelry should be avoided.

Chapter Six

"Funny things happen
Learning and creating
I do not always see
Labels on spices and containers
So I come up with some pretty
HOT dishes…"

~ Marcia McDermott
(Cooking a Meal, 2006)

Readiness Training for Living Independently on the College Campus and in the Community: Essential Skills Checklist for DeafBlind High School Students of Transition Age

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Like many students exiting secondary programs, deafblind students often lack proper preparation for life after high school. It has become apparent that more effective strategies are required much earlier than at the high school level to guarantee post-school outcomes that are reflective of deafblind students' actual aptitude and aspirations (Petroff, 1999). The exact factors that lead to clear-cut positive post-school outcomes have yet to be identified; however, a compilation of the frequently cited skill sets that determine the need for training have been gathered, and will be discussed in this chapter.

Due to the demanding academic course load required to obtain a high school diploma, many independent living and life-skills, essential for the deafblind student to live independently, are eliminated from daily school schedules. Parents and educators report that, like all secondary students, deafblind pupils are unable to pack any additional time into their already challenging educational programs (Ingraham, 2001). As a result, deafblind students are often forced to utilize time at the end of the school day, summer vacation or extended holiday breaks to address skill deficits related to independent living skills. In rare instances deafblind students have extended time at the secondary level to allow for adequate training in independent living and other essential life skills.

Defining Independence

While still in high school, or even during the middle school years, students who are deafblind should have access to secondary and post-secondary resource personnel who can offer a clear understanding of what life after high school will require (Ingraham & Anderson, 2001). These key service providers can be transition coordinators, education team leaders or advocates with specialized skills in deafblindness. The specific services available can and often do include: orientation and mobility instruction, print-to-Braille transcription services, notetaking services, interpreter support services, adaptive technology evaluations and

training, funding resources for equipment acquisition, and vocational assessments to determine academic and employment potential. In addition, the student, if not already assigned, should be given chores related to personal needs and household routines. Assuming as much responsibility for personal attire, grooming, organization and social activities as early as possible will help the deafblind student gain more self-assurance and life-experience prior to entering high school. An assessment by a Rehabilitation Teacher may also be in order. Such contacts can be made through the Vision Instructor working with the student. Also, in some states, vocational rehabilitation agencies have lists of Rehabilitation Instructors who can be accessed on a contractual basis for students who may require independent living skills training in the home.

Though essential to a successful education placement for deafblind students, many students are naive about how services such as those listed above are typically coordinated. Often students exit the school system uninformed about the wide array of service options, frequency, practicality or rationale for why access to these services may help to make the educational experience both possible and positive. Even though many deafblind students have reached the age of maturity by the time the initial college semester begins, many have not been afforded the opportunity to engage in practical life experiences that involve problem solving or time management. As a result, after arriving on the college campus or entering the adult service system, scores of deafblind students often report feeling lost and before long have squandered significant time trying to figure out all the policies associated with the new academic, residential environment and new level of responsibility (Ingraham & Anderson, 2001).

The more time deafblind students are given to exercise self-determination while still in high school, the better equipped they will be upon graduating from the secondary program and taking on primary responsibility for the direction of their adult lives. Yet, for many deafblind students who are entering college, exercising this level of self-determination based on clear and thoroughly researched options may be a very new and frightening concept. This is especially true when students are not accustomed to independently making critical life decisions or problem solving.

One very engaging approach to teaching critical thinking and problem solving skills to deafblind students is through the use of board games. Games such as: Othello, Catch 21, Chess and Scrabble offer students an opportunity to plan each move and to consider the consequences of each move that is made. These games can also be played in groups or teams so that students can become familiar with the role each member of a team plays when working toward a common goal. For students whose disability preclude them from

joining sports teams in high school, the use of these competitive board games can help to create a sense of belonging and affiliation like that experienced by popular high school jocks or members of social cliques.

Getting Started

Often, as was just suggested, the road to post-school success for deafblind students begins long before high school transition plans are devised. Family members, early educators, and deafblind students put in many long hours and lots of hard work to make certain that every opportunity available for support and growth is seized and fully utilized. For deafblind students who are preparing to transition from high school to college, the need for independent living skills may be another in a very long list of essential skills needed to help ensure a successful college experience. However, many students and their parents often report that they are not really clear on what it means to have independent living skills. Independent living skills are more than just the ability to cook, clean, select appropriate clothing for weather conditions or to travel safely in the community. A very simplistic definition for independent living skills would be the ability to get through the day-to-day tasks of life, doing as much as possible by oneself (Brown et al, 1991). Knowing when to request assistance and when to exercise self-determination are also a part of independent living skills and may be based on individual maturity and comfort levels. Still, there are some basic steps that students and their families can take to develop good decision making skills.

Laying the Ground Work

While students are still in high school, every effort should be made to help them to actively participate in or even facilitate their own team meetings (Ingraham, 2001). A process such as this offers a sound approach to developing decision making skills that have an immediate impact on deafblind students' current and future needs (Brown et al, 1991; Ingraham et al, 1998; Ingraham & Anderson, 2001).

When beginning the transition process earlier, using the results from independent living readiness assessments for living in the community or on the college campus can help identify appropriate post-secondary goals the deafblind student should target during the remaining years in the education system (Ingraham, 2001). By developing self-awareness and self-determination skills prior to graduation, the deafblind student is afforded greater opportunity to practice making critical decisions. Also, the student will acquire a better understanding of important things needed to help ensure a good quality of life. However,

one very crucial word of caution for professionals and parents working with transition-aged students who have never been given responsibility for their own critical life decisions -- some students may find the process a little intimidating. Initially, many deafblind students who engage in self-determination activities and assume a greater responsibility for their daily lives may appear angry, disengaged or even weighed down. Or, some students may even believe that professionals and family members are no longer interested in or care about their well-being. When greater expectations are placed on the shoulders of deafblind students, some may feel threatened by what may be perceived as an attempt to prove they are less capable than they believe themselves to be. The *process* of developing sound decision making skills in students with such severe disabilities will require measured steps and a lot of patience on the part of all team members (Brown et al, 1991). Often, the end result of all the resistance, hurt feelings and discomfort is more capable and self-assured deafblind adults capable of assuming full responsibility for significant life choices which will directly impact their future.

Basic Skills

In order for a deafblind student to live independently a number of very basic skills will be needed. These skills include, but are not limited to: shopping, budgeting, cooking, cleaning, and creating organizational systems and demonstrating appropriate behavior when socializing with others. Parents and educators should help deafblind students begin to focus on these skills for independent life after high school. If the deafblind student has never gone to the grocery store alone or prepared a hot meal, it is best if these skills are introduced, taught and mastered before arriving on the college campus. Some cities offer grocery delivery services; however, the route to and layout of the local grocery store should always be taught if the store is physically accessible to the student. If the deafblind student did not attend a school for the blind or a specialized training program for the deafblind, it is highly unlikely that he will be familiar with the cooking or proper organizational systems used by the blind. Depending on the deafblind student's literacy level and computer skills, information on safe cooking, cleaning and labeling techniques used by blind and deafblind individuals can be accessed on line (www.visionconnection.org or www.afb.org). Also, most state vocational rehabilitation agencies and community rehabilitation programs offer very convenient options that can also be tapped. For transition-aged students who are preparing to attend college or live independently in the community following high school graduation, these resources can be very valuable. This is especially true when goals specific to independent living skills training are included in the deafblind student's IEP. Such goals

should be included in students' IEP as soon as possible; and most definitely by age 16. If the school program is unable to offer this level of training, local community rehabilitation programs for the blind or specialized training programs such as the Helen Keller National Center can be helpful resources.

Home Management Skills

Domestic skills are just some of the areas that professionals and parents working with deafblind students will want to explore prior to graduation. Moving to an apartment on or off campus may be a possibility for some deafblind students, even though many students begin their college experience living on campus in a dorm room. Members of the student's education team are encouraged to plan ahead to make sure safety is addressed (see Chapters on Emergency Preparedness and Orientation and Mobility). The use of signaling systems that either have flashing strobe lights or vibrating clip-on receivers should be investigated whether the student resides in a dorm on campus or an apartment nearby. The issue of safety is paramount so deafblind students who desire to live in their own apartment should be required to undergo an independent living skills assessment and to take part in any available training to make certain that living alone in the community can be done safely. It is strongly recommended that during independent living training the student receive instruction regarding the exact precautions to take both when inside the dorm/apartment and when accessing the local community. Learning how to safely and properly use cooking utensils, appliances and proper safety techniques for cleaning are only a few of the crucial skills that deafblind students will need to consider when preparing to move away from home.

Organization

Keeping track of important documents such as reports from doctors that certify the student's disability will require a reliable organizational system. This system will include a list of the student's specific support needs, prescription medication, health insurance providers, bank and credit card statements, along with the names and contact information for important service agencies in the community. Containers that are easy to store, retrieve and have sufficient space for all the information the student will frequently access should be set up prior to the start of the college semester or before moving into an apartment in the community. During the final years of high school, deafblind students can be given responsibility for keeping track of these documents using a system at home that is similar to what will be used on the college campus or in the community. The student should receive

training in how to scan print copies of any important documents and how to store them on a portable flash drive or DVD should be provided to the student. Maintaining protected files on a home computer, portable notetaking device or in a cyber file can also facilitate quick access to important information when applying for services, employment or in the event of an emergency.

Labeling

Coupled with the need for an organizational system, the deafblind student will require a labeling system that is clear and uncomplicated. Whether the student decides to use Braille, large print, recorded audio messages or even tactile symbols, the system must be one with which the deafblind student is most comfortable and finds easy to use. Simply placing legible labels on the surface of storage containers or file folders can help the student keep track of important documents. However, the labels should be clearly written, placed on the appropriate containers, and easy to access as well as accurate. Each student's vision

loss and organizational preference will determine which filing system and labeling method are best. For example, many file folders are offered as third cut which mean that staggered along the top of each folder are tabs where labels are placed for easy viewing. Some deafblind students who use Braille may find it more efficient and less confusing to use file folders with

File folders that are staggered are a lot easier to read when tabs are labeled using large print.

tabs that line up sequentially. Tabs that line up sequentially provide deafblind students who use tactile markings (i.e., Braille, tangible symbols, etc.) with a neatly arranged system that is not randomly scattered or difficult to track. On the other hand, third cut folders (staggered tabs) may be a lot easier when using large print labels or visual markings that would otherwise be covered up or obscured by tabs that are lined up in a single row.

For Braille readers, it is less confusing to use file folders with labels tabs that are lined up sequentially.

Another adaptation which will afford easier reading and access for students who use Braille is to place Braille labels upside down on the reverse side of each tab which will make the label easier to read. The student can curve their fingers over the tab and read the label naturally, as opposed to removing the folder from the drawer to read it on a firm surface.

Another variation would be to place the Braille label upside down on the front of the tab and simply turn the file folder around. This method will help the student to both read the folder title and have easy access to the folder's contents without having to remove the folder from the file drawer. Additionally, students who use Braille may find that labeling a particular corner, the top or bottom of individual documents within folders will reduce time spent rummaging through cluttered file folders looking for a particular document. Other students have found that creating individual file folders for each important document, while somewhat tedious, is less frustrating when they are required to retain print copies of important documents.

When a file is removed from the drawer, a large binding clip, large potato chip bag clip or clothes pin can be used to mark the space in drawer where the folder should be returned (www.visionconnection.org). By far, scanning and saving print copies of printed reports conserves space and reduces the need for bulky fire retardant storage units.

Similar labeling systems can be used for labeling food containers, clothing and specialty devices. It is important to place the label in a position that can be easily and quickly accessed which can save time and lessen frustration. Arranging clothing or food containers in order of importance, frequency of use or size of container can also help reduce the amount of time spent hunting for a particular piece of clothing, food item or specialized device.

Lighting

The use of lighting both indoors and outdoors is very important to consider for students who will be living away from home. Rarely are dorm rooms or apartments equipped with sufficient lighting for students with low vision. Purchasing extra lighting that is stationary or portable may be an easy remedy. However, the student will need to check to see if electrical circuits can accommodate their adaptive technology along with additional lighting fixtures. For a number of reasons, the size of the lighting source used will be very important. There are many very powerful lights available that run on AC power or are battery operated and may serve the deafblind student well in certain situations when electrical circuits or outlets are limited. However, to prevent potential fire hazards, it is extremely imperative that any dangers associated with high intensity lights are reviewed with the student. Many college campuses prohibit the use of halogen lamps or high wattage lighting fixtures. The student should check with the Director of Student Residence Services before bringing lighting fixtures to campus. Portable high powered flashlights such as long lasting LED (Light-Emitting Diode) lights can offer illumination over an expansive area

(Chapman, 2001). But, the deafblind student should take care not to shine these LED lights directly into the eyes or toward the face of others. These powerful compact units produce intense illumination that can cause damage when exposed to unprotected eyes.

Dining Skills

Whether the deafblind student is planning to eat meals in the campus cafeteria or in a private setting, good dining skills are important. Not only will the student have to determine the level of support required to access cafeteria menu selections, but the skills required to consume the food will also need to be considered.

Choosing food based on nutrition and not the ease by which it can be consumed should be priority. For example, if the dining hall selections are pizza with the works or baked fish, baked potatoes and green beans, the deafblind student will have to decide which menu item is more nutritious and which one would be easier to eat. It may be less complicated for the student to use his hands when eating the pizza, as opposed to having to use both a knife and fork, which are required for the baked fish. Though easier to eat, the pizza may not be the healthiest choice. In a pinch, when the student is unfamiliar with how to cut meat, a request can be made to have the meat cut by the server or assistance from a friend can be sought. Nonetheless, cutting meat safely and properly is a skill that can be easily acquired and the deafblind student should practice whenever possible. Likewise, using a spoon or fork without dropping or spilling items takes practice and patience. Requesting lids for beverages or sealed containers for entrees can help lessen mishaps associated that can happen when transporting food or when moving around crowded or large dining halls. The use of a napkin as a clothes protector or other techniques to reduce spillage should be reviewed with the student at home or during high school. It can not be stressed enough how important proper dining etiquette is for all students. Practicing at home or receiving a few hours of training from a specialized program or instructor for the blind or deafblind can stave off potentially embarrassing incidents.

Time Management

By far, the biggest challenge most college students, and deafblind students in particular, admit facing during their initial college years is the ability to juggle a variety of tasks, assignments and interests. Time Management is probably the single most important skill that deafblind students will need to learn in order to be successful at college or on the job. Regardless of how capable a student is and/or how proficient when executing specific academic tasks, success may remain illusive, if he can not initiate or complete assigned

work on time. Whether the student follows a strict to-do list, has a timer, uses a watch alarm or staggered class schedule, good time management and punctuality are needed for any degree of success to be realized at the collegiate level. This will include strategies for effective study sessions and course selection based on anticipated homework. In high school some deafblind students may have been given permission to leave classes early to avoid the throngs of students moving through the hallways, but the size of the college campus may require even greater preparation. Leaving larger blocks of time in between classes, selecting courses that are in close proximity to one another and the student's dorm or the cafeteria may be best. Planning to this extent may afford the deafblind student ample time to travel in between class sessions, set up and disassemble adaptive equipment, arrange for support services or meetings with instructors.

Documenting Progress

The checklist below can be used during transition meetings or activities within the Individual Transition Plans (ITP) or with the IEP team. The skills and interests of each student will determine exactly which target areas are relevant. Providing instruction to deafblind students around self-determination and independent living is a process and may take several years before progress is realized. It is best for team members to think of ways to involve and educate students about how and why certain services are delivered. Initially students may not wish to remain in school longer in order to have these skills addressed or they may not want to forfeit holiday or vacation time for remedial instruction in cooking, cleaning or personal hygiene. But, in the long run the student will see that taking such early steps to independence and self-awareness will definitely be advantageous.

Summary

After many years of being passive and reliant on others to obtain support services and accommodations, deafblind students of transition-age must be encouraged and supported to assume a more proactive role in planning for the future. The student's support team should maintain a delicate balance between supporting, providing mock experiences and testing the student throughout this process. Requiring students to get involved earlier by taking part in, or arranging their own support services, transportation or supplementary skills training while still enrolled in high school offers a great opportunity to practice strategies/skills that will be needed once college begins. Self-discipline can be encouraged, by providing real consequences for poor time management or failure to fulfill obligations. If deafblind students are not given the opportunity to problem solve while under the tutelage

of seasoned professionals who are responsible for and experienced in facilitating the high school transition process for many students, there may be little chance such guidance will be obtained after leaving school.

The strategies and recommendations compiled in this chapter have been gathered directly from deafblind students, family members and service providers as a guide for developing this individualized readiness inventory checklist. The etiology, severity of disabilities, preferred communication mode and educational background will help team members keep in mind the individualized nature of the checklist. Not all possible support or training areas are listed. Some areas are left blank intentionally to accommodate additional skill areas for individual students. However, even though the suggested list is not exhaustive, it does offers a foundation upon which team members can design individual portfolios or training programs to prepare deafblind students to live as independent adults following high school. A more comprehensive list can be located on the Michigan Department of Education website (http://www.cenmi.org/msdb-LIO/ILS.asp).

INITIAL INDEPENDENT LIVING SKILLS CHECKLIST FOR DEAFBLIND STUDENTS BEGINNING COLLEGE

Name_____
Etiology _____
Vision Loss: _____
Hearing Loss: _____
Age: _____
Gender: _____
Communication Mode: _____
Technology Needs: _____
Educational Background: _____
Other: _____

DOMAIN: Dressing
Can dress properly according to occasion (i.e., special event, weather, casual outing, etc.)
DOMAIN: Hygiene
Understands personal hygiene responsibilities and needs (i.e., grooming, proper attire, matching clothing, etc.).
Has understanding of safe sex and how to practice universal precautions.
DOMAIN: Eating Skills
Has awareness of proper dining etiquette.
Can identify nutritious food choices.
DOMAIN: Cooking/Meals
Can safely use common kitchen appliances.
Is aware of proper safety techniques for cooking.
DOMAIN: Household Chores
Knows proper procedure for domestic cleaning including: laundry, dishes, floors, bathrooms,

etc.
Is aware of current independent living skills limitations.

DOMAIN: Safety/Emergency Procedures
Understands what procedures to follow in case of an emergency (i.e., fire, flood, hurricane, tornado, blizzard, etc.).
Has knowledge of basic first aid for common accidents (i.e., cuts, burns, sprains, etc.).
Has a proven evacuation plan mapped out for campus and community.

DOMAIN: Telecommunication Skills
Can initiate and receive telecommunication correspondences using a variety of methods and devices (i.e., two-way pager, VP, TTY, email, etc.).

DOMAIN: Time Management Skills
Can initiate important tasks without prompting.
Has understanding of time management skills necessary for success.
Completes all assigned tasks in a timely manner.
Promptly arrives to each class.

DOMAIN: Money Skills
Has proven money management skills (i.e., savings account, checking account, debit card, credit card, etc.).
Has a budget that is commensurate with personal revenue.

DOMAIN: Personal Information
Knows all personal information (i.e., SSN, address, emergency contacts, medical history, medical coverage, etc.).
Assumes the lead role in locating, coordinating and scheduling any needed support services.

DOMAIN: Medical/Health Care
Is aware of safe health and fitness options (i.e., diets, exercise, nutrition, etc.).
Has a copy of all prescriptions for medications or therapy sessions.
Is aware of own personal medical history and other important health related issues.

DOMAIN: Social Skills
Has access to resources to form social network and friendships.

DOMAIN: Self-Determination
Self identifies as an individual with a disability.
Is aware of services offered through Office of Students with Disabilities.
Is aware of how to locate accommodation resources and make arrangements for services (i.e., vocational rehabilitation counselor, interpreter, CART, C-print, orientation and mobility instructors, rehabilitation instructors, adaptive technology, etc.).
Has ability to advocate for self.
Has knowledge of civil rights.
Understands how to properly request services.
Understands individual support, technology and accommodation needs.
Understands personal learning style.
Is able to identify areas of interest.
Understands the difference between and is able to establish appropriate long and short term goals.
Can differentiate between interests, hobbies and career ambitions.

Assumes the lead role in locating, coordinating and scheduling any needed support services.
Assumes responsibility for following up all team meetings or activities on executed on his behalf.
Understands civic responsibilities as member of community.
DOMAIN: Independent Living Skills
Is aware of current independent living skills limitations.
Engages in activities, tasks and programs to develop independent living skills (IEP, work experience, cooking, shopping, banking, etc.).
DOMAIN: Orientation and Mobility
Is aware of local transportation options and how to access services.
Is aware of campus layout including entrances and remote areas.

SUMMARY

Chapter Seven

Effective Practices to Ensure Successful High School Transition for DeafBlind Students: Biographical Outcomes of Struggle, Self-Determination and Achievement

Cynthia L. Ingraham
Deidre Dockery

Formal research has not yet been conducted to determine which factors lead to definite successful post-school outcomes for deafblind students. However, this collection of personal lessons learned by deafblind students and their parents before, during, and following the transition process is meant to serve as a guide for others preparing for post-secondary transition. One unique aspect of this collection of biographical essays regarding high school transition stories that are *shared by* deafblind students who have already made a successful transition from secondary education to adult life or are in the process of doing so. Each student addresses the numerous issues of accommodation, preparation, and support services often faced by many deafblind students. It is hoped that by each student sharing their individual transition realities, light will be shed on effective practices for high school transition that have been successfully utilized by educators, family members, adult service professionals, and deafblind youths from K-12 and residential settings. Through the use of biographical essays, key factors which led to individual student success will be revealed.

The global nature of our society has made a college education or some training beyond the secondary level virtually indispensable for anyone seeking competitive employment. Most especially, this is true for students with disabilities. Because college affords students access to the skills necessary for employment at a competitive level, it is imperative that each student have access to the support needed for success in post-secondary education programs. Training in time management, study and interpersonal skills, orientation and mobility, or understanding of individual learning styles are only a few of the key areas in which deafblind students will need top-notch skills in order to compete with their peers at the college level. Making certain that the deafblind student has the intellectual capacity and academic guidance to select courses or employment that match their individual talents and interests will help to lessen the likely disappointments and feelings of uncertainty encountered by recent high school graduates.

Like any potential high school graduate, deafblind students have a number of critical decisions to make which will impact the remainder of their lives. These decisions should not

be made hastily, but should be closely considered and weighed after a thorough examination of all available options. In addition to exploring college or training programs, the deafblind student should also consider independent living and transportation support needs, banking and budgeting skills, as well as social and recreational interests. With so much to consider and so many choices, students have frequently shared that time management was one of the major obstacles that impeded their post-high school success.

DeafBlind students who are new to the vocational rehabilitation system may not realize how important it is to have frequent contact with their vocational rehabilitation counselor. Taking on the primary case management role for themselves is a very formidable undertaking for many students, and not many are capable of handling such responsibility right away. However, it is the student's responsibility to alert all members of their support team of any challenges or need for additional assistance in coordinating needed support services. If a student has never been given the task of managing his/her own team of support services, this new role can be overwhelming and intimidating.

Like the high-wire performer who prepares for his balancing act within the safety of gymnasium by practicing his routine walking along a straight line etched on the floor, no true consequence is realized when his footing is unsure and balance is not maintained. The floor is nearby and remounting the line takes little or no support from others. As the performer upgrades his practice to a balance beam that is several inches off the floor, again minimal consequence is realized when a misstep occurs. However, for the final performance it is crucial that the performer possess the top skills for such a high-wire feat or any misstep can prove life altering – to say the least. With no safety net below the performer is forced to be prepared for the unexpected and to have in place "a backup plan" which can be implemented independently. DeafBlind students who are expected to perform immediately upon exiting high school should follow the "groundwork" of the high-wire performer and begin their transition process early on during high school when support is greatest and life altering consequences minimal.

Begin Early

Even if college is not a definite reality for the deafblind student, early transition planning is vital. There is a tremendous amount of forethought must go into the transition planning process. This is especially true for students who require extensive support services such as orientation and mobility, one-to-one interpreting services, modified support for testing; independent living skills training, alternative communication methods for a progressive disorder, or support from a personal care attendant. Any specialized

accommodation that is present during the last two to three years of high school should be viewed as a necessity once the student begins a college. This is also true when a student begins an adult service training program, or moves to an independent apartment in the community.

With so much planning required for post-school life it is easy to see why the transition process for deafblind students should begin as early as possible. Unfortunately, many deafblind students who are considering college may have to begin even earlier to properly prepare for the rigors and expectations of college life. DeafBlind students who are not familiar with their accommodation needs may find themselves in a very precarious position once they arrive on the college campus. Prior to exiting the secondary program, the deafblind student should be guided through the process of developing an individualized portfolio that contains, in addition to information regarding their etiology, severity of disabilities, and personal and emergency contact information; a list of all their equipment, preferred layout of the classroom environment, transportation, and communication support needs (Enos and Jordan, 1996). Many deafblind students are not aware of their specific equipment and support needs while in high school. Thus, it is of the utmost importance that this information and/or resources for obtaining or purchasing necessary adaptive equipment be made available prior to the student exiting the school system.

To avoid having the student's first experience as his own case manager occur when he has already begun college or is living as an independent adult, it is best to use the transition years prior to graduation for practice. Securing accessible class-related resources, materials, and equipment, or other support services such as a mobility instructor, sign language interpreter, or tutor may be new areas for which the deafblind student will need training.

As noted, the average deafblind student is not properly prepared for life after high school. So, better and more effective strategies are required much earlier at the secondary education level to ensure post-school outcomes that are reflective of the student's actual aptitude and aspirations. Many deafblind students have access to some type of resource support while in high school. These support services can and often do include: orientation and mobility instruction, print-to-braille transcription services, notetaking services, interpreter support services, adaptive technology evaluations, specialized training on adaptive equipment, resources for equipment acquisition, and assessments to determine academic and employment potential. Though essential to a successful education placement for deafblind students, many students are unaware of how these services are typically coordinated. Often students exit the school system without ever having any prior knowledge

of the vast array of assorted support services, or the frequency, practicality, or rationale for having access to certain types of support services to make their educational experience both possible and positive. Upon arriving on the college campus or upon entering the adult service system, many students are lost and often lose valuable time trying to figure out all the rules associated with their new environment.

Timeline

Ideally, the transition process should begin as soon as the student enters the secondary program or turns 14 years of age. In some rare cases, beginning even earlier than age 14 is necessary. Often success stories for students who exit the school system begin long before actual transition plans are devised. Family members, early educators, and students themselves put in many long hours and lots of hard work to make certain that every opportunity available for support and growth is seized and fully utilized. The following group of students has all experienced post-school success; however, this success was not achieved without strong individual determination, resiliency and team support. Many of the students attended school following the passage of P.L. 94-142 and thus were able to benefit from a free and appropriate education in the least restrictive environment. A few of the students exited the school system before the passage of P.L. 101-476 which mandated that transition plans be drafted for each student with a disability by the age of sixteen. However, before their educational programs were completed, this subgroup of students did have the benefit of resourceful and forward-thinking professionals who, in essence, embarked on a transition process similar to that set forth in P.L. 101-476. Only one student attended school prior to the passage of any significant education legislation for students with disabilities. All individuals are now thriving by living independently, working in competitive settings, and/or making full use of their community resources.

Depending on the severity of the student's combined vision and hearing loss, etiology leading to these losses, and their previous educational experience, he may be capable of getting by without any specialized services. Other students may require constant one-to-one support to receive information, travel in the community, and live independently (Kinney, 1972; Smithdas, 1977; Ingraham, Carey, Vernon, & Berry, 1994; Ingraham, 2001). To begin the process of planning for successful post-school life, the transition team should contact all adult service providers from whom the student could presently benefit (Ingraham & Anderson, 2001). These providers can include: state vocational rehabilitation agencies (VR), Centers for Independent Living (CIL), agencies that focus on specific disability groups, and even the Social Security Administration (SSA). By far, linking with the

Social Security Administration and the state VR agency provides access to two of the most critical adult service partners for the deafblind student. Any adaptive technology that the deafblind student requires to ensure success in the classroom and in the community should be provided before he exits the school system. This will enable the student to experiment with the equipment while entitlement support services are available to help with any adjustments or additional training concerns (Ingraham et al, 1994; Ingraham, Belanich, & Lascek, 1998; Ingraham & Anderson, 2001).

When the student reaches his 16th birthday, the state vocational rehabilitation agency and any other adult service providers should be active participants in helping to develop the student's transition plan. The level of participation can include actual attendance at IEP meetings or via telephone conference; and in some cases, input and feedback can be provided electronically prior to or following the team meeting. It is advantageous to make use of the knowledge of these professionals while the student is still enrolled within an entitlement program, rather than to wait until the student has completed education and has entered the adult service arena where services are based on eligibility (Ingraham, 2001; U.S. Department of Education, 2003). In many states VR counselors have helped to fund an array of support services, assessments, and even training before the student exits the school system (Ingraham, et al, 1994; Ingraham & Anderson, 2001). These creative and astute VR counselors were able to see the benefit of early partnership with the transition team as the foundation for a consumer case that was more likely to reach successful closure status.

Ensuring Post-School Success

As will be seen from the following biographical essays written by parents and students, planning early in the educational process with some type of definite outcome in mind is most helpful for keeping the student on course. Each student had a support system that enabled them to access an assortment of early education support services in the environment which was least-restrictive based on their individual needs, and not their disability label. Occasionally, it was necessary to change educational settings, level of support services, and even adaptive equipment. However, each student exhibited resiliency and flexibility when change was needed. This ability to "go with the flow" helped to ensure that not only would these students be prepared to make any necessary adjustments later in life, but it also enabled them to acquire substantive coping skills.

Career exploration, peer interaction, and self-awareness were a key part of each student's education experience. Not only did all students participate in their IEP and

education planning, each was given the opportunity to develop self-determination skills by speaking up and advocating for themselves (degree of participation varied). Whether career exploration takes place through an on-line search or in the community, it is very important to expose deafblind students to a variety of post-school employment possibilities (Folska, 2001). Often students who are deafblind are so adept with adaptive technology that they are guided into that field. However, it is important to remember that an individual who possesses great knowledge in a particular area may not always be the best instructor on that subject. As with any other student group, the opportunity to interact with and discuss career objectives with peers and professionals in their field of interest was extremely helpful to these deafblind students. Often times career choices were clarified after meeting another deafblind adult with similar interests or skills.

Finally, as many of these students will confirm, it is important to ask deafblind students early and often what they really know about themselves both intellectually and functionally. Also, students should be asked if they truly believe that they possess the self-care skills needed to live independently. The short checklists below are a great place to begin when attempting to assess whether a student is indeed ready for life after high school, or if a successful outcome is on the horizon.

Checklist for Success: (Questions for Instructors)
1. Does student know how to use an interpreter?
2. Is student comfortable with his disability?
3. Does student know what accommodations are needed and how to use them (TTY, amplified phone, relay, etc.)?
4. Can the student explain his own accommodation needs?
5. Does student have orientation and mobility skills?
6. Does student understand and value the responsibilities of employment?
7. Does the student have to deal with disincentives of any kind (SSI, over accommodating parents, etc.)?
8. Does the student have family support and transportation?

Developing a Post-School Profile (Questions for Students)
1. What type of job would you like to have in the future?
2. In what type of environment do you most prefer for work?
3. Does your employment goal require a college education?
4. What type of people do you prefer to be around?

5. What are your communication, equipment and transportation support needs?

6. Where can you go to get this support or to learn about available services?

7. If you have worked in the past, what jobs have been your favorites?

8. At which jobs were you most successful?

9. Why do you feel you were successful at these positions?

10. What are your dreams for the future?

11. What are the different things you feel are essential for you to have a successful life after high school?

Developing a Resource Book (Compiled by and with student)

1. Personal information (address, DOB, SSN, telephone number, medications, specialized equipment for travel and communication, etc.)

2. Emergency contact information (parents, counselor, case manager, etc.)

3. Special accommodation needs (i.e., equipment, lighting, personal attendant, SSP, etc.)

4. Local and national resources

5. Sample applications, extra resumes, samples of art working or writing sample of published or non-published work

Chapter Eight

EMERGENCY
EXIT
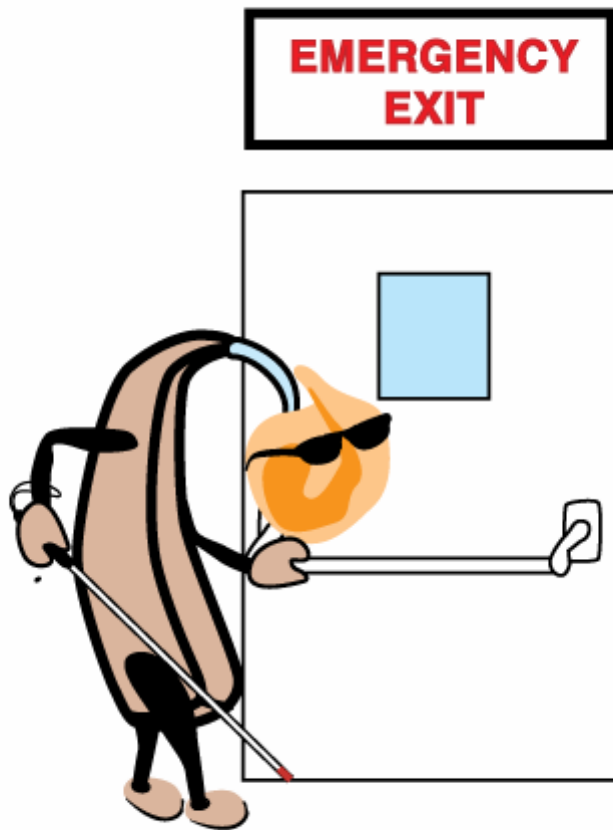
Why is Everybody Running? Emergency Planning for Young Adults who are Visually and Hearing Impaired

Valerie Chmela

Beginning a new job or college can be a very exciting time. There are so many new people to meet and experiences to be had. For deafblind students it may also be a little scary to have their family and friends so far away. Even if the student lives at home there are so many more grown-up responsibilities. It is important for deafblind students to always remember that they have the power to keep themselves safe even when not at home. All that is needed is a little information and some practice, and deafblind students can be safer than many of their dorm mates or co-workers who never give much thought to safety concerns.

Below is a brief story; identify the different ways this deafblind person made mistakes.

It's Friday afternoon. Work or classes are finished for the week, and Student-X rushes home to her dorm room or apartment. It's now time for some serious relaxing! So, she walks into her room and drops her book bag in a corner of the room. Both her cane and Braille Notetaker are inside her book bag. Student-X doesn't bother with clipping the receiver to her alert system onto her belt because she can never remember where she put it last; and besides, she is always forgetting to recharge it.

Next she spends the next few hours playing computer games, chatting on-line and instant messaging with her friends. She is planning to go out to the pizza place in a few hours to meet her friends. She decides to dress up a little before heading out so she goes through her closet to pick out the perfect outfit. She throws clothes are all over the place, but its okay. She knows that she has the whole weekend to clean up.

Suddenly an alarm is rings inside her room but she doesn't know it because she doesn't have her alert system hooked up. Soon she begins to smell smoke, but she figures that someone must be burning popcorn again since that happens all the time. A few moments later, someone begins banging on her door, but she can not hear them. However, she soon feels it – heat – and now she really smells smoke and

begins to panic. Is the building on fire? She rushes out into the hall, but feels the intense heat and it pushes her back inside her room. She wants to call for help, but can not find her notetaker to place the call. She decides to try to escape out the window, but it will not open and her room is on the third floor. She wonders how she will get downstairs to safety. She begins to think about the firemen and when they will come to her rescue.

This is not a true story, but it easily could be if a deafblind student didn't know what to do for protection. The truth is that every deafblind student is responsible for his/her own safety. That doesn't mean the deafblind student is alone, but <u>she will</u> need to set up her own plan to keep as safe as possible in emergency or disaster situations. If one thinks about the story, there are many things that Student-X could have done to have kept herself safer. The first step would have been to think about safety at the time she was assigned her dorm room. Some deafblind students may be better off on the first floor or on the second floor of a dorm. Making a safety ladder available so that those deafblind students who are able to climb out the window can do so may also be a useful safety measure.

When an emergency happens, deafblind students often times are left with no escape because the student may believe she is very familiar with her home surroundings and does not need to keep her cane or communication devices nearby while at home. When evacuating a building quickly, a deafblind student often cannot find the things needed for a safe exit. This is why it is important to assemble an emergency bag. An emergency bag is different than what is called a Disaster Kit, which will be explored later in this chapter. The emergency bag is designed to help the deafblind student make a quick exit and to be ready in an emergency. Like an emergency in the middle of the night when the vibrating fire alarm goes off. It is a good idea for the deafblind student to keep her emergency bag under her bed or

The collapsible or folding cane can be used to break a window if no other solid objects can be located.

on the bedpost where it can be easily grabbed when quickly exiting the building, as would be the case if there was a fire in the building. What is in an emergency bag? What are the things a deafblind student should have in her emergency bag? It is best to begin to assemble the bag with the following items:

· A folding cane. The deafblind student can use it to break the window if the student can't get out any other way. The cane can also be used by the student to find her

way once outside. There may be a lot of confusion and crowds of people around whom the student may have to navigate.

- Printed communication cards that tell emergency workers how to communicate with the deafblind student.

- In a sealed, plastic zipper bag: Phone numbers for family members or other people who should be contacted. A personal medical information page with current phone numbers, insurance information, doctor's name, and a list of any medications that the student has been prescribed should be documented and the page laminated and placed inside the plastic bag. Flash drives can be used to store more detailed medical information, scanned copies of ID cards, birth certificate, photo ID or other critical medical or personal information that can not be listed on the laminated personal history page.

- If the deafblind student has a dog guide, including copies of licenses and vet papers for the dog is a good idea. Only licensed service animals are allowed into evacuation shelters.

- A pair of shoes or slippers. Old ones are fine, but the student should put them on before exiting a window to avoid broken glass or other things on the ground.

- Plastic garbage bag. This is a good way to keep dry in the rain until help arrives.

- Sweatshirt or jacket for the cold, but also to put across a window frame if the glass has to be broken to exit the building.

- Money. It is good to have some small bills and change worth about $5.00.

- Hearing aid batteries, if needed by the deafblind student.

- A whistle and a flashlight so the student can be found in the dark.

An Emergency Preparedness or Grab and Go Kit should have essential items such as: gloves, money, and flashlight, batteries for hearing aid or radio and hygiene supplies just to name a few.

With these items, a deafblind student should be able to escape using a practiced route. This means the deafblind student will need to practice fire drills and have some training with an Orientation and Mobility Specialist. This should be something the student thinks about for each of her classes or work place. The student will need to give thought to how she would get out of the chemistry lab or the cafeteria or the library in the event of an emergency.

Whether in the dorm, at the work site or when traveling, every student should have a signaling system that alerts the student when the fire alarm is activated, the alarm clock goes off or someone knocks on the door.

Another emergency precaution the deafblind student will want to set up is some type of personal alert system inside her dorm room. In the story above, people were banging on the door and the smoke alarm was going off. If Student-X had been wearing a vibrating alert system, it would have given her information about the smoke alarm going off or indicated that the people were ringing her doorbell. However, this device needs to be charged, and the deafblind student must clip it onto her waist as soon as she enters her dorm room. There are also personal alert systems that can be purchased which hook up to the telephone. This type of system has a waterproof button that can be worn around the neck. If the deafblind student needs the police, an ambulance, or the fire department, she can press the button and a person will call for help. When the system is initially set up, the student will be asked for medical information and contact names of family members so, that when an emergency situation arises, this information can then be pass onto the police who will contact the student's family. Connect America has a web site where students can explore which option works best for them.

Cases of Natural Disaster

Using any of these things could have helped Student-X get out safely during her example emergency, but what about a disaster like a hurricane or a tornado? What would Student-X do in a natural disaster? First, it is important for the deafblind student to set up a circle of support; these are people that the student asks in advance if they would be willing to give the student assistance in the event of an emergency or disaster. These people can be neighbors, the residence advisor, friends and family, or campus police. People in the student's circle of support will not come and save the student, but instead may be able to help search for her. The deafblind student is also encouraged to set up a communication chain to be used during a disaster. When family cannot be reached, a relative in another state can be contacted on behalf of the deafblind student. That family member can pass information along to the student's parents.

It is important for the deafblind student to know how to locate the Emergency Exit in each building where classes are held. Also, it is important to be aware of the safest and closest route to use when exiting a building in the event of an emergency.

It is really important for the deafblind student to contact the local fire department. All across the United States, the local fire departments are responsible for emergency and disaster response. It helps to inform them about the deafblind student's support needs, communication systems or other pertinent medical information. Furthermore, the fire department will need to know where the deafblind student is currently living and how to best communicate with the student in an emergency or during a disaster. Often times in a disaster situation, people need to evacuate, which means leaving quickly. The deafblind student may not have time to collect all of her belongings to bring along. The fire department personnel will enter the deafblind student's home or dorm to retrieve the student and maybe a small bag - but that is all. The deafblind student may want to ask the local fire department about disasters such as tornados, wild fires, or hurricanes that may be common to the area where her college is located. The deafblind student should ask the fire department the best way to evacuate the dorm or classroom building and the best way to protect herself if a disaster occurs while she is outdoors.

If the student is attending college or at the workplace, school administration or work supervisors should be asked about their disaster plans for people with disabilities. What will the deafblind student be expected to do? Where are fire exits located in each building? Do the stairwells lead directly outside or to a place that is familiar to the student? If someone tells the student to stay in one place and wait for help, the student should always ask for alternate plans or request that someone help her make an individualize plan for escape. In a disaster the deafblind student needs to have an action plan; sitting and waiting is not a good idea.

Having a flashlight handy is very important is case there is a power outage.

Knowing that a disaster is happening or about to occur is very important as well. The student should explore resources that can be used in different types of emergencies or natural disasters. The NOAA weather radio can be investigated at any of these sites: WeatherRadios.com, HomeSafe Inc., Silent Call Communications, or Harris Communications, Inc. A list of URLs for these companies is provided at the end of this chapter. The NOAA weather radio can be set up anywhere, and can be set to a particular county or area. If a tornado is in an area, the radio will flash an alert message. It can be read under a CCTV, hooked up to a pillow or clip-on vibrating alert system, or hooked to a flashing strobe. When the alert happens, the deafblind student can check on the NOAA website; type in her zip code to find out what is going on. Along with that, the deafblind

student can also sign up for free emergency email service, such as Emergency Email & Wireless Network. This service will inform the student of severe weather and can alert her via e-mail, two-way-pager, fax, cell phone, or other wireless devices such used by the deafblind. The student can decide which specific alerts she wants at the time she activates her subscription.

There is so much more that students can investigate to learn how to keep themselves safe at home, at school and in the workplace. The American Red Cross website or the Gallaudet University Accessible Emergency Notification and Communication website have a lot of very good resources and both are updated frequently.

The most important thing for the deafblind student to remember is that she holds the power to make her life the best it can be. Whether the deafblind individual is working or attending college, she can choose to make herself as safe as possible and a good action plan is all that is needed.

Internet Resources

American Red Cross: www.redcross.org/

Connect America: www.connectamerica.com

Emergency Email & Wireless Network: www.emergencyemail.org.

Gallaudet University - Accessible Emergency Notification and Communication http://tap.gallaudet.edu/Emergency-Resources.htm

Harris Communications, Inc.: www.harriscomm.com/

HomeSafe Inc.: www.homesafeinc.com/

NOAA website: www.weather.gov

Silent Call Communications: www.silentcall.com/

WeatherRadios.com: www.WeatherRadios.com

Chapter Nine

Student Perspectives

"It wasn't easy
It was a long, hard
Journey in life
For us both...

But our love
Held us together
Through the traumas
The ups and downs
Of Life."

—Marcia McDermott
(Being A Mother, 2006)

Transition Partnerships: One Family's Chronicle with Usher Syndrome

Benjamin Belisle
James M. Belisle
Mary Belisle

Benjamin Belisle

When I was in high school I was assigned an interpreter who would work with me in all of my mainstream classes. Because I attended a public high school that had a resource room for deaf students, I did not need an interpreter for those classes because the teachers in the resource room could sign. If I had problems seeing the board or did not understand what the teacher was saying I was allowed to sit in the front row with my interpreter so that I could see better. Other than that there were no other accommodations made for me and I did not use any special equipment for the blind when I was in high school.

Benjamin Belisle at the age of 16.

At the age of 13, I was told that I had Usher Syndrome. My doctor told me, and the words he used to explain the condition to me were not very clear. I was a little scared when I finally understood what he said. Because I was the only deafblind student in my entire school, this news was very shocking for me. After I was told about Usher Syndrome, nothing really changed in my school life, so I was able to push the information to the back of my mind. I continued on through high school and, during the summer, I attended a few training programs that focused on transition services and planning. During two summers in my sophomore and junior years in high school, I attended a transition week at the local rehabilitation center for the blind. I learned a lot about how a blind person uses a cane to get around, or how to cook when you can not see. The best thing I learned while I was there was that there were other students just like me with Usher Syndrome. These students helped me to see how I could cope with my vision loss and how I could still do well in life. Because there were no other deafblind students in my high school, meeting other students with Usher Syndrome made this a very important program for me to attend. On occasion I would attend the Metro Washington Association of the DeafBlind (MWADB) support group/social meetings where I could interact with adults, but there were no teenagers there who were my age.

Recently I visited the Helen Keller National Center (HKNC) to see their program and to attend a meeting for my job. I learned a lot from my visit to HKNC. There were many

deafblind people there who were participating in the training program to learn how to live independently. This visit to HKNC made me wonder what types of skills I would like to learn if I would ever attend as a student. Improving my orientation and mobility skills, receiving information about how to be safe in the community by myself, and how I could live independently and take care of my own home would definitely be areas where I would begin to focus my training. Right now I live with my parents, but I would like to find an apartment near a bus stop so that I can get out to find a full time job and to get around my community.

Benjamin Belisle high school graduation photo

Walking around the community is a lot of fun. It is especially fun to go around and window shop for different things that I see. Right now, because I live in a very remote place that does not have a lot of sidewalks or public transportation; it is hard for me to get out into the community. But, whenever I have the chance, I really like to get out and walk around my local community to see people and to shop and stop in the stores to look around.

There are no people that I hang out with in my hometown. Most of my friends live far away or in areas where I cannot get to without a car. I am often on-line or in chat rooms or doing IM with my friends, and that is how I stay connected with them. Technology has really helped to improve my life and to help me keep me in touch with other people. When I am on-line and not chatting with my friends, I like to surf the Internet for information and other resources that interest me. I really wish that when I was in high school that I would have had someone available to help me label my appliances in Braille. If I had the opportunity, I would have changed my major in college to Social Services instead of computer technology. I think that it would have helped me understand all the different services I need and to help other people too.

At home, I have a SilentCall wireless paging system. This system is connected to my video phone, doorbell, and fire alarm. I get a vibration and indicator light when one of the sensors is activated. My fire alarm also has a bright strobe light. To stay in touch with my friends, I also have a Sorenson video phone. The video phone is very clear and I can see well enough to sign with my friends or call a hearing person through the video relay. I like all technology. I am a gadget-guru (aka Techno-nerd).

James and Mary Belisle, Parents

We learned that Ben had a hearing problem when he was just a two weeks old. After

months and months of erroneous testing at the University of Virginia, we finally took Ben to Gallaudet where we learned that he was profoundly deaf. He was 1½ years old at that time. It wasn't until elementary school that we learned he also had a vision problem. We were upset when we were told about the problems with his eyes, but knew we had the tools to deal with it. The most upsetting thing for us was the manner in which the professional at the University of Virginia discounted parental observation, most especially the accounts that only a mother experienced with deaf and hard of hearing people would know.

When it was time to decide what education path to take with Ben, we chose the least restrictive educational environment. It took 3 years to fight our county to get this service for Ben. In order to receive the proper services, they had to transport him across two counties. We wanted our son to be at home with us and did not want him placed in at a state institution. After many successful years in the public school, Ben went on to college at the National Technical Institute for the Deaf. He graduated a few years back with an associate's degree.

Looking back, we were not overly-satisfied with the quality of education he received in the public school system. We believe that his early education should have concentrated a lot more on his English language skills. Ben has what is viewed as the typical English language delays that many deaf kids have despite the best education offered when he was in grade school. Other aspects of his early education that we did appreciate were the many opportunities he was given to make friends. He was a part of the community in school, and he had several friends with whom he was able to communicate freely.

We do believe that Ben can live independently; however, he requires a location where public transportation is available since he is unable to drive. He is able to cook, clean, and perform all functions required for independent living; he only needs a community that is accessible for him. Ultimately, our hopes for Ben's future are that he will one day be able to obtain a good stable job, find a nice girl, and provide us with lots of grandchildren. Even though Ben is deafblind we know that he is very capable of succeeding. With the right support services, our son can have a fulfilling life.

Not In My Footsteps:
A DeafBlind Mother's Transition Lessons for Her DeafBlind Son

Christy Cummings-Reid

Throughout my entire educational experience, I have always received support services related first to vision loss, and then hearing loss. But it was not until my parents, younger sister and brother, and I moved to Poplar Bluff, a small town in southeastern Missouri, when I was in the fourth grade, that support services became more efficient.

My journey began when I was five years old and entered Kindergarten; my family lived in Fort Worth, Texas. I failed the standard eye examination required for all new students and was referred to an eye specialist. My parents suspected something was wrong with my vision even before I failed the eye test in kindergarten, but it had never been confirmed. After examining my eyes and several more visits to the hospital for additional tests, the doctors concluded that I had Optic Atrophy. He told my mother and father that I would grow up as a legally blind person. Later, we moved to Cincinnati, Ohio where I started first grade and received the Bubble magnifier. The Bubble became my special tool for the next several years. My parents began implanting this concept in me so I could begin preparing myself to lead a life as a legally blind person, knowing there would be some things I couldn't do and many more things I could do.

A few years later when we moved to Poplar Bluff, a town of 30,000, I met Mrs. Lauderdale, a trained vision teacher. At that time I did not realize that this would be the person who would help salvage my education. I attended public school and Mrs. Lauderdale worked with me for an hour daily, to help me with any vision related tasks that I was having trouble with in the regular classroom. She worked with me on Math, Reading, and handwriting. The rest of the time, I spent in my regular classroom, sitting near the teacher's desk. During fourth and fifth grades, I could still hear well enough to fully participate in class activities. I enjoyed school and had many friends, even though I didn't know any visually-impaired or blind students.

When I was 11 years old and in the sixth grade, my hearing loss began to change the picture. Even though I still sat in the front row, near the teacher's desk, I could hear her voice less and less. I began to get bored, restless, and lost interest because I didn't understand what was being said. It had not occurred to me that at that time I was also losing my hearing. As much as I could, I tried to continue functioning as I always had – the only way I knew how. As I entered Junior High school and began the seventh grade, I didn't

have any special accommodations in my classroom. However, Mrs. Lauderdale continued to work with me daily as she had previously if any accommodations were needed. At that time, the only accommodation that I was given was the Bubble magnifier that I had received in the first grade. In addition to the large print books that Mrs. Lauderdale ordered for me, I used the Bubble to read regular size text, so I was able to have access to all the materials that my classmates were given. Still, I couldn't understand what teachers were saying. This caused serious problems for me and I began falling behind and failing my classes. It was at that time that Mrs. Lauderdale, my parents, and school authorities decided I needed more help than I was getting. The decision was made for me to attend the Missouri School for the Blind (MSB) in St. Louis. It was hoped that smaller numbers of students in the classroom at MSB and more one-on-one help from teachers would better meet my needs.

In the eighth grade at the Missouri School for the Blind, my spirits began to lift again, even though communication was becoming more and more difficult. The smaller class size allowed me to get involved in activities. At MSD, I joined track, swimming, and cheerleading teams. I made friends and could still hear well enough to participate in small groups and one-on-one situations.

The speech and hearing specialist at MSB, Miss. Consin, recognized that I needed to learn new ways to receive information. She helped me to get my first hearing aid and was firm about my wearing it. I complained that it would fall off when I did cartwheels during cheerleading and she told me to tape it to my head. She was a very insightful person and I owe her many thanks for helping me learn how to approach hearing loss combined with vision loss. Although she did not know ASL, she did use fingerspelling to help me understand how the hands could be used to receive information that my eyes and ears missed. She also taught me how to ask a person to please repeat things if I didn't understand the first time; or if after struggling to hear, I needed to ask the person to please write down in large print what they had said. This became my foundation for learning how to cope with deafblindness.

Another important skill I learned while I was at MSB was how to use a white cane to get around and how to cross an intersection safely following the traffic pattern. It is fascinating how these very basic skills have become extremely important throughout every facet of my life.

After I finished ninth grade at MSB, I returned home to enter Poplar Bluff high school. My hearing loss had become so severe that I could no longer understand speech. I started tenth grade with a class aide (today this person is called an Intervenor) who

accompanied me to all my classes. She sat next to me in each classroom, writing large print notes, summarizing lectures, class discussions, and writing down homework assignments. Mrs. Lauderdale resumed her daily meetings with me to help with vision related issues. In addition, another special teacher who worked with deaf and hearing-impaired students in the Poplar Bluff school district began meeting me daily. She tutored me in biology, since it was felt that I would get more out of one-on-one instruction in this subject than from being in the regular class with the other students. The Teacher for the Hearing Impaired also began introducing me to sign language.

In my sophomore year, I took typing class and began to learn the keyboard and proper finger positioning. I enjoyed cooking and took Home Economics class for 2 years. In the Home Economics class, the first year focused on dining room skills such as eating, setting a table, clearing off dirty dishes, learning proper dish washing techniques, and preparing simple dishes such as casseroles, easy to prepare breads and candies; along with other treats. The second semester focused on international foods and we were also required to cover the cultural and geographical facts related to each dish. This was an especially interesting course and, among other things, I learned how to make Sophias, which is a delicious Mexican dessert. In my senior year, I took an independent study course with the Home Economics teacher. I was required to complete several projects. One project involved going to a local grocery store and drawing a map of the store's interior layout. Accompanied by my aide, I went through all the aisles, and copied down on the map where all the foods were located in each aisle. It is real clear to me now how that experience has played a very important role in my ability to live independently. That was the way I learned how grocery stores are typically arranged and set their shelves within each department.

While in high school, I met another student who was deaf. She was a year ahead of me, and we became friends. She was fluent in sign language and had a sign language interpreter. She began teaching me many different signs and we used sign language to communicate with one another. The teacher working with deaf students was a strong advocate for deaf people. She encouraged me to apply to Gallaudet University, thinking Gallaudet would best meet my needs. So during my senior year, I applied to Gallaudet and was accepted. In the fall of 1982, I entered Gallaudet University not really knowing what I wanted to major in other than wanting to major in something that would enable me to work with people. During my freshman year, I received a one-on-one course in career study with a career counselor as my instructor. In that course, I began exploring different careers and major fields of study. At a major career fair, I spoke with Dr. King Jordan who was the chair person of the psychology department at that time, about different careers related to

psychology. After talking with him, I decided I wanted to major in psychology, as it could lead to many types of opportunities to work with people.

At Gallaudet, I began meeting and socializing with other deafblind people. I joined the Gallaudet Association of the Deaf-Blind (GADB). By attending these support meetings, I realized that this was a great way to share with other deafblind students and to learn how to solve problems related to my deafblindness. After graduating from Gallaudet, I continued to be involved in deafblind support groups in all the different cities in which I lived.

At Gallaudet, an Orientation and Mobility (O&M) instructor orientated me to the Metro bus and subway system. After learning more basic white cane skills and how to cross intersections following traffic patterns, I continued to learn more and more skills that helped me to travel independently. I loved riding the bus to the Metro subway stop, getting on a subway train, and going out to shopping malls and restaurants. My favorite mall was the Pentagon City Mall because it was right off the Metro stop, and was bright and airy. Most of the stores were expensive, but it was fun to just sit and watch the busy people hurrying

back and forth. The O&M instructor taught me how to go to the Customer Service Desk to request help if I needed to buy something specific. Before each trip, I would write a note explaining that I was deafblind and would list what items I needed help finding. I would do this if I went to a grocery store or a department store. Notes were written for the bus driver if I wasn't sure of where to get off the bus. On the note, I wrote that I was deafblind and asked the driver to please tap my arm when the bus arrived at my stop. I always tried to sit right

Christy Cummings-Reid participates in DeafBlind Support Group in Pittsburgh, Pennsylvania (one of the cities in which she has lived).

behind or opposite the driver's seat. Most passengers were very accommodating when they saw me get on with my white cane and would move to make room for me so that I could be near the driver.

After I left Gallaudet, I got a job in Baltimore teaching work and independent living skills to deafblind persons with mental disabilities. I moved into an apartment and lived alone for the first time. The apartment community was next to a subway stop, and there was a grocery store down the road. It was an ideal location for me to live and I was able to access essential stores and areas in the community independently. An O&M instructor taught me the route to and from work using the subway and the bus. The O&M instructor also showed me where nearby malls were located that were accessible using the subway. I

felt very grown up, living on my own, going to work, going grocery shopping, planning and cooking my meals. A doorbell/telephone alert system with a pager was installed in my apartment and worked fairly well. Most of my co-workers were deaf so I was able to make many friends. If I needed help, I knew who I could call using my large print TTY.

Years later, after I got married and my first son was 3 years old, I went to Leader Dogs School for the Blind in Michigan and met my first Dog Guide, Milo. He was a big yellow Labrador and a great Dog Guide. We spent eight wonderful working years together. I had always been interested in having a guide dog after I had heard about how helpful they were for other blind and deafblind people who had Dog Guides. Milo was everything I imagined a guide dog would be and so much more. With Milo leading the way, I could walk much more quickly, almost like when I was much younger. I felt safer with him. And he was a true friend - loyal and attentive. The only drawback was that he developed a reputation as a food thief, sneaking into the kitchen to help himself to unguarded food left on the counter, stove, or table. After Milo served eight years as a Dog Guide, he made it clear he was tired and needed to stop. He retired in April 2006 and went to live with my parents. Fortunately, I was able to return to Leader Dogs at the same time Milo retired and I met my second Dog Guide, Brogan. He is also a yellow Labrador, but smaller than Milo and much more active.

At 32 w/ First Guide dog Milo

Christy Cummings-Reid with her first dog guide, Milo.

Looking back, if I could change things about my high school education, I would say that spending more time developing strong math skills would have better prepared me for college; especially learning algebra and/or geometry. I spent 3 years struggling with these subjects and they were one of the biggest barriers I had to overcome.

Also, if I could change the past, I feel I would have benefited greatly by entering the Helen Keller National Center (HKNC) after graduating from high school so that I could have prepared for college. Training at HKNC would have helped me learn tactile ASL, Braille, computer technology using a Braille display, and how to become skilled with other adaptive equipment like a TTY with Braille display and the vibrating doorbell/telephone alert system. If I had learned these skills before entering Gallaudet, I would have been much more efficient in the beginning when communicating with people and would have been able to keep up with all my course work without straining my eyes. Instead, my interpreters in the classrooms and my friends used close vision ASL to communicate with me. For all my reading and paperwork, I used a CCTV or the screen magnification program on my desktop

computer. The large print display TTY was what I used to place telephone calls. Despite all those struggles, I successfully earned a Bachelor's degree and went on to study in a Master's program at Gallaudet. However, having to use my eyes to receive information just required too much time, and became an overwhelming struggle.

Back when I was in the fifth grade, Mrs. Lauderdale wanted me to learn Braille; but I said I didn't want to because "I could see." If I had learned Braille back then, things would have been very different for me in high school and college. As I got older and busier in my life, learning Braille had become just too difficult. Finally, I reached a point where I had to learn Braille as I found it too hard and too much of a strain on my eyes to rely on the magnification equipment only. Subsequently, in order to receive proper training, I had to leave my family. My first son who was 5 years old at the time, and my second son who was just a year old, were left with my husband. The training program required me to be away from them for 2 months and it wasn't easy. Unfortunately, I didn't go to HKNC, because it was too far away. Instead, I went to a program in Kansas City, Missouri which was closer to Poplar Bluff where we were living. An interpreter was with me throughout the program and I successfully learned all of Contracted Braille and began learning computer access technology using a Braille display. These skills have changed my life tremendously.

Today, I enjoy accessing the Internet to read the daily news, conduct research, and read books on the National Library Service website. On my computer, I use JAWS, which helps me to access the Windows XP operating system and Braille display. To read text I use a scanner with the Open Book software. Using this technology, I can scan and read my mail and any letters that my boys bring home from school. Soon, I will be getting a new Pac Mate 4 and am very excited about that. In addition, I will be receiving training to learn how to use my equipment to prepare for a career in the publishing business.

I've had several jobs over the years and have a lot to share with parents, school personnel and other deafblind people. Currently, I am in the process of finishing up my autobiography and very excited to be able to pass along everything I've learned throughout my many transitions in life.

I have 3 sons now. My second son, Ben, also has Optic Atrophy and he is showing signs of hearing loss. He is 7 years old now and may grow up to be a deafblind person just

Christy Cummings-Reid with two of her three sons, Ben (age: 4) and Timothy (age: 3 weeks).

like me. But he is preparing early; he is learning Braille, white cane skills, and is already using tactile sign language. I understand exactly what he is going through and will do everything to help him develop into a successful adult.

Christy Cummings-Reid pictured with her sons, husband and dog guide.
Left Cummings-Reid works on her biography at her home computer.

Chad Fullerton

Most people take for granted pouring themselves a glass of milk, or just getting up and walking across a room. Both tasks take very little thought or effort. However, for me this is not the case; pouring a glass of milk is difficult because I have no depth perception and I have to mentally concentrate just to walk across a room, hanging onto things as I go. Just going to the mall with friends involves taking apart my motorized scooter, loading it in the trunk, unloading it at the mall, putting it together and repeating all this again when it's time to go home. Everything I do can become a major chore and takes extra time, including something as basic as having a normal conversation.

Chad Fullerton high school year book photo.

I was diagnosed with optic neuropathy at the age of five, auditory neuropathy at age 12, and neuropathy of the peripheral nervous system at age 15. This progressive degeneration of my nerves has left me deaf and legally blind, with no balance, no reflexes, and severe mobility issues. These disabilities may seem daunting; and yes, they are very frustrating most of the time – academically, socially, wherever I go, whatever I do, they impact everything. Some of the doctors I have seen over the years have told me that I am "unique" because that is the only answer they can give me. My disabilities are not what make me unique; what does is my determination.

My determination to be successful far outweighs my disabilities and I will continue to strive upon entering college. I am determined to achieve academically despite the difficulties I face. There have been many people involved in getting me to the academic and personal level I am at now, most of all my parents, who have given me love, support, encouragement, goals, and a sense of importance. My high school teachers and support staff were all very accommodating and have given me one-on-one time to enhance my skills. They recognized my efforts, realized my potential, and gave their time and expertise to make sure that I received a full education.

Chad Fullerton at his high school graduation. He graduated second in his class.

I am a voracious reader and am constantly reading one book or another. In high school, I used a closed-circuit television (CCTV) to read, and tactile sign language or a large dry erase board (print only) for communication. In addition, I used a laptop connected to the CCTV at school to receive class notes and for social communication with

teachers and fellow students. I am no longer able to write so everything has to be dictated (I am still able to speak) or typed whenever possible. In high school, I had two close friends that learned how to fingerspell and that was how I got all of the high school gossip. Getting through a day at school usually left me quite exhausted as it took me twice as long to accomplish my work. There were times when I got home and would just fall asleep, but I would get up the next day and start again because I am strong-minded when it comes to obtaining my goals.

As one can imagine, every aspect of my life has been and always will be influenced by my disabilities; these are just a few examples. The choice I have made is not to allow my disabilities to deter me from my goals, and this is why I feel I will succeed when I enter college. I am in all other respects just like any other high school graduate; I have the same feelings, hopes, fears, and dreams for the future. My goal is to get a college education so that I can become an independent, productive, and successful member of society. I may have a different path to travel, one with obstacles and detours, and it may take me a lot longer, but I know that I will eventually arrive at my destination.

Artistry and Beauty through Hazy Muffled Moments

Christian Markovic

When I was in high school, I had interpreters who assisted me in my classes. I attended a public school with hearing students, but there was a resource room for the deaf and hard of hearing students where I received support services. Whenever I would leave the resource room to go to one of my mainstream classes I was given an interpreter. When it was time for me to receive support from the deaf resource room I would not need an interpreter because those instructors could sign with me directly.

My deafblindness is the result of a disease that also affects the nerves in my hands, feet, and legs. I was diagnosed with the disorder when I was thirteen years old. The doctor informed both my mother and father about my condition. When I was in high school I never met any other students who were deafblind, but there was one student in particular that I had heard about who had Usher Syndrome. That was my only knowledge about another deafblind student who was about my own age. This student attended my high school, but not at the same time that I did. Even though he had Usher Syndrome, he did not call himself deafblind. He called himself a deaf person with vision problems.

I attended a number of different schools throughout my education, and as a result of all that bouncing around, I did not graduate from high school until I was 20 years old. My educational journey took me from New Jersey to Massachusetts and back to New Jersey. The support group meetings I attended in high school helped me to understand the Deaf community and what I should expect from my educational experience. After I graduated from high school, I went on to college to major in Fine Arts. I was the only student with a disability in the entire college.

When I finished college, I realized that there were still some things that I needed to learn and that is when I decided to go to the Helen Keller National Center (HKNC) to learn how to be independent enough to live on my own. As soon as I arrived at HKNC, I fell in love with all the things I saw that could help to make my future successful. There was tactile sign language, vocational training and the independent living skills department where I learned how to cook and clean, and so much more. This was really first time in my life that I

Christian Markovic is an accomplished graphic artist, who has his own design company.

understood what it meant to be deafblind. I heard the term before, but could not see how it related to me. After meeting the other students at HKNC and then learning different deafblind techniques to be independent, I really understood. It took about one month for me to adjust to the HKNC program and to begin to see myself as a deafblind person. Now I can see just how I fit into this unique world of deafblindness.

At HKNC I learned how to live on my own. Currently, I have condo where I've set up my own design business. I am very comfortable in my private space and am able to cook and clean for myself. I've even set up an area in my apartment so that I can do my required floor exercises to help strengthen my muscles. The only thing I would change about my condo is where it is located. It is so hard for me to get out into the community to walk around because my condo is not in an accessible location. I do not like walking in the street to catch the bus, and the paratransit van takes too long and requires me to call ahead several days in advance for a pick up. Once I get into a more accessible part of town, I am able to travel by myself or with friends. Most of my friends do not live close to me, but I hope to move closer to the city so that I can get around by myself more easily. When I am at home and not creating new designs for my business, I like to surf the web and visit sports pages or other information sites like CNN.

With all my new skills that I learned at HKNC, I am now ready to settle down and start a family. It would be great if I could find a wife who was an artist like me and we could design things together. The adaptive technology that I use right now for my design business includes a Macintosh computer, CCTV, a screen reader and ZoomText software. If I could change any aspect of my life, I would return to school to acquire additional skills so that I could earn more money designing graphics and images for major corporations. I would also have started using adaptive technology a lot sooner than I did. My exposure to ZoomText and other assistive technology did not occur until my junior year of college.

Overall, my transition from high school to adult life was not very good because I was not given enough information about my options. Now that I am older, I better understand what it is that I need to do for myself. But if I had this information a long time ago I think my career and design business would be further along by now.

Desire Intertwined with Reality

Aimee Massey

I can't really remember when I first learned the particulars about my condition, Leber Congenital Amaurosis. For as long as I can recall, I've always understood that I didn't see or hear as well as most people; however, it wasn't something I thought much about unless it presented a specific challenge for me. It wasn't until I was almost out of high school that I began to fully grasp or think about the fact that both my vision and hearing were deteriorating.

Early Learning Links

There was just one other student through my years at school who was hearing impaired. We had known one another since kindergarten, but were never more than casual friends. Since we didn't have any classes together, I was not aware of what type of educational accommodations this person received, or if she received any services at all. One thing that was clear about this student was that she wore hearing aids and was a lip reader, but that's about all I ever knew about her. We have not seen one another since high school graduation. In my everyday life I do not know or interact with any other deafblind people who are my own age – except for my younger brother. We both have the same condition and are both considered to be deafblind.

From an early age, I was taught to care for myself at home. My parents treated me as they would any other child, so I learned all the things the average child would learn. The only exception was that my parents and I would experiment to see if we could develop different ways of doing things that would be easier for somebody who had very little vision. From the first through the tenth grades, I received orientation and mobility instruction once a week for about an hour. My mobility instructor was provided by the Division for the Visually Impaired (DVI). At the age of five I learned Braille. During that time (I was in kindergarten) my day was split in half with part of the day in a special class for the visually impaired and the other half in the regular kindergarten classroom with the hearing-sighted kids. Finally, in 1994, I graduated from high school just a few months before my 18th birthday.

Fortunately, while I was in high school I didn't need an interpreter because I had some hearing left. I used an FM system which helped me to hear my teachers. Each instructor would wear a microphone and I would wear a receiver. I had very little trouble

hearing what happened in class, even when the instructors moved around the classroom. My school district assigned a one-on-one vision teacher to work with me. This special instructor was in charge of transcribing my Braille work into print for my teachers. Also, he would transcribe into Braille or read aloud to me any printed material such as worksheets or handouts that I received from my classroom teachers.

Although, my vision teacher was in school most of the day, we typically only got together during the lunch period and during my study hall time. I went to regular classes the rest of the time. My vision teacher also helped me in Math, which was my weakest subject. We worked on Math during individual instructional periods and often after school as well. Because of all the mobility training I received from the first grade through the tenth grade, I was able to independently travel to and from each of my classes without any difficulties.

In class, I was able to take my own notes using the VersaBraille machine. During my senior year of high school I was given a machine called the Alva Braille Carrier that I began using to take notes in class. It was a very small portable unit that I could also use to communicate with someone face-to-face if I could not understand or hear what they were saying.

Making Transition Connections

All throughout school, I knew that I was expected to go to college. By the time I graduated from high school I had already been accepted at Mary Baldwin College (MBC) in Virginia. At the outset, I wanted to major in History because that was always my favorite subject in high school. However, eventually I switched my major to Communications because I thought about becoming a journalist or a broadcaster.

Leaving home and arriving at MBC was certainly a whole new experience for me. I didn't know a single person there; whereas in my small hometown, I went to school with the same kids year after year right from the start. In fact, back in high school everything was familiar and there was always a good chance that one of my teachers had taught at least one member of my large extended family. Of course, getting around the college campus was a totally new challenge for me, so I had to start from scratch and learn how to find my way around.

The only time I came in contact with other deafblind students was when I went to Camp Landis Lodge in upstate Delaware or the Children's Beach House in Lewes, Delaware to attend the DeafBlind Family Weekend once a year. Before that time, I had never met any other deafblind adults in my community. Back in 1999, I attended a conference on Leber at

Johns Hopkins in Baltimore. It was very interesting to hear about the latest research on my condition and to take part in genetic studies to try and trace its cause.

I had heard about the Helen Keller National Center (HKNC) in high school. I think I can remember that I considered going there, but I honestly can not recall why I didn't go or what I had in mind to learn if I had gone there. A place like HKNC, I think would be a good idea for a deafblind person who wanted or needed intensive training in things like daily living skills or orientation and mobility.

Training at a rehabilitation center might give me some more confidence since I tend to be very reserved and shy around new people and situations. Having always lived in small towns, it has been very difficult to imagine myself moving to a larger city and using public transportation or the other services that small towns offer. Keeping up on the latest adaptive technology is a real interest for me and I am sure such skills would be essential for me if I ever chose to move to an urban area.

Currently I live at home with my parents and younger brother. However, I would like very much to live on my own within my hometown or very nearby. No doubt, I would need to get a better paying job first, because my current massage-technician's job does not garner the type of salary I need to sustain myself. I'm not married, but if or when I do get married, I certainly don't plan to depend on my husband to totally support me.

Aimee Massey is a licensed massage therapist in her hometown of Seaford, Delaware.

My hometown doesn't really have public transportation, but we do have a para-transit bus that I can use to go to work each day. This is the same form of transportation I use whenever I have meetings with my VR counselor. The area in which I can take this bus is somewhat limited due to the fact that changing from one bus to another is required if I want to cross county lines. Also, the transportation company does not transport people over the state line. Not to mention the fact that the system is not very reliable in terms of being on time to pick you up. My ideal transportation would be a chauffeur-driven luxury limo, but obviously that's out of my reach right now.

Because I need too much help to find things or to get around, I don't go to stores or other places by myself. It is because of this challenge in locating things that I choose to go to stores in the community with a friend or family member. Going out to restaurants is not something I do alone either. Dining out alone is no fun at all. Also, I'm saved from a lot of

this trouble because I don't like to shop anyway. I only want to go to a store when I have something specific in mind that I need or want.

All of my friends are or have been sighted and hearing. As I said, I have never really known any other deafblind people my age except my brother. Since I've always gone to mainstream public schools and a regular college for hearing students, I've always made friends with the people who were around me; and those people just happened to be sighted and hearing.

Becoming One with Assistive Technology

I LOVE the Internet. I talk via E-mail with various friends, some I've known in person and some not. I do research on anything that interests me. On the Internet, I enjoy looking for job and educational opportunities, or generally I just explore different sites in order to learn new things. From the National Library Service (NLS) Web-Braille site I also download books to read, which has been a godsend because now I don't have to depend on them to send me Braille books, which tend to take up a lot of space.

To access the Internet, I use a Dell desktop computer connected to an Alva Braille Terminal, and I utilize JAWS software. With JAWS, I can use either text-to-speech or text-to-Braille to read the computer screen. I much rather prefer the Braille because it's quieter. Sometimes the synthesized speech software will mispronounce things, which is a big hassle. Although I will admit that the quality of computerized speech has gotten much better over the years. I also use an Open Book Scanner so that I can scan printed material and transcribe it into Braille. This way I don't always have to have somebody read things aloud to me.

The piece of equipment that has had the biggest and most positive impact on my life is the cochlear implant. I was implanted in my right ear in 1995 and in my left just about a year ago. Having hearing restored to me has literally saved my life, and I don't want to imagine what would have become of me without this miracle. The only way I can think to improve this technology would be if it could be totally internal with no external processors or microphones visible at all. Unfortunately, that type of unit isn't available now, but I am sure it will be before I'm too old to care.

Something that would have helped me greatly in college would have been if more college textbooks were available in Braille or on cassette. Only a very few of my college books were immediately accessible to me. I had to rely on readers to help me, which was tedious and very often mind-numbingly boring for both of us. Often the few books that were available on tape from Recordings for the Blind and Dyslexic were poorly done. As a result, I

had a hard time understanding the readers. Throughout all my years in college, I recall having only one textbook available in Braille and wouldn't you know it had to be the Math book!

What Ifs and Do Overs

If I could, I really would like to live very close to where I am living now. Maybe not everybody feels this way, but I am very close to my family. They've been my biggest, and sometimes my only anchor and I want to stay close to them. I would like to live in my own place, but first I will need a better-paying job, which I am in the process of seeking right now. Of course I'd need orientation and mobility training to get around my new neighborhood and job site. This training I would request from my state VR agency.

If I could go back and do high school all over again, there's no question in my mind that I would have done everything differently. I had something of an attitude problem which I didn't try to do anything about until my senior year. As a consequence, I am lucky I graduated on time. If given the chance, I would go back and work harder at my schoolwork and get better grades. Also, I would try to get into less trouble because of my laziness and bad attitude. Without question, I would try not to cause myself, my parents or my teachers so much grief. Regrettably, when I was in high school I did not want to have anything to do with school activities; but now I would be more involved in those different school activities. Sadly, in high school I had no real friends. Even though I know that some high school kids can be mean and exclusionary, I could have tried to reach out to my peers a little more and might have had an easier time making friends.

Future Ambitions

In the future, I want to be less passive and take a more active role in advocating for myself to get the things I need to improve my job and living situations. Lacking confidence and being too passive has always been my biggest liability. Given another chance to speak up for myself, I would have insisted on receiving more intensive mobility training after I got out of high school. Once I got to college I kind of let my skills go, which in the end did nothing to help my sense of independence or my confidence. In 2000, I went to Leader Dogs for the Blind in Michigan to receive a guide dog, but left after only a few days. At the time, I thought that having a guide dog just wasn't right for me. In hindsight, I think I just got discouraged and overwhelmed by the whole idea of putting my safety, my life and all my trust in a dog. Even if I was right and it wasn't the best time for me to try a guide dog, I

could've given it more of a chance. And exploring a guide dog is definitely something I would like to try again in the future.

My years spent using the Alva Braille Carrier, FM system and personal computer with speech software throughout high school and college have resulted in my acquiring excellent typing skills in both Braille and print. I type very fast and am usually pretty good at catching and correcting my mistakes. My Braille reading skills are also very good, which is a feat in an age when Braille literacy is way down because too many people rely on speech software and are not proficient Braille readers. Given all my skills and my new attitude toward learning, I am very excited about getting more training so that I can find my dream job and move into a place of my own.

The Extended Transition Journey into Adulthood:
One DeafBlind Woman's Ongoing Struggle for Independence

Marcia McDermott

Introduction

My transition from high school ended many years ago, but as my physical abilities continue to decline, I feel as though my overall life transition is ongoing. The journey began shortly after I recovered from the encephalitis virus at age 18 months. My parents informed me that I had vision and hearing loss and would have problems walking. I had been born with normal hearing and normal vision and was developing just fine. Before I became ill, I was walking, talking and reaching all of my developmental milestones. However, following my illness, there was a lot of work that needed to be done after I was finally released from the hospital.

Marcia McDermott as a toddler enjoying moments with relatives.

Redefining Normal

My maternal grandfather, my Pamper, taught me how to walk again. Initially, my vision and hearing were not as bad as my balance. Both became progressively worse over

Marcia McDermott playing with her siblings.

time. Even though, my parents wanted me to have as normal a life as possible and did not go into depth about my disabilities, the impact that my balance had on my ability to resume walking was a major challenge for me. Throughout school, I had hearing assessments (which I hated),

Marcia McDermott as a teenager.

speechreading classes, and other specialized programs to address my newly acquired disabilities. School personnel and disability professionals discouraged my parents from allowing me to learn sign language, so it was not until very late in my teens that I began to learn how to sigh while at a camp for disabled students called Camp Isnogel. However, the

instruction I received was mostly focused on fingerspelling and Signing Exact English (SEE).

Back in 1960's when I attended high school, there were no such things as interpreters or Intervenors to help me when I started school. I relied solely on textbooks and the notes others were willing to take for me in order to complete course work. The high school I attended was not a special school; it was a regular high school for hearing students called Muncie Central High School. All of my work was done exclusively on my own without help from a tutor. Instead, I relied on textbooks and when something was left out of the textbook, the teacher occasionally would give me her notes. There were other deaf students in my high school, but their hearing losses were much less than mine and they never really connected with me. For the most part, my educational program was the same as the hearing students except I did not have to take the science course. I guess they were worried that I would blow up the chemistry lab!

Throughout my years in school, there were no services such as orientation and mobility, or independent living skills, or even adaptive technology offered to me. However, it was in high school that I realized that I had good skills in English and for memorizing details. My memory helped me to retain the information I read in all my textbooks, so I frequently got good grades on tests. Because I read so much, I was able to graduate from high school in two years as compared to the four years that most other high school students took to get their diploma.

The Initial Transition – Act I

In 1967, I graduated from high school with plans to go on to college. First, I went off to Gallaudet College in Washington, DC. At that time Gallaudet offered no advanced classes, so I majored in English since my writing and reading skills were so strong. I also attended

Marcia McDermott high school graduation photo. Marcia completed high school at the age of 16.

several other colleges as well. My dream of becoming a psychiatrist or some type of doctor was not possible due to the lack of support available for deafblind students back then. In fact, the services available for all disabled students at that time left a lot to be desired! I wanted to do something more intense, more purposeful with my life than what was offered to me.

When I arrived at Gallaudet, there were no other deafblind students in the program. My time on the campus was very, very lonely since many of the deaf people at that time

avoided being around people with multiple disabilities. As a result of this rejection, I tried to hide my disabilities but I was not very successful at it since my balance problem was so

apparent. Having received no guidance and being given no true encouragement or support to achieve my dreams, the brief time I spent at Gallaudet felt very isolating. So I used all my energy and time to focus my attention on my studies. During that time my vision began to worsen. I felt isolated and removed from the other students and was never really able to develop a good support system or connection with them. My halting hand coordination and lack of body control did not permit me to produce ASL quickly or smoothly, and this created a serious communication barrier. Because I grew up in a hearing-sighted environment using speech and had attended mainstream schools, I was slow to understand ASL and often signed more English. That did not go over well at Gallaudet. Now that I know Gallaudet has support for students with low vision, I wish I could return to finish my degree and maybe even go on for a Master's degree.

Transition Hiatus - The Intermission

After the hard time I had at Gallaudet, I decided to leave and return home. After my vision loss having progressed to the point that I was considered legally blind, I was encouraged to attend the Helen Keller National Center (HKNC). By that time I was in my late twenties. Unfortunately, I was in a bit of denial about my disabilities and did not learn a lot my first time at HKNC. This denial has become evident after many years of going through a variety of evaluations, training programs, and numerous job interviews; I was still being rejected because of my disabilities. I finally decided to return to HKNC for the training I rejected years earlier. I learned so much more my second time around at HKNC than what I had permitted myself to learn during my first visit. During this second enrollment at HKNC, I learned how to better cope with my body's lack of motor control and with my balance problems. I was encouraged to slow down and try to avoid becoming too stressed or too tired, as both can have tremendously adverse effects on my balance. Another very important thing I learned was that there is really nothing wrong with asking for help; and when you allow someone to help you, it does not mean that they are helping out of pity. That fact is very critical in my life now. Instead of getting stressed out, angry or feeling rejected because my sign language skills or speech are not clear; the staff at HKNC suggested that I use a white board with dry erase markers to help me communicate with people who did not understand me.

Marcia McDermott posing for a keepsake photo during her first visit to the Helen Keller National Center in the 1970's.

Marcia McDermott during her second visit to HKNC in 2003, when she was more focused and committed to learning.

Second Chances

There were so many *firsts* for me when I attended HKNC the second time. The only support group meetings I've ever attended related to my disabilities were when I was a student at HKNC. And even there at HKNC, I was the only one participating in the group with vision loss, hearing loss, and mobility impairments due to nerve damage. The other students in the support group had some type of Usher Syndrome or some other kind of syndrome and had been raised in the Deaf community. However, the meetings were still very helpful and I learned the nitty-gritty details regarding my type of vision and hearing loss which were not always easy to accept.

Over the 18 months that I was at HKNC the second time, self-advocacy training became a very important skill for me. I learned how to speak up for myself; usually, I am extremely shy. And learning not to hold things inside until I was overcome with anger had been so hard for me to deal with in the past. Still today, I have to remember to share my feelings and frustrations before they overtake me. Now I can most definitely say that I am better able to cope with my feelings whenever I become frustrated or angry. Through counseling sessions, group meetings, and interactions with the other students I learned that my feelings are indeed valid and that I can be successful even if others think I can't. My ability to express myself verbally also improved with help from the most wonderful speech teacher! Special techniques for cooking safely and the proper way to clean my apartment were other things I learned how to do while a student at HKNC. It was during my training in the on-campus apartment that I realized that when I returned home I would need to hire a person specifically to help with any heavy cleaning. I could write a book about all the things I learned at HKNC when I returned the second time. It would take me nearly forever to document everything. So many of the skills I acquired there are ones I still use today. But one of the most important things I learned is that genuine love and concern is never patronizing. This has been a true revelation for me through many hard patches in my life since returning home from HKNC. Just knowing that there were others out there who understood what I needed, what I was going through and that I was not alone has made a big difference in my life.

During my training at HKNC, graphic design skills using adaptive equipment, software and more advanced ways of writing poetry were all made available to me through a course I took at Nassau Community College. The college had very good services for

disabled students; and this time when I attended college, I had success with interpreters, accessible textbooks, and receiving help from instructors.

Learning how to cross streets safely by waiting for the next cycle of traffic to stop as opposed to crossing immediately upon arriving at the cross walk has really helped me to be more independent and a lot safer in my home community.

At HKNC, my skills in sign language improved, and I learned many signing shortcuts that have helped speed up my conversations with people. Now when I have the opportunity to interact with people who use sign language, I use these shortcuts. Unfortunately, there are not many deafblind people near my home with whom I can converse, so my skills have fallen off some.

The arts and crafts class offered at HKNC was a very relaxing and therapeutic class for me. Not only was I able to calmly work on creative projects, I learned to make "I Love You" hands using macramé. This is something that I enjoy making for others when I want to acknowledge special occasions or special people. Macramé is something I can do even when I do not have the funds to purchase gifts.

In the vocational services program at HKNC I wanted to learn data entry, but I type too slowly because my eyes and fine motor skills don't work well together. It was hard for me to pass the test for data entry jobs. I felt strongly that I needed more time to get used to the program I was using for data entry, but funding support from my state VR agency had been exhausted. My interest in caring for plants and flowers was not fully addressed either, as the flower agency was not unable to take on anymore students. Typically, it takes so much longer for a deafblind person to complete a basic training program, but due to my additional disabilities, it took me even longer. As a result of the barriers created by my motor disabilities, I was not able to accomplish everything that I wanted to my second time at HKNC. If I had more time, I would have pursued my interest in giving effective oral presentations; but there just was not enough time.

Transition to Independent Life – Act II

Living in my own apartment is something I really enjoy and always have. I love the space, the solitude, and being able to do what I want without people dictating or controlling me. When I first moved into my apartment, the only things I needed were accessibility devices such as grab bars in the bathroom, a chair for the shower, and a raised toilet seat with handles since I often tend to lose my balance. Now, the one thing that would help improve my level of independence is to have a companion dog. However, this is a major problem because of my vision and hearing loss and use of a motorized scooter. It is very

difficult to find a service dog that can support all of my disabilities. Sometimes, I feel as though I need three different types dogs to help me when I go into the community. One dog to help with my physical limitations, a hearing ear dog and a guide dog to help me get around the community safely!

For now, to access the community, I do not use the regular bus system. Instead, I use either my motorized scooter or my three-wheel adult tricycle. In my community, there are no support service providers (SSPs) or volunteers available to assist me all the time. My visual acuity is adequate enough for me to cross streets on my own. Sometimes if I get in a jam, a kind person will help me out. Using my tricycle, I can go grocery shopping on my own and since there are many stores around me, it is easy to find a variety of places where I can shop. My typical outings include going to doctor's appointments or stopping by Starbucks for a cup of coffee. My son works at Wal-Mart, and once in a while I make the four-mile trip to go shopping there. Using my adult tricycle as one form of transportation has really helped me to take care of my daily errands. Frequently, I go over to Staples for computer supplies and special papers to make greeting cards. If something goes awry with my tricycle, I can simply take it for repairs at the local bike shop. Nearly all of my errands, like going to the pharmacy, or to the market to buy food, or just to get out of the house can be done using my motorized scooter or my adult tricycle.

Most of my close friends live in other states or towns. By using e-mail, I am able to keep in touch with them. There are professionals here that I do consider to be my friends; however, there is always the boundary line I have to respect and to be careful not to cross. To pass the time away, I enjoy surfing on the Internet for things I can read or write about. I also enjoy searching for things on the Internet that I can buy or to keep up with the latest news. Using the ZoomText software is what helps make the Internet accessible for me. I can use ZoomText to enlarge the fonts on the computer screen or change the colors to contrasting ones. The voice output from the computer is audible, but I can't understand all the words. The ZoomText software also lets me change the color and size of the cursor or make it so that the screen displays a full-page or half-page of text at a time. Without this software, trying to access the Internet would be impossible and very frustrating for me. Right now I have all the adaptive technology I need; but may need a video magnifier with a larger screen in the near future.

Ending Transition – Curtain Call

Some type of employment involving work with animals is an area in which I would really like to receive more training. If possible, I would also like to work from home writing

articles and poetry for magazines. Starting my own stationery business is something I've also tried to do, but I could not find the right financial support. Right now, I do a lot of writing and reading for pleasure; and I make personalized greeting cards that I sell to a small group of people. One day I think I would really like to write a book.

While at HKNC the second time, Marcia participated in a work experience at a local pet store.

Sometimes I fear losing more vision, which could mean being less independent than I am right now. My balance is not necessarily as much of a major concern for me right now as it used to be -- thanks to extensive physical therapy. If necessary I can always use my motorized scooter, my walker or my tricycle to get around. As I get older I think about the other disabilities or limitations I may face. It is scary for me to think of losing this independence that I cherish so much. I fight to do all that I can to remain strong physically and mentally so that I can continue to live on my own in the community that I choose for myself. I do not want to be forced into an environment that is restrictive and stale.

So far I have not had a real job here in the town where I currently reside. This area does not have services for people who are deafblind, but a group of us are working together to try and improve this serious situation.

Traveling back in time, I wish I had stuck it out and graduated from Gallaudet; and then gone on to pursue a master's or even a doctorate degree. I've always loved school and got such great pleasure from learning. The only regret I have is that there were not better services for deafblind students when I attended college in the late 1960s and early 1970s. I know that my life would have turned out a lot differently if I had been given access to the same type of support services and technology that deafblind students have today.

Today, Marcia designs greeting cards and writes poetry. She would like to open her own business producing graphic designs and greeting cards.

Transition Memories and Future Aspirations:

A First Person Retrospective on Life without Vision and Hearing, but with Exceptional Talents

Janna Nelson

Although I've been out of high school for several years now, I live with my parents. I do not find this to be an ideal arrangement for me, but I must admit that there are things about home life that I enjoy very much. My youngest brother Eric still attends high school and is still at home. Along with my parents, his company is valuable. Eagerly though, I await the day when I too, like my other siblings, can move out of my parents' home. However, I enjoy being in an environment with which I am familiar and where I have my family around me – despite their extremely busy schedules.

The experiences of my youth are numerous and hold many fond memories for me. Now that I have more time to ponder these special moments, I can see how many of the experiences related to school life I would now change if I had the chance to go back in time.

Since age 5, I have been totally blind. I wish that I at least had more memories of the time before age 5 when I had some light perception. Only for a year and a half of my life did I see normally. My kindergarten teacher recounted for me experiences from my life at the time when I did and did not have vision. She informed me that when I first started school, I had a little vision and then later on during that same year I could no longer see. When trying to remember how my blindness was explained to me, I think my mother attempted to name the condition, but all I can remember is being told that no one knew the cause. It arose from a disease so rare that doctors couldn't put a name to it. Around age 7 my hearing loss began. Or did it indeed start at the same time as my vision loss? Perhaps the majority of my hearing loss occurred when I was 7 years old. That was when I made several trips to the ear doctor. At night time, which was frightfully silent, there was a continuous musical note that sounded in my ears. It's quite a

Janna Nelson as an adult wishes she could live independently or in her own apartment in the community.

wonder that I didn't enjoy or couldn't control it since I love music so much. But as it kept getting louder and louder I cried for attention. At this point my mother informed me that a doctor found out that I was losing my hearing. I don't really recall when this musical note

finally stopped ringing in my ears, but I do remember that it was an E-flat in the middle octave. Later, my mother shared with me that I'd been saying, "What? What? What?" all during that spring when I was 7 years old. Because my hearing loss was progressive, my mother said that the tiny nerve endings in my ears were what had been occasionally causing the ringing in my ears.

Early Foundations for Learning and Life

My first schooling came at the Western Pennsylvania School for the Blind. I vaguely remember working on cooking skills in kindergarten. Later on, I had classes with a woman who taught me to not only make sandwiches but also to make my bed and hang up my clothes. I also participated in a food preparation class where I learned how to prepare a lot of very quick snacks and small meals. My mobility instructors helped me to identify coins and the proper way to fold paper money. But the real difference in my education that stands out most is that at the school for the blind I took music lessons. During my lessons, I read Braille music and learned to play a few pieces on the piano by following my Braille music sheet. Later I also learned to play the flute. Both the piano and flute are wonderful hobbies!!

In elementary school I only knew a couple of other people in the school who were also deaf. There was a deafblind man who was in charge of school supplies, and a student who received instruction from my mobility teacher. During this time, my hearing loss was not yet so severe that I considered myself to be deaf. However, I was encouraged to learn some sign language when I was at the school for the blind just in case my hearing loss progressed. In my last year at the school for the blind, I was introduced to someone who came to speak with me about the benefits of having an interpreter. She signed to me whenever I needed during class, although I still used the TeleBraille with the classroom teacher. Other technology was introduced to me at that time as well. At that same time, I was given an auditory trainer which was meant to amplify sound and a VersaBraille unit to record my writing onto a tape.

Moving Forward

At the age of twelve, I was mainstreamed into a middle school, and had to repeat the sixth grade. When I entered the mainstream program I was assigned an interpreter for all of my classes. The first interpreter I had stayed with me for two years. Then, my second interpreter picked up from where my first interpreter left off and stayed with me throughout my last year of middle school and all throughout high school. Both interpreters worked with

me all day or at least most of the day. The only time we'd separate was either during lunch or for 45 minutes after lunch. In my late teens, I began using a wheelchair and another paraprofessional came to help me and worked alongside my interpreter. It was at the time that the aide began working with me that I didn't have my interpreter with me during lunch. Instead, my aide was able to fingerspell, so she would facilitate communication and tell me what I needed to know. Unfortunately, due to her limited sign language skills, we were not able to have in-depth conversations. Before I received the aide, my interpreter went to lunch after I did, and I would either use my TeleBraille to communicate with the other students or sit alone to complete schoolwork on my computer. At other times I would sit alone and read when the interpreter took her lunch break.

In middle and high schools, I spent only a fraction of my time in a resource room for hard of hearing and deaf students. The deaf students in high school were easier to talk with, and my memories of those interactions and friendships are more vivid than my interactions with the middle school students.

Physical therapy was, at first, another time when I was without my interpreter. My physical therapist spoke loudly, and I could understand her quite well back then. This doesn't mean I understood everything though. Once when asked to walk to the wall, I asked if the therapist told me to walk into a ball! I'd truly heard her this way and couldn't make sense of what she had said to me. I do not recall exactly when I became uncomfortable trying to hear my therapist without the benefit of an interpreter; but soon after I shared that communication break down with my mother, the interpreter was then permitted to stay in the room with me during all of my physical therapy sessions.

Importance of Assistive Technology

My use of the computer really began back when I was in middle school. At that time, I used a laptop that had a Braille display. Sometimes problems occurred in its functioning, and I was given a backup unit from the school system. During that time, I could still use the typewriter; however, having to revert back to using it when my laptop was out for repairs was very upsetting for me. My mother tried to comfort me by saying that the sun would rise the same way! What she meant by that was the world would not end because I had to use a typewriter. But once I was exposed to hi-tech equipment and gadgets I did not want to go back to the more conventional way of doing things. Those old ways were too slow for me.

At the high school I attended, there was a woman who worked in the resource room who Brailed papers for me to read. She also showed me and my interpreter how to use the Raised Line Drawing Kit that is used to make raised lines on plastic paper. This kit enabled

me to feel geometric angles and shapes. In class when the teacher gave assignments that required that we draw particular shapes, I would describe to my interpreter how it was to be done. At my dictation, the interpreter would draw arcs or lines where needed and add indications such as a box to represent a right angle. I had the help of a Braille protractor also. In German class, I initially had access to a Braille textbook. Later, there was an instructor from the local school district who was assigned to come to my home to teach me German 3 using the TeleBraille.

Preparing for the Transition

Once I arrived at high school, each year I would have transition team meetings that were set up to assist me with planning activities for my remaining years at school. At the meetings we discussed such things as my future work with computers and other possible career options. The team decided that I should go through a physical and vocational evaluation at a local Rehabilitation Center, which I did. The evaluation helped me understand why certain careers like marine biology were not suitable for me. Someone working with me at the rehabilitation center suggested I pursue one of two or three jobs: 1) German translator, 2) Proof reader; and 3) Braille Transcriptionist. I do recall that the job of Braille Transcriptionist was mentioned, but since I can not remember specifically what things were discussed regarding the position it probably means it wasn't discussed much. The transition team helped to get me enrolled in an English class at the Community College near my home. This accomplishment had tremendous impact on me. At the community college I had experience with peer editing for essays and other written work; and I participated in group discussions on various literary topics. During this class I had a note taker who was a classmate of mine. With these notes, I was able to review what was discussed in class; and I could use my TeleBraille or my interpreter to share my views with the group.

A few years before I completed high school, I went to the Helen Keller National Center (HKNC). At first I was there for only a short time. I did some work in a class that required me to string six washers onto a long bolt and to sort through some index cards. In the art class, I was able to do some work stringing beads. In the mobility class, I was given instruction on how to use a tactile map to locate areas in the dorm, such as the bathroom and other essential places on campus. This wasn't the first time I used a tactile map, but it was the first time that I had received such extensive exposure to one. A number of years later I returned to HKNC and stayed for a year. I thought of my second visit to HKNC as a real triumph and a highly pleasurable experience. I felt as though, during that period in life,

I discovered infinitely more things about myself and life than I had ever thought I would. Just before returning to HKNC, I prepared to be more independent by participating in a two-month program at Erie Independence House (EIH) where I learned what my role and responsibilities would be when accessing attendant care. I practiced creating my own menus for meals and going shopping at the grocery store to purchase the ingredients.

Reinforcing the Foundation

 I always loved artwork, but somehow the specific works I tried at HKNC felt more exciting during and after the year spent there. One reason is I couldn't complete my entire ceramics projects at home. Not only clay, but beading and other crafts came to quite a climax at HKNC. I was also given the opportunity to do some macramé. Craft and leisure activities were such an important part of my day, and I was always able to work with crafts in the residence hall after my classes and on weekends.

One of the most profound skills I acquired during my one year training at HKNC was cooking. This critical life function is also a great interest of mine. I think that HKNC was most effective in improving my knowledge in this area, even more than what I learned at the school for the blind. In the residence I was able to practice the cooking skills I learned during the day by participating in different activities at night. One activity that I enjoyed very much was making pizza. At an apartment on campus, I was given the opportunity to practice my cooking skills by preparing my own meals in the microwave. I was also given the opportunity to make sandwiches, prepare and pour hot and cold drinks, and to clean up afterwards by washing dishes by hand or placing them in the dishwasher. The staff also taught me how to use labels for identifying my food. Just like I did when I was at EIH, I also made shopping lists and meal plans for the week while I was in the apartment at HKNC. When my list was complete, staff from HKNC helped me to get to the local grocery store to shop.

I've always had an interest in computers, which some people have viewed as excessive. The approach to learning computers used by HKNC was something I welcomed very much. Through my computer training at HKNC, I acquired skills in how to use the JAWS speech output software in ways that exceeded what I used up until that time. This new approach required some adjustments and more variety, and I was glad about that. Because of the computer access skills I learned at HKNC, I can now write emails, view an assortment of web pages, and use Google to search for things of interest on the web.

Life Beyond Transition

At my current job, I do a variety of work-related tasks in a resource center that is somewhat different from the occupations I explored at HKNC. The job sampling in which I participated at HKNC has left me with memorable accomplishments. It is always nice to recall my restaurant work of wrapping silverware and, occasionally, crayons for patrons. My tasks at the Rehabilitation Center, where I am currently working, do not vary at all. It is strictly manual labor. At the Rehabilitation Center, my options for work consist of sorting small items or jobs that are somewhat reminiscent of the simple assembly tasks that I did at HKNC before I graduated from high school.

The only other job I had for a short period was when I wrote environmental essays for a group located close to the HKNC training program. This was a great opportunity for me, and I was glad that I accepted it! Not only did I gain more information regarding environmental research, I was shocked to realize how easily I forgot the need to honor short deadlines and how important it is to write down appointments! My duties as a writer were layered. I had to complete my drafts of the essays in time for my HKNC Communications Learning Center instructor to assist me with editing so that I could get the completed document to the environmental group on time. This entire process required me to work using a desktop calendar which enabled me to be more cognizant of deadlines. In the library, I learned to construct orderly search strings on the Internet using the *AND, OR, NOT* separators. In technology class, I conducted various searches and was told that the *AND* separator was unnecessary. However, both these experiences increased my understanding of how varied computer settings can be, and how flexible I would have to be in different work settings.

The wonderful social life at HKNC motivated me to explore more activities I already knew and to learn about ones with which I was not yet familiar. At HKNC my aide helped me gain more experience selecting which clothes to wear and sewing Braille tags on them so that I could easily identify them. She accompanied me on a few trips, and it was she who helped me explore a miniature golf floor through touch. Other recreational games I learned to play at HKNC included both the table top and computer versions of Skip-Bo and Tic-Tac-Toe. It was simply fascinating to me the number any variety of games I could play alone with the electronic setup or with another person.

Currently I use a desktop computer with JAWS and Braille display at home. My Screen Braille Communicator (SBC) has really helped me to communicate with other people and is more convenient than the TeleBraille I used for many years. The Braille note takers that are currently on the market are some of the best pieces of technology that I have seen.

Many of these units are even smaller than the SBC and can do so much more than facilitate communication. However, these units only have one set of Braille keys and no visual display for the sighted person, and thus will not permit the kind of communication that is possible with the SBC or TeleBraille. Back in high school I received training on a Braille note taker, but that was some time ago. When face-to-face communication has to take place the TeleBraille or SBC work very well for me. The SBC fits into my wheelchair bag, but not everyone feels comfortable with its smallness. However, I must admit that with both the SBC and Braille note taker I have so much more to learn.

For transportation from and sometimes to the BCRC resource center, I use a DART bus with a wheelchair ramp. Using this form of transportation, I can get out in the community on my own quite a bit, particularly for horseback riding lessons. Occasionally, my mother comes along with me to interpret. Sometimes there are others around who may help interpret, but few people can sign adequately during this type of rigorous activity. Certainly technology like the TeleBraille and SBC are not ideal while I am riding a horse! Even though at HKNC I learned to use communication cards that could help me out in the community a bit; since returning from HKNC I haven't been able to use them in any stores on my own. The shopping chore is still performed by my mother.

Opportunities to develop friendships with my neighbors have been limited as well. I have friends in nearby Pittsburgh with whom I have been able to visit, but only on a sporadic basis. Even my high school aide who at one time was my neighbor, who thought so much of me, has had very limited contact with me except for the brief time she worked with another person at the Rehabilitation Center where I am currently working. This is mainly why e-mail has so much of my attention!

Future Reflections

Frequently, I reflect on my many unused skills. I am aware that other students also worry about not using all the skills they learned in high school or at HKNC. If my past training could have been at all altered, I would wish those who provided me with training could have anticipated my future as a person with vision loss, hearing loss, and physical limitations. In the past, I was told by doctors that my balance would eventually deteriorate. Looking back, I wish my transition team could have known the degree to which my physical challenges would limit my ability to accomplish all that I desire. I am left to wonder how similar to or how different from other deafblind individuals my accessibility needs are. Yes, I remained in school for some time after I began using a wheelchair, and there were still some transition meetings that I attended. However, I still would like to have answers

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regarding the similarities/differences in my accessibility needs due to my added challenges as compared with my peers. If my team had discussed more of what would become of my life after I completed school, I wonder how my overall transition process would have differed.

In the future I certainly wish to get married. Until I have a companion, I dream of traveling constantly while continuing to work. I'd like to work from home using the Internet to access different employment opportunities if this could allow me to explore different career areas until I am able to find one that is ideal for me. However, a lot must be considered before such a job is really possible. In the meantime, I will reach out to potential friends and employers via e-mail. Through the Internet it appears I can gain greater community access to strengthen valuable friendships, and work as productively as I can. I'm so grateful that opportunities are still open to me using the Internet to access the world.

Believing in Success, While Waiting To Grow

Cristen O'Neal

When I was in high school I had an interpreter who would go to all my classes with me. The high school was for hearing students, but there were some deaf students in the high school also. I was the only deafblind student there. When I was 17 years old, I went to a transition week in Virginia without my parents. That was the first time that I was away from my parents by myself. I was independent, and my parents were very proud of me. I can not remember everything that I learned in Virginia, but I did have a nice time.

When I was 18, I went to the Helen Keller National Center (HKNC) for two weeks in the summer. The summer program at HKNC was a lot of fun. I learned how to cook in the independent living program and how to make things with clay in the art department. All the students in the summer program at HKNC went to New York City to see the Statue of Liberty and to walk around. That was a very neat experience. After HKNC was over I went back to the hearing high school to finish my senior year. At my last IEP that year, my parents and my IEP team decided that, instead of graduating it would be a good idea for me to go to the deaf school until I turned 21 years old. So, for two years I went to the Western Pennsylvania School for the Deaf (WPSD) in Pittsburgh, Pennsylvania. At WPSD I met a lot of deaf students and stayed in the dorm during the week. On the weekends I would go home

Cristen O'Neal works on her computer at her apartment. She lives independently and enjoys entertaining friends and family at her apartment when she is not working.

to be with my family. When I was at WPSD, I learned a lot of new things in English, Math, History, and Science. Also, at WPSD I learned how to read Braille and how to use my cane to walk around in the community. Just like when I was in high school with hearing students, I was the only deafblind student at WPSD.

After I finished all my education at WPSD, I turned 21 years old and went back to HKNC for one year to get more training so that I could become more independent. When I was at HKNC, I learned how to read contracted Braille and how to make communication cards to use in restaurants and out in the community. These can be used when I am working, or if I have an emergency and people do not know how to sign. Also at HKNC, they

taught me how to cook many different kinds of food by myself. In the technology department, I practiced keyboarding skills and learned how to use the Internet for email. I also learned how to look for jobs on the Internet in the vocational services department. While at HKNC, I tried a lot of different jobs to see which one I liked best. I worked in a bakery cutting up bread and putting the bread into bags with a label on the outside. I worked at St. Francis Hospital in the laundry service folding sheets, blankets, towels, and gowns. Then I worked at Wal-Mart, and my responsibilities were to unpack the clothes, hang them up, and fold the jeans and other clothes on tables. When I traveled to work, I would take a taxi by myself or get on the bus. At HKNC, I was also able to live in an apartment by myself to practice for the future.

Cristen works at a pizza restaurant near her home. She travels independently on the bus to get to and from her job.

Today, I live by myself in an apartment. I clean, do my own laundry, and enjoy watching television. My part-time job is at a pizza restaurant, and I take the bus on my own. When I am at home I enjoy playing games on the Internet and writing emails to my friends. Sometimes I check the Internet to see what the weather is like, read the newspaper, and search for things on Google. Also, I like to make scrapbooks of my family, my cats, and my friends. I have a friend who visits me every Tuesday and Wednesday, and we go out in the community to get food at Subway. The building I live in has a lot of older people who are very friendly and nice. In the future, I hope to get married, move into a house, and then maybe have children.

Focusing on Goals even when the Path is Unclear: A DeafBlind Student's Story of Self-Determination and Vision

Joshua Robertson

As an 18-year-old honors graduate of Tolsia High School in Fort Gay, West Virginia I can now look back on my journey and see just how much I was able to overcome to get to where I am today. As long as I can recall, I have suffered from a hearing loss, and minor visual problems. However, at the age of 14, I was diagnosed with glaucoma. This eye disease is very rare in people my age, and it can eventually result in permanent blindness. My initial reaction to the diagnosis was shock, confusion, and fear. Up until that time I had no knowledge of such a thing as glaucoma, nor did I know what it meant to have this disease. All of a sudden, everything in my life changed, and I had to take on new responsibilities.

Joshua Robertson would like to write a best-selling novel.

As I adjusted to life with the knowledge that I had a progressive eye disease that could take my sight from me, my educational path remained the same. I was determined to overcome my challenges and succeed. So far I have indeed succeeded and show no signs of slowing down. During my middle and high school years, I more or less supported myself. I learned to pay very close attention in class, and to even read lips so I could understand the material better. The only favor the teachers did was to give their permission for me to sit at the front of the class. It was mostly up to me to make sure everything else was in order. My mother was the only other person who paid close enough attention to make sure I was doing what needed to be done.

As a senior in high school, Joshua Robertson became aware of the term "deafblindness" and what it meant to him.

Throughout my last years of school, I was mostly an outsider. What I mean by that is I spent the biggest part of my day by myself. The education I received from Wayne County schools is not something I brag about. Given the chance, I would have changed quite a bit in my school program. First, I would have changed the level of one-on-one involvement between students and teachers. The way the material was presented by the teachers, and an over all sign that they cared whether students learned or not would have been a big improvement.

During school I did not have the use of many pieces of adaptive equipment. My hearing aids never worked right, my glasses were never strong enough, and so on. I was a self-advocate in that I taught myself ways to do well in school, despite my disabilities. The schools offered tutorial services but I always did well in school, so I did not require them. I had a Medicaid card, so I did not have to pay for my hearing aids even though they did not work.

The school did offer limited opportunities to bond with my peers; however, I just could never fit in. I did not consider myself a part of any particular group. I literally had only a couple of friends, but not a best-friend. It was hard for me to find friends; in grade school things were different. I had a lot of real friends and then suddenly all of that changed in middle school, and it kept getting worse for me. After a while I got used to being alone all the time, so it didn't bother me as much. Now I can see that I am a stronger person because of it.

Even though I've had it fairly rough in life I've done well so far.

Joshua Robertson and his fiancé, Brittany visits Alice Lloyd College in Pippa Passes, Kentucky.

As I begin my life after high school, I think that I am fully capable of living on my own; however, I will admit that a few years ago I had my doubts. Now I'm fully confident that I can do it. The only thing that could change my mind about my ability to live on my own would be if my glaucoma suddenly turned severe and I went completely blind. Other than that, I see no reason why I can not successfully survive on my own.

After struggling through so many years on my own, my final year of school was really intense. My life changed and was crammed full of additional concerns related to adaptive technology, classroom accommodations, and post-school possibilities. I was fortunate to have a very good team of professionals that began working really hard to get me through my last year of high school successfully. Without the help of these professionals it would have been very difficult for me to navigate my way through this process called transition. It is not easy to understand the service delivery system and what is required to receive the support services I need, but I am learning. As in all other areas of my life in the past, my mother was a constant pillar of strength and encouragement for me throughout my final year of high school and she continues to support me as I move on to the next chapter in my life.

As far as my future is concerned, things are really looking up for me. I'm engaged to the sweetest person I've ever met, and we both plan to start college in the fall. I will be majoring in journalism with the hope that one day I'll write a best-selling novel, or screenplay. While that day is still so far away, I hope that my future job, whatever it may be, will equip me with enough knowledge and experience to fulfill my dream. I know that such a goal is difficult to reach, but I'm stubborn and I have confidence in myself that I will make it. The confidence I have in myself hasn't disappointed me yet, so I'm very hopeful about the future.

Joshua Robertson has dreams of graduating from college and marrying his high school sweetheart.

Despite the slowly increasing shadow that glaucoma threatens to cast over my future, I remain committed to staying focused on the vision I have for my life. Even if glaucoma robs me of my ability to see and I continue to loss more hearing, I know my future is bright and full of unlimited possibilities. Great novels are often written about life's journey through adversity and overcoming obstacles -- I already have my opening chapter!

One Student's Pathway to Self Awareness through the Guidance of Others

Yashaira Romilus

During my high school years, I had an interpreter in the classroom. This was a public high school and sometimes I would have two interpreters in some of my classes. There was only one classroom for deaf students in the whole high school. I was pretty much mainstreamed in all my classes; but when I needed more time for tests or to do my class work or needed assistance with anything, then I would spend my time in that deaf classroom. The school had an audiologist who came in whenever I or another deaf student needed adjustments for our hearing aids, new ear molds, etc. There was also a vision therapist who came in once or twice a week to assist me when

Yashaira "Chari" Romilus baby photo.

I needed help; the therapist provided me with the tools necessary to complete my school tasks.

The deaf classroom was open all day so I could access it anytime I needed help with

Yashaira Romilus at age 12.

anything. The instructor and interpreters in the deaf program would usually do more than necessary to see that their students, including me, succeeded in everything. They would even go as far as to help us in our personal lives too. We all had note takers and tutors in our mainstream class. In addition, I was given some mobility training for a short period of time. Through the state blindness agency, I received vocational rehabilitation services while I was still in high school. My counselor authorized summer training at a community training center for the blind. This summer program offered different kinds of classes such as mobility skills, cooking skills, and communication skills that helped the blind with adaptive services in the outside world.

I always knew at an early age that I really couldn't hear well and that was why I started learning sign language at the age of 4 or 5. My father always told me as I grew up that the doctors said that my hearing loss was due to unknown causes. As for my vision loss, my father told me in 1997, "You need surgery on your eye." After the third surgery, I stopped asking my father what the doctors were saying whenever we had appointments in the doctor's office. I always depended on my father to make the right decisions regarding

my health; it was not until much later that I found out myself about information related to my vision problems.

There were a total of nine deaf and hard of hearing students during my high school years and five graduated before me. I graduated with the other three deaf students and we were the last four students to graduate from our high school as the deaf program closed behind us forever. Throughout my high school experience, I met other blind friends but never a deafblind person. I was the only deafblind student, and it was very difficult for me to accept my blindness. When it came to doing class work, I was usually the last one to complete assignments or tests; and I was the only person who needed special assistance to *see* things throughout my education.

Yashaira Romilus at age 10.

When I was about fourteen years old, I had my first eye operation on my right eye. I made a fast recovery and began seventh grade needing only minor accommodations, such as having large print reading materials. Occasionally, my teachers would use dark-colored markers to write on a white board. But, when I had eye surgery on my left eye, people all around me at home, at school, and in the community began to behave awkwardly. They weren't sure what to do with me. At that time I recall experiencing major changes to my vision. In the classroom, I could no longer see the board, I needed more assistance with reading materials and the interpreters had to sit closer to me. The vision therapist at school taught me how to use a hand-held

Yashaira Romilus as a high school senior.

magnifier and the CCTV. When I went to the summer training at the rehabilitation center for the blind, I learned how to use ZoomText software and developed other blindness-related skills. At home, I began learning how to *feel* for things and groom myself independently. Also, a mobility instructor started coming to my high school to teach me how to use a cane both at school and in my neighborhood.

At the age of 18, I graduated high school and two-and-a-half months later, I started college at the National Technical Institute for the Deaf (NTID) in Rochester, New York. When I arrived at college I didn't know what to study, and I ended up leaving four months later after experiencing a multitude of problems. It was a challenge at NTID because I didn't know how to ask for help or how to find a support system. Also, the pace there was

Yashaira Romilus high school graduation day.

extremely fast and the college didn't seem to have the right courses for me. There was no orientation and mobility training provided to me when I arrived on the campus; the buildings all looked alike and it took me a long time to find my classes. I felt overwhelmed, depressed, and lonely.

The only deafblind person that I can remember meeting at NTID used a special doorbell system that I now know is called the Vibra Call System. He was a nice guy, but I didn't keep in touch with him. I do not ever recall going to a deafblind support group while at NTID, but I wish I had known about them. A deafblind support group would have been great for me when I was drowning in all the newness of being a college student.

Today, Yashaira Romilus is happily married and planning to return to college.

After returning home from NTID, I heard about the services that the Helen Keller National Center (HKNC) offered on a small, beautiful campus that was easy to get around. The fact that many deafblind people 18 years of age and older from different states would be attending HKNC was something that really interested me. My initial reasons for going to HKNC were to learn Braille and meet different deafblind people. By meeting other people who were deafblind I thought it would help my own personal growth and feeling of connection with a community. I knew that I needed to accept myself and felt that understanding the backgrounds of the other students and learning the true reason for my visual problems would really help me understand who I was. As it turned out, meeting other deafblind people was a major step in my life because I was finally able to accept myself as a deafblind person. Originally, I wanted to learn Braille to prepare myself if my vision ever worsened or I became fully blind. However, I learned a lot more than just Braille at HKNC.

The HKNC training made me more aware of the ADA law and the services a community can offer a deafblind person. At HKNC, I learned more about ZoomText software and how to use the video phone. I plan on utilizing my technology skills when I return to college soon and even in my life after college. The video phone technology has opened many doors for me to communicate with others. Also, there is less stress on my eyes since I started using ZoomText on my computer. Another thing I learned at HKNC was how to obtain services from my vocational rehabilitation counselor and how to handle myself under pressure so that I could get the things I need to make my life better. While at HKNC, I received training in how to travel on different types of public transportation. I practiced

using the Long Island Railroad (LIRR), the subway, and buses, which resulted in me feeling more confident in myself while traveling.

After I learned the specifics about my visual problems and how to better accommodate myself, I was able to teach my family and friends how to help me. One thing I am still struggling with is why human nature allows people to be so cruel or refuse to understand a person's disability.

After I completed my training at HKNC, I married someone who has been very special and supportive to me. I like living away from my family and my new life being married. I can experience and learn about the real world and what it feels like to have freedom and to be independent. My husband provides me with emotional support and a feeling of security in my life.

I am able to independently travel on the bus to go out into the community. Whenever I have some money to spare, I like going to the mall. It's a place where I can enjoy looking around, having fun, and ease my mind from whatever problems I'm having that day. More than anything, I love visiting friends in New Jersey and Pennsylvania because they are the people who know me best, and I don't need to worry about trust, judgment, or other problems when I'm with them.

At HKNC, Chari learned a lot about herself and how what it means to be deafblind.

Getting to the stores independently in my community is a lot easier now that I've had extensive orientation and mobility training. Usually I don't need any support whatsoever, but I do write on paper as a communication tool. Periodically my husband offers sighted guide assistance when I am crossing streets. The only friends I have near my residence are the pastor of the church I attend and his wife. They provide information on community services and offer guidance and support through their church. Also, they allow me to use their office and many other things. Most of my friends are deaf; however, I have become more comfortable with deafblind people because they have a greater understanding of visual and hearing problems.

Chatting online, writing emails, and surfing on the search engines are other things that I really enjoy doing in my spare time. The only accommodation I need to access the computer is ZoomText, which enlarges the print on the screen. The vocational rehabilitation

agency has purchased a laptop, a CCTV, and a signaling system for me to use when I go away to college.

All the education and training I received so far from high school and at HKNC have been good for me. In the past, I' had some experience working at places like Wendy's restaurant; where my duties included cleaning and handling money in the drive-thru section. That was a good starting point for me to learn how to follow directions. I've also worked during the summer at the Overbrook School for the Blind, where I was a camp counselor for preschool kids with disabilities. That was my first time being responsible for someone else's safety, and it was an overwhelming feeling of accomplishment for me to take care of kids with such profound disabilities. The other job experience I had was as a teacher's assistant for an elementary school program at The Cleary School for the Deaf while I was in the training program at HKNC. My responsibilities were to help teach the deaf students in a classroom for students who were autistic or who had learning disabilities. There were also other small seasonal positions at department stores like Macy's during the Christmas holiday. That particular work was not very hard; I just folded and organized clothes on the shelves or racks.

Today, I don't know what kind of job I want, but I am thinking about a *career* in counseling. As long as the job pays well, allows me to enjoy myself at work, offers flexibility, and involves helping others, I think I will be satisfied. In order to obtain this career goal and my dream of owning a home with three or four bedrooms in a quiet and safe neighborhood, I know that I would need to obtain a master's degree. Now that I have a better understanding of myself and my vision and hearing loss I feel that I am ready to return to college to officially begin my life as an adult.

Emerging Through Unlikely Moments and Flourishing in Reality

Randi Shelton

I came into this world three months early, in August 1967. Those first months were spent in an incubator receiving high levels of oxygen. This was standard medical procedure in the 60's. Doctors didn't know that exposure to high levels of oxygen could cause blindness or other disabilities. My blindness was diagnosed by the time I was a year old, but my hearing loss wasn't diagnosed until I was six.

Family Foundations

As a very young child I didn't know there was anything *different* about me. I am the youngest of eight, and as far as my mother was concerned, I couldn't see, but I could do everything else. I've often thought that if a child has to have disabilities, being in the middle or the youngest in a large family is the best place to be. Siblings can teach things parents and other relatives can't teach as easily. This was certainly true in my case.

My brothers and sisters were the best teachers I ever had. They often took me with them when they played ball with friends. I learned to play too, and developed a life long love of both football and baseball. They taught me to ride a bike and roller-skate. (I tried ice skating too, but I couldn't stand on the ice unless someone held me up!) We wrestled on the living room floor, jumped in the leaves in the fall, and went sleigh riding in the winter. We took vacations to the beach in the summer and spent hours playing in the sand. We played board games and cards. They taught me these things, but they also taught me the finer points of social interaction – how to get along with others, turn taking, sharing.

Educational Foundations

My introduction to school came when I attended a nursery school program in a local church near my home. I was the only child in the class with disabilities of any kind. At that time, I had no special services in the classroom. However, there was a rehabilitation teacher from the Blind Association who came to my home. She was the one who first taught me Braille.

One of my earliest memories of learning Braille is of my mother standing behind me while I sat at the kitchen table – her hand over mine. A piece of newspaper was on the table in front of me with part of it in a slate. I would hold a stylus in my hand, and my mother would teach me how to write the letters. We were both learning the Braille alphabet. She

learned it, so she could help me. I figure I was probably about four years old at the time. Since this took place before I started kindergarten, and I was five years old when I entered kindergarten. The Braille lessons were earlier, so I'm guessing I was about four. It was around that time that I got my first Braille books and a deck of Braille playing cards.

I attended kindergarten at the same school my brothers and sisters had attended. One of my brothers was in fifth or sixth grade at the time, and we walked to school together. He came home for lunch since there was no cafeteria in the school, and I would walk back to school with him since I was in the afternoon class. Teachers from the Intermediate Unit (I.U.) were with me in the classroom. They provided Braille instruction and support for my classroom teacher.

My mother had always planned that I would attend public school, but in kindergarten, it was discovered that *someone* had taught me how to make the letters *I* and *E* incorrectly. Confusing these two letters is a common mistake that many sighted braille readers make. It took years to reverse this confusion, and to this day, I still find myself double-checking my spelling to make sure I'm reading correctly.

Blind Skills for Life

I entered the Western Pennsylvania School for Blind Children in first grade. It was during that year that my hearing loss was diagnosed. Throughout the previous six years, teachers and others had suspected that I had a hearing problem, but they couldn't prove it. I spoke very clearly, and they were unable to test me because I was so young. The staff at the School for Blind Children had experience working with little kids who had both vision and hearing impairments and picked up on mine right away. They insisted that I be tested, and when I was, it was discovered that my hearing loss was significant. Most people with my degree of impairment are unable to understand speech and most sounds without hearing aids. I can hear conversation well with hearing aids, but without them, the sound has to be very loud for me to hear.

I vividly remember getting my first hearing aid. Everything suddenly sounded very loud to me, and I didn't like it much. The first thing I taught myself was how to operate the volume control, and most of the time, I left that switch in the off position. Fortunately, I had an excellent audiologist who had the patience of a saint. She spent many hours training and encouraging me to use my hearing aid. There were others involved in this process, but my audiologist was the one I responded to the most.

One of the things that frustrated me the most when I was in school was that the mobility instructors didn't seem to know how to deal with my hearing impairment. They

were quick to tell me what things I could not do; and I often felt they did not give me a chance to try. I was probably about seven when I held a cane in my hand for the first time. My early mobility training was done around the school, and only inside the building. Over the next few years, residential street crossings were gradually included along with other outside travel.

I began learning to write Braille on the Perkins Brailler in first grade, and using the slate and stylus in second or third grade. As the years passed, I noticed that my classes were filled with children who were older than I was but they were learning the same things. This was especially true after third grade. There were seven of us in my class during the first three years, but after that, there were about ten or twelve in the class. Some were older, and some younger. Each student learned at their own pace.

We were all required to take music classes and, for me, that was torture. The hearing aid I had then was the best for its time, but sounds like music, running water, and traffic on the street were too loud and harsh. We were required to learn an instrument, but I couldn't stand it. I had my own little silent protest. I refused to practice, so I could never play the song in class. For me, reading the music was much better than playing it!

Moving Forward

I left the School for Blind Children after completing six years there, and went back to the same public school I had attended in kindergarten. However, instead of moving to the middle school for seventh grade, I repeated the sixth grade for adjustment purposes. I remember this as being an easy adjustment socially. Since I lived in Pittsburgh, I was able to commute to the School for Blind Children every day. That meant I could participate in activities in my neighborhood. I was in the local Girl Scout troop, and I was happy to find out that many of the girls in my troop were in my class when I went to public school. Other friendships were easily made and I often spent time with my friends outside of school doing the things typical girls around eleven or twelve do. Going to movies, roller-skating or visiting at one another's houses.

Regrettably, despite my success on the social scene, moving on to the public school began a challenging time for me academically. I needed to catch up in some areas and often spent hours working with my I.U. teachers on Math and English skills. I remember spending many nights working on these subjects at home with my mother or one of my brothers. Math tutoring was something I needed all the way through school, including college. I even went back to the School for Blind Children two half-days a week after I returned to the public school. My guess was that the professionals thought this would help me with the

adjustment. However, I remember thinking at the time that this set me apart from my hearing sighted classmates, and I already felt singled out in some ways. The teachers often didn't know what to expect from a blind student, and they would treat me differently than the others. They would give me less work, or send me to another room to listen to my books on tape instead of giving me headphones or braille copies of the material to read with the other students.

I used a brailler to write my homework, and the I.U. teacher would then transcribe my homework into print for the classroom teacher. That same year when I returned to the public school, I began learning how to use the manual typewriter. In seventh and eighth grades, I used an electric typewriter to type most of my homework except Math. Math was written out in Braille, and transcribed for my teachers. In middle school, I had a Math teacher who learned Braille well enough to read my homework herself. She also took time out of her day to tutor me. My reading teacher in seventh grade also learned enough Braille to correct my work herself.

I was lucky. My school was in a good district. The school district accommodated my needs with no problems, and between the I.U. and the school district, was given the latest technology as it came out. I used an electric typewriter until I was in tenth grade. In ninth grade, I got a VersaBraille that used a cassette tape. It was the first machine that could be connected to a printer so that Braille material could be translated into print for a sighted person to read. It could be used as a tape recorder too, but I chose not to use it that way. I don't think I got a printer right away, so I didn't use it for all my work initially. My I.U. teacher taught me how to use the VersaBraille.

I also got a Mowat sensor that I used in the building as a mobility aid. This was a small hand-held device that vibrated the closer I got to a wall or other object. It could be used in conjunction with a cane or by itself. Since it didn't pick up curbs or steps, I didn't use it without the cane outside. My Physical Education teacher as well as the I.U. teachers learned to use it first and then taught me.

One of the things I continued to struggle with throughout my high school years was mobility training. This was the one area of my education that was very weak. Again, the I.U. teacher I had for mobility at the time didn't seem to know how to teach someone who had a hearing problem as well as blindness. I was told I wouldn't be able to do many of the things I was asking to learn. Finally, I had the happy experience of proving this instructor wrong during my senior year. Regrettably, I had been working with this instructor since at least eighth grade.

During the summer between my junior and senior years of high school, I went for training at the Greater Pittsburgh Guild for the Blind in Bridgeville, a small town near my home. This was a wonderful experience for me! My self confidence got a much-needed boost that summer, especially in the area of mobility. For the first time, I had an instructor who believed in me and worked with me to find out what I could and couldn't do. For instance, I had been wanting for a few years to be able to travel independently to a shopping area that was just down the hill from where we lived. My mobility instructor in high school said this was impossible because there were no sidewalks. But, my mobility instructor at the Guild began teaching me the route immediately. Within three weeks, I was able to do it on my own. Needless to say, I had fun showing off my new skills when I went back to school in the fall.

Planning for Next Steps

In high school, most of my friendships were confined to school hours. For the entire four years of high school, I wrote on the school newspaper. School was something I enjoyed very much and I had always planned to continue on to college. Even though I didn't know what I would major in, there was never a question in my mind as to whether I would go or where I would attend. I had heard about Seton Hill from one of my I.U. teachers and my mother. I was looking for a small school with high academics standards where the teacher to student ratio would be low. From all I had heard this school fit the bill. I was even more certain after I toured the campus at the beginning of my senior year. Immediately, I felt comfortable there, and the staff was very receptive to my unique needs. It was during my tour of the university campus that someone suggested I get to know the coordinator for disability student services before I enrolled.

Later that spring, I met with the Coordinator to discuss my needs. She was very resourceful and gave me information for getting books on tape. This was something I hadn't done for myself except for pleasure reading. I already had a relationship with the volunteer braillists at the university because they had brailled some things for me in the past. These same braillists would end of brailling my college Math books. The thought of going to Seton Hill was very exciting for me. Before I could go however, I was required by my VR counselor to attend a program at Edinboro University for six weeks that summer. I was told that if I didn't complete this program, I wouldn't be eligible for college funding. This was a very traumatic experience for me.

The program was six weeks long and very rigorous. We were required to take one college course, and the rest were prep classes. I chose to take Psychology. There were

student aides who worked in the program as our guides and readers. I had never worked with readers before, and there were many times the material I needed each day wasn't ready for me to study that night. I had one or two chapters to read for my psych course each night. I would give the aides my assignments to be taped after each class. We had quizzes daily. We were literally in class 12 hours each day which left little time for studying each night.

For me, this was the first time I had been in a situation where I didn't know anyone. My best friend and I had done everything together up to that point. We had been friends since the first grade, and remained friends after we both left the School for Blind Children to attend public school. We had gone through training at the Guild together the previous summer, and she had returned to the Guild the summer when I was required to attend the Edinboro program. She had been given a choice of going to the Guild or Edinboro, and chose the Guild. We both would end up going to Seton Hill, but I was told I had to go to Edinboro first. To make matters worse, I had also gotten braces on my teeth days before I left for the Edinboro program. I had to have a palate expander at the same time, and this was very painful. The expander went across the roof of my mouth and was cemented in place. It had to be cranked twice a day for the first few months. Added to that, I had the normal feelings of homesickness everyone experiences when away from family and friends. It wasn't easy, but I forced myself to stay. I was afraid to let myself go home on weekends for fear I wouldn't go back. The campus itself was too big and sprawling for my liking. All of us in the program were living in one of the oldest dorms on campus, and the phones in the rooms were not accessible for someone with a hearing problem.

I had always done well in school. My grades in high school were high, and I had been inducted into the National Honor Society during my senior year. So, I expected college to be no different. That summer was the first time I failed a test, and this was a bitter blow for me. My grades in that first psych class went up and down, and I worried that I might fail. Failing the course meant that I would not receive funding for college, and this was a worry for me. Luckily, somehow I was able to pass this course with a high grade.

Post-Secondary Discoveries

Having survived those six weeks at Edinboro, I entered Seton Hill as a freshman in the fall of 1986. Settling into my life at college was easy after the time I had spent at Edinboro. I felt comfortable there immediately and settled into a routine of going to classes, studying, and socializing with friends. I was involved in many extracurricular activities on campus over the years including volunteering and student government. Classes were small,

and most of the professors were willing to work with me. Since it was a small school, Seton Hill didn't have many students with disabilities. I learned to get the titles of books that I needed for my upcoming classes halfway through the semester before those classes would begin. The book titles were then sent out to be made into audio tape. If I was taking a Math class, I had to plan for that at least a year ahead in order to have the book brailled in time. I often started each semester with parts of all my books, and the remaining sections would trickle in throughout the semester as they were completed. If I needed a chapter read before I got the tape, I had to rely on readers. My readers also helped me to read tests, write my answers and do research in the library. It was my responsibility to find my own readers and I learned early on to set schedules and prioritize my assignments.

The Versabraille II helped me to take notes in class and write papers. This was a disk-based machine that had a Braille display and brailler-style keyboard. Like the tape-based model I had used earlier, it could be connected to a printer to translate Braille into print for a sighted person to read. The I.U. teachers I had worked with most of my life came to the college to give me training on the unit. Unfortunately, this machine was unreliable. It broke often, and I had to send it out for repairs. Again, my friends at the I.U. stepped in to help me get a loaner to use until my own unit was fixed.

Mobility was not a problem on campus because most of my classes were in one building. Even when I needed to go outside to another building, I didn't have busy streets to cross. I continued to work on my mobility skills during the summers. Two summers I worked at a day camp for children with disabilities. The worksite was on the trolley line, and I wanted to try using the trolley to get there. The mobility instructor from the state VR agency worked with me, but I was never able to do this. The camp itself was only six weeks long, and my inability to travel safely in busier areas kept me from using public transportation.

My major at Seton Hill was Social Work and I was required to complete several internships. My last internship was done at the Westmoreland Blind Association. I continued working on my travel skills during this time. One of my goals was to take the intercampus bus to and from my internship. Getting there was no problem because the bus dropped me off in front of the building. On the way back however, I had to cross two main intersections which did not have audible traffic signals. After working on this skill most of the semester, I recall one afternoon, as I was standing at the intersection with the wind blowing and rain falling, when I suddenly realized that I would never be able to cross those streets safely. Because of all the noise, I couldn't even hear someone walking by, let alone detect which way the traffic was going. Fortunately, my mobility instructor realized what was happening

and intervened. He continued working with me after that and helped me to learn what was realistic and what was not.

Maturity Through Acceptance

In May 1991, I graduated from college with a Bachelor of Arts degree. I remember this as being a difficult time in my life. I continued working on mobility skills and didn't feel I was ready for the working world.

Not long after graduation, I got involved with the Blind Association in Pittsburgh. They had just received a grant to provide employment services to adults who were deafblind. We worked on interviewing skills and resume writing. Staff provided transportation to and from my job interviews as well. I also did volunteer work for the social service department. Through my involvement with the Pittsburgh Blind Association, I got to know several other people with vision and hearing loss. It was because of these new friendships that I decided to take sign language classes so that I could communicate with deafblind or deaf people who used ASL as their primary means of communication. During this time, I had many job interviews but no offers of employment.

One of the places where I had interviewed was the Three Rivers Center for Independent Living in Pittsburgh. They provided services such as attendant care to people with physical disabilities which allowed the consumer to stay in their homes rather than live in a nursing home. Many of the staff at the center were disabled, and I knew I wanted to work there. I learned that there were centers throughout the state and even the country that provide similar services. I had several interviews at the center in Pittsburgh with no luck. I interviewed with other agencies too, but I was determined to work for an independent living center one day. Getting rejection after rejection was discouraging, but I never lost sight of my goal. I had never given up on anything and had no intention of starting.

Settling Into Reality

In the summer of 1995, four years after graduating from college, I had another interview at the center for independent living, but this time the center was in Washington, Pennsylvania. I had sent my resume to other centers in the state a few months before. The long search was finally over. I was hired and started working as a service coordinator that following September. I found an apartment close enough to the office that I could walk instead of relying on the local cab service. A long time ago, I decided not to use buses; and Washington is in a rural community where bus service is limited. Nevertheless, because of

my hearing loss, I feel safer using cabs. I was able to walk to work from my apartment and lived there until July of 2004 when I purchased a condo nearby.

Over the years, the state VR agency and education system have provided me with the equipment I've needed and mobility training. I started in my job providing such services for people as attendant care, transportation, skills training and peer support. Since many of the consumers have acquired their disabilities as a result of accidents and need to adjust to life with a disability, peer support and mentoring are very important. In July of 2002, I was promoted to supervisor and now oversee the work of at least seven people. Most of my work is done on the computer now. I use JAWS with a Braille display and have a PAC Mate with a Braille display for taking notes in meetings. When I first started, I relied heavily on clerical staff for assistance in completing forms and reading materials. Now, whenever I have to access reading material I use the Open Book scanner.

Much of my free time, when I am not working, is spent surfing the web and exchanging email with my friends and family. I have purchased my own computer system for home use. Since I am no longer able to walk to work, I rely on the paratransit service for people with disabilities for both work and recreational purposes. For exercise, several times a week I go to a local gym where I have a membership. The Blind Association is very active and often has activities in the evening or on an occasional Saturday. My family is scattered around the country, but we get together often.

Looking back now, I can honestly say I wouldn't change a thing. There have been many bumps in the road. It hasn't been easy, but I've been fortunate. I've always had support and encouragement. All my hard work has paid off. I have everything I've always wanted: a home of my own, a job I love, and support from my family and friends. What more could I ask for?

From There to Here

Scott Stoffel

I never looked at my high school diploma. Couldn't tell you what it says.

Attending public schools all the way through high school graduation as a boy with low vision and some physical disabilities was like doing the Indy 500 with two flat tires and a busted carburetor. When that long race was finally over, I was just glad to be done with it. I had no feeling of accomplishment – didn't even bother with the graduation ceremony.

Why so negative? I guess I will forever be bitter about some things relating to those school years. On the one hand, I passed academically. But on the other, I failed socially. I often wonder which is more important. If you'd ask my state Vocational Rehabilitation (VR) counselor, she would've told you the academics were more important, so much so that the state only provided services to assist with academic success. Socially, you're on your own and expected to simply be normal. You see, multiple disabilities only present academic problems; they have no affect on the social development of a youngster. Besides, learning to get along with people and find ways to fit in is nowhere near as critical to human development as passing biology.

I did get academic help from special education services in Maryland and Connecticut -- large print books, tutors to help with things I missed on the chalkboard, and toward the end, some computer magnification equipment. Of course, the PC enlarger didn't arrive until the computer class I signed up for in my junior year was over. But that's the way things worked with special education services – slow. It provided enough to get me to the diploma, though.

But I've always wondered why there was no help on the social level. As a young child and before I knew I had any disabilities, I was very outgoing. I was always in a hurry to go outside and find playmates. I loved groups. But when the disabilities kicked in, that little kid found out he couldn't do a lot of things at a par level. I couldn't catch the ball, couldn't run fast – couldn't shoot hoops – aw, haven't you heard this sob story a million times? That right there is the same dismissal I got from people I went to for answers to those problems. The problems created rifts between me and the so-called normal kids. Things got worse as the disabilities progressed, but the solution stayed the same: Stop whining.

I was told how *lucky* I was to attend regular schools – the academic programs were much better there than in schools for handicapped kids. So what if I was the only kid there with multiple disabilities and well below the norm in many categories? The special education

services and the teachers were there to help me pass the classes; that's what was important. Everything else was irrelevant. Stop whining – just be nice and fit in.

I lost my extrovert personality before I finished elementary school. When other kids complained about my inadequacy or mocked me, I'd retreat and stay away from the group. It made me defensive because, as a kid, I just didn't understand why I was so sub-par by default, nor did I understand that there were ways I could have improved myself somewhat. Over time, the defensiveness became a disease – it made me critical of others in response to my own shortcomings. With each bad experience, I became more reluctant to attempt to interact socially, and the retardation of my social skills made it harder to find friends. It was a progressive decline that culminated in what I call a "Frankenstein Complex" – intense self-hatred.

But I graduated on schedule in 1986. Call it a complete success.

When I finished high school, I didn't have the faintest clue how I was going to build a life for myself. Everyone said, "Time for college." Not being able to drive, and living in an almost rural area of Connecticut made getting a job unrealistic. So I applied for college at the University of Central Connecticut. Thanks to the help of two very good tutors I had in high school, I did well on my SAT and entrance exams. But I ran into an unexpected problem with the state VR services: Unless I moved away from home, I was no longer eligible for services after turning eighteen. My parents' income was too high and I could not have lived at home without their income factoring into the equation and adversely affecting the level of VR support I was eligible to receive.

I call this chapter of my life "Acts of Stupidity." With my nonexistent social skills and no VR assistance, I took a crack at college. It takes someone truly remarkable to surpass that level of idiocy. For one thing, my "strategy" for dealing with visual aids and blackboards – no VR services, no tutors – was to simply listen more carefully to the lecturers. I should mention here that while I could hear, I didn't have perfect hearing and sometimes misunderstood speakers. Brilliant tactics, eh? On top of that, I had terrible writing skills coming out of high school – a good vocabulary but horrendous grammar. And I entered an adult environment with the social maturity of a twelve-year-old. As can be deduced, I sank into a quagmire within a semester, turning in bad grades and accomplishing nothing on the social level. So I quit and considered suicide.

I guess my family was worried about my mental health. They set me up with a job at a family-owned business in Tennessee and got me an apartment within walking distance. It was an easy job, too – all I had to do was talk to customers at a computer software store. It might have worked out, except that I lost my hearing six months later.

At this point, I think I reached the septic tank in Hell and was still digging. I spent a few years going back and forth between chasing hopeless whims and wanting to end the wretched story. I made one actual attempt at self-destruction but was "saved" by instinct at the last moment. The only good things that came out of this chapter of my life were that I taught myself how to write and learned Basic programming from a reference manual.

For whatever reason, I decided to regroup in '94 and find a way to deal with deafness on top of my old problems. A stay at the Helen Keller National Center (HKNC) in New York got me thinking that I should try college again. I started "Round Two" at Hofstra University, mainly because it was near HKNC. I wasn't even sure what to major in – I loved creative writing, but a career in computer science seemed more practical. So I took classes in both categories. The disability resources at Hofstra were okay, but I got most of my help through my HKNC counselor and several outstanding professors.

For two years, I really gave college my all. I had to split the time between classes and doing some part-time teaching at the Helen Keller Center. Couple that with the fact that I read about one-fifth as fast as a person with 20/20 vision, and you can guess how much time I had left after academics and work – none. And I actually chose that time to get married! Go ahead and raise your brows – logic has never played a role in my life. But I needed motivation and someone to fill the social void. I was back to my old habit of avoiding social contact with "peers" at the university. All I did there was work on academics. One difference now was that I had a goal – I wanted the college degree so I could get a job with solid pay. I'd never had a well-defined goal before this.

I really pursued the academics this time around. In fact, I even found out I could get high grades, provided I gave up all my spare time to class work. I did, promising the wife it was only a temporary circumstance that would mean good things for us later. Endure now, be happy later – that was my motto. It might have worked out all right, except that I ran out of money to pay for school.

My HKNC counselor had been confident I would have no trouble getting scholarships for deaf or blind students after I turned in some good grades at Hofstra. But she was quite mistaken about that. The deaf community slammed the door in my face because I wasn't born deaf. Basically, I was told to seek a place of solitude and do something that normally requires a partner of the opposite sex. The blind community had a few scholarships I was technically eligible for, but the award committees preferred younger people, especially women. I ended up with zero between the two. Wow, I'd never realized what a worthless freak I really was! People never ran out of reasons to reject me. Student loans and, ultimately, credit loans got me through fifty-eight credits of classes and into a bottomless

money pit. It didn't help that Hofstra was on the expensive side as was the student apartment I rented. Strike two.

I remember going home after withdrawing and looking at myself in the bathroom mirror. "There's the Ultimate Loser. I hate you, too."

The idea of giving up – again – after all that time and effort and with bankruptcy pounding on the door was a tough pill to swallow. So I looked into less expensive universities and cheaper areas to live than Long Island. I found out that state VR services provided different amounts of tuition support for different areas of study. All of this led me to Temple University in Philadelphia six months later and a major in engineering. I'd been thinking about robotics engineering ever since doing a term paper for a computer science class on artificial intelligence, so the change in direction wasn't as drastic as it may sound.

I found the disability resources at Temple were excellent, and some help from dedicated faculty made the engineering pursuit possible for me. Sticking to my academics-only approach, which included full-time summer course loads, I made it to my Bachelor's degree in three more years of non-stop school. The director of the Disability Resource Center at Temple helped me pick up a few small scholarships (pulled some strings) as did the head of the Electrical and Computer Engineering department. That financial aid, combined with the higher amount I got from the state VR for the engineering major, carried me to the finish line without a cent left in the bank.

It was an academic success. I finished at the top of my class – not that I knew anyone in my class. I received a few honors, group memberships and was a *magna cum laude*. My senior project was a sort of *giant* Braille computer display to help people who had trouble reading small Braille. It drew some media attention. Academically, I guess it was a big success.

But I never escaped being the Ultimate Loser. I accepted an induction into the Golden Key National Honors Society and decided to attend the ceremonies and reception. It was time to get involved with something and meet some people. I had a tactile sign language interpreter sitting with me to summarize what was said. Now I realized interpreters could be distracting to others, so I intentionally positioned us at the outer end of the row of seats. But no sooner had she started signing into my left hand than all the people in the row just behind us grimaced and moved elsewhere. Despite a crowded house, the row remained conspicuously empty the entire time. Ah, there's nothing like being a part – in my case, a hemorrhoid. Then my interpreter needed to leave after the ceremonies. I contemplated the reception for a few minutes. Let's see -- here was a room full of bright, young human beings chattering away the evening. And over here was a 30-something

worthless freak with no way to interact. Reality check time. Forgoing the preposterous notion of mingling, I left the legitimate people to their fun and went back to my empty world. It was so pathetic I couldn't stop laughing at myself.

My disabilities continued to get worse. My marriage was ailing. My social life was buried and forgotten. Nobody could understand why I wasn't happy on graduation day. I only attended the graduation ceremony because it shocked so many people that I didn't have any desire to go. Why should I? I'd been nominated to be the student speaker – it was something to do, at least – but the Board of Trustees had a reason to reject me, too: they didn't want an engineering student. Well, at least this time around I only needed to change majors, instead of gender, age, or auditory sense at birth.

I went anyway and sat there with 5,000 graduating students. I didn't know a single one of them. Was I a part of something? If I was, it sure didn't feel like it. I felt more like a sideshow at graduation. I guess I was a sideshow, really – the first deaf and legally blind engineering graduate ever to come from Temple. Come see the amazing Mr. Weird – he even talks!

To save the marriage, I had to find a good job in a hurry after graduation. I made use of the Federal Workforce Recruitment Program while at Temple and got an opportunity in Systems Engineering with the Federal Aviation Administration (FAA). I qualified for a job as a General Engineer because of my dual major (Electrical and Computer Engineering). And since it was with the feds, there were sufficient disability resources for me to get by on. So I jumped, moved down to Washington, DC, and started working three months after earning my BSE.

The work environment proved to be very different from college. For one thing, there were no longer textbooks for learning what I needed; most FAA training was oral. That created an immediate problem with my limited ability to accurately follow tactile sign language interpreters. In college, I'd always had the books to fall back on. I also had to rely more on public transportation. Meetings became recurring nightmares – try following a rapid discussion bouncing around a room through a tactile interpreter with my half-dead hands.

Desperately (stupidly) wanting to be something besides a one-man freak show, I held a lunchtime "class" for a few weeks on sign language basics and deafblindness to try to make my coworkers comfortable with me and see if there might be some communication between us. Wishful thinking, I guess. Maybe tactile sign is just too awkward – nobody was comfortable with it. I had to suffice with email and dry-erase boards to interact with my co-workers during those situations when I didn't have an interpreter. After attending a few office socials, I realized my lack of social skills coupled with the inadequate communication

modes available meant that I wasn't going to fit in at the office, either. But at least I got paid for my misery now.

To avoid being put in a wheelchair by my rapidly withering legs, I started devoting my newfound spare time to working out. When I started out, I could only walk a quarter of a mile on a treadmill. It scared me when I realized just how much I'd wasted away. Not only did I feel like the living dead, but I was starting to look like it, too. Took over a year to reverse the deterioration, but I stuck to it and finally started getting some results. I made lifting weights and treadmill work part of my daily life. Wish I'd started that a long time ago, but there just hadn't been time for it.

People sometimes ask me for advice about helping kids with disabilities "succeed" like I did. My answer is simple: Just remember that academic success is only part of the issue. Kids with disabilities need help finding ways to compensate for their limitations and to fit in socially. Happiness and a sense of belonging do not come just because a student earns good grades. Believe me, I know.

From Hearing High School to Deaf High School Life: A DeafBlind Student's Discovery of Self

Philip Wismer

Before coming to the Western Pennsylvania School for the Deaf (WPSD) I attended a hearing high school at Central Bucks County West (CB West). I only attended there for one

Philip Wismer uses his AlphaSmart device to communicate with people who do not use sign language.

year before I transferred to WPSD. At CB West, the hearing high school, I had two interpreters every day. One interpreter would work with me in the morning, and then I would get a different interpreter in the afternoon. Communication access was well-covered at CB West; but I needed to have more interactions with deaf peers. So my family decided that WPSD would be a good place for me to go to school. Even though WPSD is five hours from my home, I really like going to school there and have many deaf friends and staff who know how to support me.

Self Awareness

My vision and hearing loss are the result of a syndrome called CHARGE. I guess I was about 10 or 11 years old when I learned about my vision loss. Before that time, I was maybe 6 or 7 years old when I learned about my hearing loss. I can't remember the exact words my parents used to tell me about my condition, but I do recall my parents telling me that I was profoundly deaf and that I had problems with the retina in my right eye. When I attended school at WPSD I met other kids who were deaf with vision problems. At CB West, there was only one deaf boy and four or five hard of hearing kids; but there were no other students like me who had both vision and hearing problems. Fortunately, one thing I did learn at CB West was how to manage life with a vision problem and how to control myself.

Wismer, who has CHARGE Syndrome, uses a Video Magnifier to read restaurant menus prior to a mobility lesson in the community.

When I was at CB West, I attended a monthly support group meeting for deaf kids through the Children's Hospital of Philadelphia. Our instructor was a woman named Louise Montoya. We discussed how our disabilities affected our daily lives at home and in school. It

was a great group and I learned a lot. That support group really helped me learn more about myself as a deaf person with vision loss.

This past summer I began to prepare for the future when I will graduate from high school. First, I went to the Helen Keller National Center (HKNC) to attend a two-week program for high school students like me who have both vision and hearing loss. At HKNC, I learned that the training program could help me to improve my independent living skills. The HKNC program also provides evaluations to help students figure out what type of job they would like to have in the future. However, the two week program I attended only focused on helping me learn more about how to advocate for myself and what types of support services I will need to be successful. After finishing the two week program at HKNC, I went on to the "Explore Your Future" program at the National Technical Institute for the Deaf (NTID) where I learned about the university campus and what would be expected of me as a college student. Both programs were a lot of fun and I learned a lot about myself and what kind of job I would like to do in the future.

Because I left CB West and transferred to WPSD I had to complete one more year of high school. So now I will be 20 years old when I finally graduate from high school. For this reason, it is really good that I am starting to plan for the future right now. If possible, I would like to return to HKNC next summer to get an evaluation. It will be fun to be at HKNC for more than two weeks because I really enjoyed learning new things and meeting new people this past summer during the two week program.

Life At Home

In my neighborhood, I have a lot of friends who live close by. I enjoy playing games with them outside or even just being in the house chatting with them online. The computer has really helped me to get in touch and stay connected with friends from my neighborhood and from WPSD. When I am at home I really enjoy playing games with my mother and reading different news stories on the computer. Right now I am working on trying to get a nice computer for when I graduate from high school. My computer skills are very good, so I really want to have a computer that is nice and powerful when I am ready to go to college.

Using Internet mapping programs to learn about my neighborhood is something that I would like for my new computer to be able to do quickly. Getting around the community is pretty easy for me right now, and so far I do not have any major challenges walking around my neighborhood. However, in the future as I prepare to be independent, I want to know where things are located and to be able to identify the safest route to take to get around. It will also be neat to use the Internet mapping sites or other special software to visit my

friends and relatives. One of my future ambitions is to become a computer technician. I really like working on computers and other electronic gadgets.

Because things are going so well for me at school right now, I really do not think that I would eliminate anything about my preparation for adult life. However, if I could add something to my school life, it would be to receive a little bit more employment training experience every week. I really like learning new things, and just receiving employment training two days a week is not enough for me. If I could have my way, I would like to receive employment training five days a week!

Future Goals

Assistive technology is a big part of my life; I use a lot of adaptive and assistive technology everyday in school and at home. All the equipment I use is very important to helping me get through the day. I use four different types of equipment to help me do things. The Flipperport CCTV, a telescope for traveling, a desktop CCTV, and an AlphaSmart note taker are my daily companions. The Flipperport CCTV helps me to watch television from across the room. I just focus the flipper camera on the television and the image on the television screen is then projected onto my CCTV that is set up on a table near the
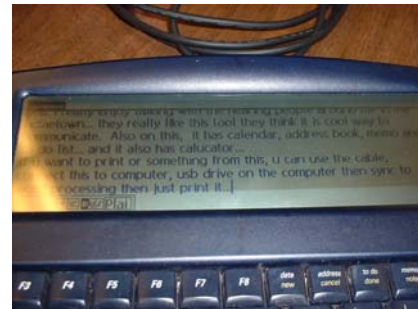
AlphaSmart device.
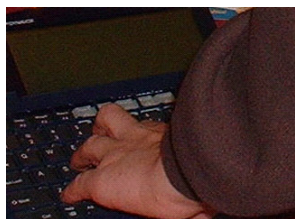
Wismer visits many technology expos to see what new equipment has come out which could benefit him.

sofa in our family room where I sit to watch television. The telescope helps me watch sports games when I am outside. The CCTV that is connected to my desktop computer is also a great tool that helps me to do paperwork or read books for school. The AlphaSmart note taker that I have is like my second pair of hands. It helps me to communicate with people who do not know sign language and also enables me to take notes in class. It is small and portable, and I really like using it. In the future I am sure that I will use the telescope a lot as an adult because I really like watching sports games and getting out into the community. The other devices will also be a part of my future one way or another.

Ultimately, my goal after high school is to go to NTID to receive training to become a computer technician. I think that all the planning that is happening right now in my life is really preparing me for life after high school. Being at a deaf high school has been a lot better for me than the hearing high school. My special needs related to being a deaf person who has vision loss and uses a lot of adaptive equipment are being addressed very well at WPSD.

Chapter Ten

"It wasn't easy
It was a long, hard
Journey in life
For us both…

But our love
Held us together
Through the traumas
The ups and downs
Of Life."

—Marcia McDermott
(Being A Mother, 2006)

From Devastation to Expectation: Raising My DeafBlind Daughter

Barbara Caudill

When she was nine months of age, I learned that my daughter was deaf. It was in December right before Christmas. By the following December, I learned that she was also blind. Not a good way to celebrate the holidays. Of course, my husband and I had already suspected that something was wrong, but those were the times when the *official* diagnosis came from the audiologist and Wills Eye Hospital respectively. At that time, she only had a mild to moderate hearing loss.

When I first learned of her deafness, I was upset with the thought that my child

My daughter at the age of 3.

would have a disability, yet I was hopeful because her hearing loss was only a mild to moderate loss. I hoped that hearing aids would help her. It was because her residual hearing could be enhanced with hearing aids that I decided to go the route of oral instruction with her. When I learned that she was also blind, I was devastated. I will never forget this strong reaction that I had in not wanting to go into her room to even look at her following the doctor's visit. I took her directly to my parents' home to regroup. My husband left me at the house with my parents. He did not return until the next day.

Initially, my daughter attended the school for the deaf. When she was in the second grade, it was quite apparent that her educational needs were not being met at that school.

Early Education

My daughter left the school for the deaf and was accepted at Wilmington Friends School (WFS), a privately operated Quaker school. She was the only child in that school with such a profound disability. My reason for choosing WFS was because at the school for the deaf, I felt my daughter was not included as much as I would have liked. Much of this was because the other deaf children were so visual and it was just too difficult for them to include her in their communications. Even though

My daughter at the age of 6, attending class with her interpreter.

I realized that at the Friends School my daughter would be the only person who was deaf and blind, I still thought that some of the children would take an interest in her and that they might learn to sign, which is what happened there. By and large, it was a give-and-take situation, and neither place was utopia. Also, I believed that my daughter would get a far superior education at WFS and that would be so important for her future needs. Because she was required to repeat the second grade when she arrived at WFS, my daughter completed her secondary education at age twenty.

New Instruction

All in all, I was extremely satisfied with the education she received at WFS. However; the only changes I would have made to her education are those countless times the educators gave her too many opportunities to complete her work in a timely manner. This ultimately was not helpful to her later on when she began college. Because many of the instructors felt sorry for her they lowered their standards instead of challenging her with higher expectations.

Except for that first year at WFS when my husband and I paid for her interpreter, the school system paid for all accommodations for my daughter throughout her education at WFS. In fact, that very first interpreter was my daughter's babysitter, and we were – and I am still – so very thankful that she agreed to do that for us. This young lady had just graduated from high school when my daughter began WFS. Thanks to this young lady, my daughter was able to learn so much immediately upon entering WFS.

New Access

Her first piece of equipment was a Perkins Braille Writer; and a few years later, she received a Versabraille unit. During middle school, my daughter was given a desktop computer and finally during her final two years in high school, she received a laptop computer, scanner, embosser, and TeleBraille. By far her favorite piece of

My daughter at the age of 16 in her resource room at the Wilmington Friends School. The school emptied out an old supply closet to accommodate her specialized equipment.

technology was the Optacon. She would use the Optacon to read my mail and anything else that she could get her tiny little hands on. She always fascinated me by how thirsty she was for language and knowledge. Her petite fingers could decipher nearly anything. Braille, print generated by the Optacon, and even plastic toy letters were no match for her inquisitive mind.

During IEP meeting the team discussed my daughter's friendships. From the second through the sixth grades, my daughter had a wonderful social life. Then, in the seventh grade, those friends began to drift apart from her. Those were difficult times for her. Although the school was aware of the friendship issues, they did not present any special programs to help address it; they tried to encourage friendships through the Quaker traditions of service and caring. Unfortunately, their attempts were not very successful.

When she went away to college, I hoped that she would develop deeper friendships since she was attending a college for the deaf. However, this was not a good experience for her either. She did not feel included and began to isolate herself in her dorm room. The computer seemed to become her closest friend. Both my daughter and I decided that it would be best if she were to leave that school and try something closer to home. After a year at a local community college, she enrolled at the University of Delaware. Initially this seemed to be a better experience for her. Although, she did not have the *normal* experience of being on campus or being with her friends all of the time, she was able to attend some parties and even went out to dinner and dancing with some of the girls she met. One very negative experience for her occurred when she was asked to pledge a sorority and then was tersely turned down.

Reflections on the Journey

As I look back on how well her transition from high school to college was, I recall how she had not wanted to attend college directly after high school. She had told me that she wanted to wait a few years. But I *encouraged* her to attend, and I should not have done that. In hindsight, I see that it would have been better for her to take some time off before going on to college. Other than that, it's difficult to say what else I would have changed about her transition process because I truly believe that we can only do our best to transition those with deafblindness, and each experience is different. My daughter's transition was not smooth, but it was much better than the stories I have heard from many other parents.

Comparing my daughter's early education experiences with her experiences at college, I can see that back in grade school when we were trying to have her fit in was when the worst problems occurred. This was during adolescence, which is an extremely difficult time for any child. All kids want to be liked and they worry about fitting in. Having any kind of difference can be difficult. To expect an adolescent to fully embrace a student with differences so that student can have the same experiences of non-disabled students is asking too much. This is a fact I have come to believe as I've been able to step away from

the daily pain and sense of rejection I saw etched on her face. After years have passed, I can assess things in a more realistic, pragmatic way. The elapse of time has aided and makes me less emotional regarding those situations when my daughter was left out of group activities and had her feelings hurt.

Looking Forward

As I see things today, I feel that my daughter is capable of living independently; but I admit that I did not always feel that way. Before, I could not imagine her being on the streets alone with her cane and with little ability to communicate with those around her. But now I think that what has changed my mind is that I see how much she wants independence for herself, and her love and zest for life. Another sense of comfort is that she has recently been placed on the list for a guide dog. That additional support will be great for her. Also, there are so many new adaptive devices that can help her interact with those who do not have sign language skills to communicate with her. However, with all that said, I still worry about her and can't imagine her traveling on a subway negotiating a major city like New York by herself.

My hope is that one day my daughter will become gainfully employed and that she will have a happy, fulfilling life doing whatever makes her feel happy and fulfilled. My genuine desire for her is that she realizes the opportunity to be as independent as possible. Often I tease her and say that she can be independent in spite of me. The truth is, any lack of confidence I have is not in her so much, but in my *letting* her go to be independent. The Helen Keller National Center (HKNC) has been a great experience for her. She has received training there in the past, and recently she returned for updated technology training. I preferred not to be involved with the training aspect of life. For many years, I have been there to help, train, and love her. Now, I just want to be there to love her, support her, and be her friend.

Although at the beginning of the journey, there were many struggles to address her educational needs, I try not to focus on those negatives. Instead, I choose to focus on those who have been there throughout her journey, including teachers, interpreters, therapists, and people from state agencies and even the HKNC regional office. Without all of the knowledge, caring, and love shown throughout the years, the journey would have been very empty.

Leaving on Time: The Story of My Son's Journey to Post-School Success

Jill Fullerton

As long as I can remember, I have been writing the story of my son's life. When he was born, I had such high expectations for the kind of life he would have. So far, my son's story has been plagued with more sadness than happiness. Graduating from high school has enabled me to reflect on all that he has been through. After recalling all that he has learned, I am hopeful that the remaining chapters of his life will be filled with more happiness than the beginning chapters.

Chad lost his vision between the ages of 4 and 5 due to optic neuropathy. He lost his hearing between the ages of 10 and 12 due to auditory neuropathy. Both losses were gradual. During that time, he also lost his fine-motor skills and much of his mobility as the neuropathy spread to other nerves in his body.

My initial reaction to hearing that Chad was legally blind was of course to cry for the loss of most of the dreams I had for him. I felt like all my balloons had just been popped. After finding out that he had also lost his hearing my mind was filled with questions and worry. *What more can this child possibly lose? How are we going to get him through school?* The questions, uncertainties, and feelings of hopelessness continued and still do today. No one has answers to explain why the nerves in my son's body are degenerating. Even though he has been seen by many doctors and put through so many painful tests, we still have no answers.

Reflections on Academic Pursuits

After I learned that my son was legally blind, he continued in regular education classes because, as he got older, we realized his disabilities did not impact him cognitively. If information is presented to him in a way that he can learn, he is more than capable of doing anything academically as well, or in some cases, even better than many of his peers.

In grade school Chad used large-print books, received extra time to complete assignments, and was presented materials auditorally. As his vision loss increased, he began using a CCTV. When his hearing loss began to worsen, he used an FM system for a short period of time. When that was no longer helpful, he received a full-time 1:1 aide in the sixth grade to assist him with accessing information. In high school he continued to use the CCTV while the support aide typed information to him using a laptop computer attached to a CCTV or a large monitor. Both methods worked quite well for Chad since he is usually

able to understand much of the information he reads. In Math class, this method of using high-tech adaptive equipment was a bit more difficult so a large dry-erase board was used instead. This approach was particularly useful after he lost the ability to write with a pen or pencil. All the math problems, equations, and formulas were written on the dry-erase board so that he could more easily complete and see his computations. Whenever possible, teachers would give him typed class notes ahead of time which made it a lot easier for him to follow the class lectures.

Because of the slowness of these approaches (the use of a large dry-erase board and laptop computer hooked up to a CCTV), it was decided that it would be best for Chad if his remaining Math courses (Algebra II, Geometry, and Trigonometry) were taught by an instructor working with him individually.

Throughout Chad's school life, I've been extremely involved in all aspects of his education programs, especially since I realized his intellectual potential early on. However, getting the teachers and school administration to realize his potential was a difficult task. I kept in close contact with the school personnel who were intimately involved with my son; and I also started working part time for the school district. This enabled me to check in with his teachers to make sure everything was going ok; or to see if they had encountered any problems presenting material to him. Since Chad's ability to communicate with other students became an issue, some adjustments had to be made when projects were assigned that required him to pair up with his classmates or participate in group discussions. In high school my need to intervene became less as Chad took on more responsibility for obtaining what he needed. During this time, Chad's 1:1 support aides were extremely important to his success. As one can imagine, we had our share of good aides and bad ones. All these paraprofessional had tremendous impact on Chad's educational success as well as his frustration level.

Chad graduated high school at the age of 17, which is the age at which he would have completed school had he not been deafblind. As a family, we decided this was the best thing for Chad since he was fully aware of his academic success. He fulfilled all the required credits for graduation, and like other students in his class, was able to go on to college. We wanted him to realize that he had the cognitive ability to learn and do well in school if he received the information in an accessible format. By keeping Chad in high school longer, we felt he would have believed that, due to his disabilities, he was not capable of achieving academic success. By law, Chad would have been able to remain in school until age 21; however, had he remained in high school any longer, my husband and I really believed he

would have only doubted all of his academic accomplishments throughout the years. So, we decided that it would be best for him to go ahead and graduate on time.

After a lot of hard work and team support, I am now satisfied with the overall education my son received. It was not an easy place to get to, though. Many years of fighting with the school district were required in order to get him what he needed. By far, the greatest struggle was to obtain a 1:1 support aide who was qualified to assist him in his AP (Advance Placement) classes. One thing I wish I could have changed most was his "terrible tenth grade year" when he had a horrible paraprofessional/support aide working with him. Not only did this person not show up most of the time or refuse to take notes for Chad during class; but this aide also took a personal dislike to him. This personality conflict made Chad's life so miserable that my husband and I had to force him to attend school everyday. I believe that during that time Chad's health declined even further due to the added stress. In hindsight, I should have insisted more adamantly that this aide be removed from working with my son. Although I did try, the school district refused to listen to me or Chad. Even Chad's classmates complained to me about how poorly this aide treated my son, but they were afraid to approach the principal on his behalf. Chad ended up being out of school for three months on homebound schooling and did not receive an appropriate education during that time. My husband and I used our own resources to hire tutors to prevent him from falling behind or losing his academic status.

Reflections on the Process

Looking back over the years, my son received a lot of extra support from my husband and myself, the Intermediate Unit and the school district in order to achieve the high level of success he has realized so far. So many sacrifices were made and opportunities presented to him that have had a tremendous impact on his life overall. Chad received vision, hearing (sign language instruction) and mobility support through the Intermediate Unit and the school district. The laptop he used was provided by the school district, the CCTV was provided by the Intermediate Unit, and the school supplied the monitor and paraprofessional who would type information to him. He also received one-on-one math instruction. In grade school we paid for three summers of tutoring and in high school my husband and I paid for whatever math tutoring he needed. We also paid for all the instruction he received during the time he was receiving homebound instruction in the tenth grade.

Friendships were one area where the school lacked any understanding of what challenges being in a regular education classroom represented for a disabled student. Two

of Chad's classmates learned fingerspelling from his sign language instructor. When he was in the eighth grade, sign language classes were offered to all students. However, most of the students did not participate in the classes and the few who did only wanted to learn signs that they could use to talk with one another, but not with Chad. The English teachers that taught my son in high school encouraged other students to type to him on his laptop if there was time, but that did not happen often. Three teachers in particular would take time themselves to type to Chad to get to know him on a more personal level. These teachers realized Chad's potential and encouraged, supported, and made the extra effort to give him every opportunity to excel in their classes. Truthfully, I feel that all of Chad's high school and middle school teachers realized his academic ability and offered him some level of encouragement and support. However, the commitment of these three high school instructors to ensure that Chad was afforded a positive education experience was really remarkable.

In high school I don't believe that Chad felt as though he were a part of his peer community. He spent so much of his time with adults (teachers and paraprofessionals) that he lost interest in his classmates. This was more because his classmates showed no interest in trying or wanting to communicate with him. He felt very isolated. In Chad's particular case, the lack of friendships was mainly due to the progressive deterioration of his hearing and mobility from the time he was in the fifth grade until the time he completed high school. Every few years we would have some new issue to deal with – not only related to medical and family concerns, but at school on a social and educational level as well. Basically, differences were a part of Chad's total school experience. As his disabilities progressed, we had to learn to be flexible and to teach the school district to be flexible as well. The biggest lesson we've learned through his transition process was to have a backup plan because things may not go as you want or expect them to.

Future Reflections on Independence

While I do not feel that Chad is physically capable of living independently now, I do feel that he is intellectually capable. Before, I thought it would take several years before he was ready for independence; but I believe that after he receives independent living skills training for the deafblind, opportunities for career exploration, and exposure to social activities with other deafblind people, he will do just fine. He needs to be taught by people who are trained in deafblindness. Through this specialized training, Chad will learn that there are different ways of doing things than a sighted or hearing person would, but that things can be done nonetheless. Chad doesn't know or realize this fact yet as he has lived in

a sighted, hearing world all of his life and tried desperately to appear as normal as he could. I really do feel he can eventually be independent. He may need a bit of assistance with some things, but he has the capability inside himself. He just needs the confidence, specialized training, and advocacy to bring it about.

I want Chad to get specialized training so that he can go on to college. Ultimately, my desire is for him to find a career that suits him and has the accommodations he requires. I want my son to be able to live a happy, independent, successful life. Each step of the way, I have been right there for him. Although I am very apprehensive about the future, I am excited at the same time. Chad is starting down a different path in his life right now; and it is time for him to start writing his own story, so to speak.

Small Steps toward Self-Determination: Learning How to Let Go with Love

Victoria O'Neal

When Cristen was about 4 or 6 months old, we discovered that she was not listening to us when we would call her name. One morning, I was in the kitchen and Cristen was playing on the floor with her back to me. I got two pan lids and hit them together, and she never moved. One doctor and then two doctors discovered she was indeed deaf. Gary and I were both in a state of disbelief. I had never smoked or drank and always watched what I ate. Of course, we went through the "Why me?" stage. One day I was talking to my mom about it, and she said something that I will never forget, "Honey, God gives those special children to people that he knows will take care of them." From that day on I was on a mission to get Cristen everything that she needed to live her life as normally as possible.

Cristen O'Neal as an infant.

We had her fitted for her first hearing aid (at that time it was a body aid) and you can guess that the aid spent more time getting repaired than she had it because food and anything she drank went right into the microphone. Cristen also had a condition her pediatrician called eye nystagmus, where the eyes continually shift from left to right. He recommended that we see an eye specialist when she was about 18 months old. The ophthalmologist discovered that Cristen also had a low vision problem and should be fitted for glasses. From day one, Cristen never was bothered by wearing her glasses or her hearing aids. She was always very responsible to take care of them, even at an early age.

Cristen O'Neal at age 3.

Cristen's audiologist recommended that we enroll her in the Easter Seals program so that we could start learning sign language. The thought, at first, scared me to death. I said to myself, "This is like learning a whole new language," and I did not know at first if I could do it. That thought soon passed, and I was suddenly buying every book and dictionary on signing that I could find. I took Cristen to the nearby town of Franklin twice a week for the Easter Seals program. Reading to my 2-year-old daughter was quite a task; for every word, I would need to stop, look up the sign, and show it to Cristen. I am sure that she never really got the meaning of the story at first because of this. Soon I decided that, instead of

signing every word, we would look at the pictures in the book. I would give Cristen the signs for the things in the pictures, and then tell her the story based on what was happening in the pictures. She then would continually bring me things around the house, and I would look up the signs for them and show her.

When Cristen was about 3 years old, we started her in a preschool program at Clarion University. Undergraduate students in Speech Therapy, under the direction of Dr. Colleen McAleer, would work with Cristen twice a week. She started to utter some recognizable words, "NO" being the first word soon followed by "Mom" and "DaDa." That was about the extent and still today is the extent of her speech ability.

Cristen O'Neal at age 5.

At age 4, Cristen was enrolled at North Clarion Elementary through the Intermediate Unit VI (IU-6). The following year she went to West Forest Elementary in her second

Cristen O'Neal at age 2.

hearing impaired class through the IU. Then the following year, she started first grade in a hearing impaired self-contained classroom at Steffee Elementary in the Cranberry School District. She continued at Cranberry through her high school years and was mainstreamed into some classes such as gym, typing, and computer keyboarding. For a majority of the time, she was in the hearing impaired classroom with four other girls who were her age.

When Cristen was in about the tenth grade, the state vocational rehabilitation agency for the blind requested that the regional representative from the Helen Keller

Cristen O'Neal at age 12.

National Center (HKNC) contact us to discuss transition services. The regional representative came to our home and discussed our daughter's education. My husband and I learned about the HKNC training program located in Long Island, New York, and we were terrified at the thought of sending our only child to such a far away place. I recall how I initially thought to myself, "No way will I ever send my child to New York!!" The regional representative also shared information with us about a one-week transition program in Richmond, Virginia. My husband and I decided to try that program first. Cristen

enjoyed herself, and I think that began her feeling of independence. The following summer, the HKNC regional representative encouraged us to allow Cristen to participate in the two-week summer program at HKNC. We decided, reluctantly, to send her. She missed us a lot, but said that she did have fun.

When it was time for Cristen to graduate from Cranberry, the HKNC regional representative attended her last IEP meeting and suggested that we consider having our daughter stay in school for her remaining two years of entitlement so that she could have

Cristen O'Neal at age 16.

more time to address unfinished IEP goals that had been identified. As a family we decided to allow Cristen to attend the school for the deaf for two years. So even after she received her first diploma from Cranberry High School we decided not to let her graduate; she went to the Western Pennsylvania School for the Deaf (WPSD) in Pittsburgh and graduated from there two years later with another diploma. I think that she really gained a lot more independence from the school for the deaf as she was only home on weekends. She also gained more self confidence in that she had many friends and more of a social life. After graduation from the school for the deaf, we knew that it would not be fair to Cristen to keep her at home. We realized that if she was ever going to have a chance of living on her own someday, we needed to let her go back to HKNC for more comprehensive training. I explained to Cristen that she would always have *home* to come to, but that she needed this experience. Eighteen months later, Cristen was in her own apartment and living independently thanks to so many caring and supportive professionals. I recall one conversation I had with Cristen while she was at HKNC, living in her own apartment there, when she shared with me that she had taken the public bus on Long Island to a large shopping center all by herself. The thought of her out there by herself scared me to death. I know that had she not gone to HKNC opportunities such as this, for her to mature and be self assured, would never have happened because I would have been too frightened and selfish to ever let her do anything like that. I am so very grateful to all the professionals who worked with Cristen; my husband and I could not be more proud of her than we are right now.

If I had it all to do over, I don't know that I would have changed anything except that we may have sent Cristen to the school for the deaf sooner. It was fear of the unknown, and the fact that she would have been so far away that kept us from doing it

sooner. However, I am very thankful also, to all of Cristen's teachers at Cranberry, who also helped me to learn how to effectively communicate with my daughter. I know that if Cristen had started her schooling at the school for the deaf, I would not have been able to communicate with her as well as I do now. Also, she has a great sense of family, since we all spent so much time as a family learning sign language together.

Cristen's home school district – Forest Area – was very supportive from day one of her education because, I think, they knew that I would settle for nothing less. I attended and contributed to all of her IEP meetings. The school district provided all the adaptive equipment that was necessary for Cristen's education. They also were responsible for arranging for an extra interpreter in the classroom the two years she attended the school for the deaf. This helped Cristen a lot since, due to her poor visual acuity, she could not see the teacher well enough.

All in all, we could not be more proud of our daughter. She has worked very hard to get where she is at today. My future hope for Cristen is that she will meet that special person and start a family of her own. I know that she would also make a great mom someday.

Chapter Eleven

Framework for Positive Outcomes

Framework for Positive Outcomes: Designing School-to-Work Programs for DeafBlind Teens

Eugene Bourquin

Cynthia L. Ingraham

Roch Jand I. Arboleda

Katrina Miller

"High expectations are the key to everything." – Sam Walton

Introduction

As with any new construction, establishing a solid foundation is imperative. Without a proven blueprint, construction can get off track and go way over budget. Both a great deal of forethought and preparation are essential to identify potential environmental changes that may cause difficulties for new projects. Much like the consideration given to new structures, a successful transition experience for high school students who are deafblind requires a lot of forethought, skilled training, and early preparation. Without such training, it is unlikely that deafblind students leaving high school and moving on to the world of work and adult services will be able to withstand unforeseen adversity or environmental risks associated with adulthood and living independently.

Recent proposed cuts to the vocational education program for high school students will have a tremendous impact on post-school outcomes for students with disabilities, and more specifically, students who are deafblind. Historically, this program has helped educators and families identify vocational and post-school goals which helped to determine preliminary transition plans for deafblind students. Because the average day for a high school student is jammed back-to-back with academic requirements, standardized tests, and community service requirements, there is often a need to take additional time to properly plan for the transition of deafblind students. It is critical to begin the process early enough to permit the student's transition team to fully maximize all the time to which the student is entitled under the law (Ingraham, 2001). Often, tutoring sessions, orientation and mobility lessons, and wading through the large volume of accessible materials can consume an entire day for a deafblind student.

Due to the need for additional academic preparation and the need to keep up with state and federal education standards, many high school students who are deafblind are frequently not afforded the same opportunities for peer interaction and incidental learning

as their hearing-sighted or deaf peers. Support services and classroom accommodations are not only provided to address basic accessibility issues, but are an essential component to a deafblind student's typical day. Care has to be taken to ensure that opportunities to develop life skills and self-awareness are consciously incorporated into the student's day.

The fact that deafblind students do not have the ability to actively view popular television programming or magazines that are age-specific, or to discuss the latest fashion trends, dating mores, and pressing societal issues can leave them light-years behind their peers when it comes to transition preparation. Socializing with peers and developing age-appropriate behaviors and expectations are as critical as career exploration, college placement tests, and meeting federal standards of learning requirements.

Transition Planning

More than just planning for linkages to service providers and systems, the transition process for deafblind students requires a great deal of self-excavating and exploration on the part of the student. An undertaking of this significance cannot be taken on without proper support from an effective and informed team of concerned professionals, family members, friends, and mentors (Ingraham et al, 1994; Lankard, 2000). High school students who are deafblind are required to master these tools, along with academic subject areas required for graduation and independent living. Unfortunately, there are not enough hours in the average school day to enable a deafblind student to achieve every required goal. As a result, more parents, educators, and students are realizing the benefits of continuing education beyond the typical age of 17 or 18. Many are choosing to remain connected with the school system until the student's educational entitlement has been exhausted. In most states, students are entitled to a free and appropriate education until age 21, provided that targeted goals are agreed upon and written in the student's IEP. In addition to an extended high school experience, deafblind students are making creative use of summer vacations, after school hours, and other extended break periods to *catch up* with their hearing-sighted peers.

It has been observed that many deafblind high school students lack perspective and clarity about life skills and basic interpersonal relationships simply because they have not experienced these situations (Ingraham & Anderson, 2001). While it is impossible to simulate all probable scenarios from which high school students who are deafblind can experience real life, effort should be made to expose students to as many natural experiences as feasible. Any exposure to typical peer and social experiences will help to equip the deafblind student with the fundamental framework and roadmap needed to make

a successful voyage from high school to life as an independent adult. Without such a roadmap, deafblind students are likely to become one of the statistics which state that students with disabilities are twice as likely to drop out of school as their non disabled peers (Timmons, Mack, Sims, Hare, & Wills, 2006).

Parents, educators, peers, and mentors are great resources and should be invited to be members of the student's transition planning team. By watching and speaking with parents and mentors, the deafblind student is afforded the opportunity to obtain a glimpse of the adult world. It is vital that team members work together to help the deafblind student establish personal goals for the short-term as well as the long-term. Many deafblind students are not accustomed to thinking beyond their present situation and may find it too challenging at first to set long-term goals. Whether the level of the bar is set high by parents, teachers, or the student, it is important to set the bar high. It has been proven that students who are expected to do well in school and are afforded opportunities to do so are more likely to have successful post-school experiences than students who are not challenged at all (Ingraham, 2001).

Initial Assessments

We know that many students who are deafblind may be uncertain of what types of jobs they would like to do in the future. For this reason, parent, teacher, and student interviews are a good place to begin the information-gathering process. Expectations in the classroom and home may not be aligned, and as a result, parents may observe different areas of interest and need than what is observed by the classroom instructor. Likewise, students may find one environment more conducive to self-exploration and creativity than another. Parents may be too rigid or overly protective, which may stifle creativity and natural curiosity. Conversely, some classroom instructors may place higher expectations on deafblind students than what they are able to manage. Thus, communication between the home and school is an essential component to the student's overall education program. Information gleaned from parent, teacher, and student interviews can also be used as part of the preliminary foundation for the student's assessment, until a more formalized tool is introduced.

While informal, this data may be the most reliable indicator of the student's interests and abilities, as there are no reliable norms for deafblind students using the existing standardized aptitude and ability tests (Vernon & Hammer, 1996). Formal standardized tests can yield very important information about the student's abilities, however, care should be taken when using the results of such testing to plan for a student's transition to

post-school life. If a test does not have established norms for deafblind students, it should not be used as the sole indicator of a student's true interest or aptitude.

Periodic Appraisals

Once information has been gathered regarding the student's observed interests, skills, and experiences, more formal testing with actual work tasks can be introduced. Begin with simulated work tasks in the classroom environment, and gradually progress to environments outside the classroom. This can be an excellent way to find out how well the student can perform a particular task in settings that are unfamiliar and how well he or she performs under pressure.

Many paper and pencil interest assessments are challenging for deafblind students to complete. Information related to types of job duties and vocations are often best understood through exposure to the actual task. Some students who have very minimal residual vision and hearing may have never seen someone perform a specific job duty before; however, very useful information can be dispensed during student interviews and interest inventories. Contrastingly, because some students may not be aware of the types of jobs they will be able to perform given their vision and hearing loss, a paper and pencil assessment tool may require some modifications in order to provide definitions and clarification of duties or to highlight possible accommodations that would enable the student to perform the individual tasks that are vital for the position. Such tests should be revisited throughout the student's time in high school.

Non-School Related Resources

As students are exposed to more work tasks and environments, new revelations regarding interests, skills, and readiness may be uncovered. Any activities that can not be accomplished during the regular school day should be offered during weekends, extended holiday breaks, or summer vacations. In such cases, the school district may be tapped as a funding source for on-the-job support services, transportation, orientation and mobility training, or any required adaptive technology. In very rare cases, the state vocational rehabilitation (VR) agency may be willing to use school assessment resources to bring together information about the employment potential of prospective VR consumers. It is prudent to ask if the student is eligible to receive some degree of support from the vocational rehabilitation agency to support career exploration or vocation training activities while they are still connected with the school system (Ingraham et al, 1994; Ingraham & Anderson, 2001).

Early contact with the vocational rehabilitation state agency can be seen as a cost-saving measure for the vocational rehabilitation counselor who would like to get started earlier than what is required by law on what may be viewed as a potentially challenging case. If all parties are in agreement and work collaboratively, the use of expertise from the school system, community resources, and key personnel to identify potential vocational goals for deafblind students can help the VR counselor shorten the time a deafblind consumer's file remains open with the state agency (Ingraham & Anderson, 2001). In addition to an emphasis on vocational skills, deafblind students may require extensive training to access public transportation, use orientation and mobility skills, acquire independent living skills, and to develop self-advocacy. Community mentorship and recreation programs for youth with disabilities, church and extra-curricular activities at school are great outlets to help deafblind students in learn from peers, gain exposure to role models, and assume leadership positions. The more self-awareness students possesses, the more capable they will be when it is time to speak up for themselves and to function as their own advocate.

Participating in IEP Meetings

By law, students who are deafblind are expected to be active members of their Individual Education Plan (IEP) meetings and, whenever possible, should be consulted before any education-related goals are established. This participation will provide the student with a clear understanding of his or her individual support needs, what adaptive technology is required for accessibility, the role that support staff plays in their lives, and how to set and achieve short-term and long-term goals. Exposure to self-determining moments such as these will provide students with an excellent foundation to better understand the level of control they are expected to have in their own lives. This includes identifying personal and work-related interests, talents, and goals that will be incorporated into their IEPs. *Appendix A* highlights target areas which should be addressed when preparing deafblind students to transition from high school to adult life. Whether students remain in school until age 21 or leave at the age of 18, these goals are key milestones that, if left unmet, could potentially have an adverse effect on how successful the transition process will be.

Job Development

While the classroom instructor, parent, and student are determining the interests, skills, and goals for employment exposure, the job developer begins to canvas the student's

home community. The objective of this search is to locate potential business partners whose services fall into identified target areas that match the student's interests and skills. Historically, many franchise stores and restaurants have been good business partners for school-to-work programs. Less success has been found in stores that are "Mom and Pop" establishments where family members are typically given preference in hiring. Sites that require some travel via public transportation are welcomed, as these locations allow deafblind students to learn about the practical aspects of planning a work day, including preparing for subway or bus delays and effectively communicating with the public to request directions or other information to ensure a timely arrival to the work site. Before work sites are selected, mobility specialists should investigate transportation during times of the day when the student will typically travel. Some students should also be given the opportunity to apply for para-transportation services and any other discount programs available to travelers with disabilities.

When the job developer and deafblind student agree upon a possible employment placement, an interview should be scheduled. Mock interviews can help the deafblind student prepare for the formal interview process and receive valuable feedback from school staff. Partnering employers can be enlisted to share questions which they would typically ask of prospective employees. Specific work tasks, schedules, rules, and responsibilities are usual topics covered during an initial interview.

On the Job

Once the job is secure, the job coach, mobility specialist, and rehabilitation teacher may accompany each student to the employment site. Any accommodations relative to communication accessibility can be established during the initial visits. Some typical reasonable accommodation for this population can include:

- Communication books to initiate common daily work-related tasks (i.e., key words representing specific duties: empty trash, clean tables, mops floor, etc.).
- Magnification equipment for reading product labels.
- TTYs for use when calling in sick or placing calls from the work site.
- Alternative communication methods (i.e., dry-erase board and markers to communicate with customers, Screen Braille Communicator, photos, etc.).
- Identification buttons, which read "I AM DEAF AND BLIND." Store badges can also be modified with phrases like "Hello, I speak American Sign Language."

Examples of Success

Some school districts operate formal school-to-work programming as a component of transition services offered to high school students. Other programs begin as early as six years of age, with teacher observations, instructor and family interviews, and exposure to work tasks in the classroom and community. It is never too early to begin the process; however, too much emphasis on vocational outcomes can stunt the academic potential of students. As with all students, a reasonable blend of vocational tasks and academic programming should be afforded to each deafblind student before he or she exits the school system. Below are examples of four programs that have provided deafblind high school students with sound foundations for successful school-to-work transition.

Washington, DC

The Model Secondary School for the Deaf (MSSD) in Washington, DC has a transition model that begins when students arrive on campus. The transition counselor works with the deafblind student by gathering as much data about the student from parental anecdotes, formal evaluations (vocational, psychological, medical, etc.), and educational reports. This data-gathering process facilitates the writing of an initial Transition Plan that will be included in the student's IEP. This plan becomes a template for the work that the student and the Transition Counselor need to accomplish together. Because MSSD is a residential program, residence education staff members are also involved in the preparation.

Each student enrolled at MSSD is expected to participate in the internship program which provides hands-on vocational experience. The deafblind student is just like any other student who is expected to fulfill and learn from this requirement. Through this work experience, students are taught the importance of showing up to work on time, dressing appropriately, requesting reasonable accommodations, following instructions, asking for assistance, and communicating with non-signing co-workers, among other things

MSSD is a unique residential program because it serves all 50 states and the U.S. Territories. Students from all over the country receive specialized instruction from a crew of competent teachers and staff whose goal it is to assure that each student exits this secondary program with experience, skills, and an understanding of themselves. This prepares the student for successful post-secondary experiences either in institutions of higher learning or employment settings. Because MSSD offers a residential component, instructional goals can be carried over and addressed after school hours by staff that possess the communication skills, cultural sensitivity, and access to resources needed by deaf and deafblind students. In addition to helping students learn work skills, apply their

literacy skills, and become independent travelers, staff provide students with instruction in appropriate daily living and self-advocacy skills.

At MSSD, the Transition Counselor facilitates a smoother transition of students from school to a post-secondary goal by connecting them with services that will help them realize their goals. Examples of these services include Vocational Rehabilitation, independent living skills programs, and other community resources that have been identified as possible service providers. This is where self-advocacy as a skill is beneficial. Without this connection, it is easy for students to get lost in a multitude of possibilities which never become realities. This transition approach provides the deaf and deafblind students with an understanding of the adult service system and how to access services with the supervision and guidance of the Transition Counselor who can help in times of confusion and provide redirection as needed.

Delaware

The School-to-Work Program at the Delaware School for the Deaf provides academic and functional instruction in the areas of independent living, domestic chores, recreation and leisure activities, and community and vocational training. This program meets the needs of students who have diverse strengths, needs, and learning styles. Participants all have some level of hearing loss and may have additional cognitive or physical challenges. Through focused training relevant to critical life skills, students maximize instructional time from the ages of 14 through 21. The goal for each student is to exit school with skills and supports that will allow him/her to work, live in, and contribute to the local community.

Officially, vocational training begins at age 14. Until the age of 17, students participate in a job-sampling program. They receive training relevant to interviewing, attendance, punctuality, and interacting with co-workers. During these years, students are exposed to real work in non-profit community and school district vocational training programs. Staff determines job preferences and performance levels, as well as supports needed to participate in the work force. Students with mild disabilities are encouraged to acquire independent work skills, targeting accuracy, efficiency, duration and other work-related behaviors. Students with significant disabilities often are paired with other students who have complementary skills. These students are supported by a job coach to ensure quality and quantity control.

Unlike many other states that have federally funded DeafBlind Projects for Children, the state of Delaware has a DeafBlind Children's Program that is a part of the State Department of Education. This unique program affords students who are deafblind in the

state with access to specially trained professionals who are available to provide technical assistance to local School Districts, guidance for parents, summer training programs for students in special areas of interest, follow-along services for IEP meetings, and work experience programs. The DeafBlind Coordinator and staff members in the state of Delaware are responsible for organizing all the transition services for the state's more than 50 deafblind students. The DeafBlind Program staff also ensures that all necessary connections are made with appropriate adult service providers on behalf of each student. Every student, his or her parents, and other family members, as needed, are encouraged to actively participate in IEP and other team meetings when decisions on academic and vocational instruction are made.

A functional vocational assessment is provided, which enables the student to identify areas of interest and skill, and possible ambitions. Specialized equipment needs are more quickly addressed when coordinated by a professional who is knowledgeable and resourceful. Promptly addressing areas of need can help to reduce the amount of time students spend without essential technological and adaptive aids that often result in severe educational lags from which many students are often unable to recover. In the past, as a way to address the need for independent living skills training, the Delaware DeafBlind Program for Children coordinated a DeafBlind Transition Week during the summer. This week-long program addressed essential transition topics such as: employment literacy and interests, the role of an interpreter, the role of the vocational rehabilitation counselor, community resources, orientation and mobility, self-identification, resources for seeking support services, and alternative methods of communication. Students were given individualized instruction in their identified areas of interest.

When students reach approximately 18 years of age, the program focuses on competitive employment opportunities. On-the-job training and support are provided as deemed appropriate by employer and school personnel. Paid employment begins only after training and job performance are at an acceptable level. Some students, due to individual needs, will always require some degree of support on the job. This support may be provided and funded by state service agencies. The employer is responsible for paying only the employee, not the support personnel.

The Delaware School-to-Work Program is constantly seeking new job opportunities for students, and carefully matches employer needs with student strengths and preferences to ensure a dedicated and consistent worker and appropriate employment match.

Pennsylvania

The Overbrook School for the Blind (OSB) operates a premiere educational program for deafblind students. Vocational assessments are begun as early as six years of age. Students are introduced to tasks which simulate actual work activities performed at local employment training sites utilized by the school. As the students progress through the program, they are given the opportunity to be exposed to a number of different employment scenarios. Required tasks at each new environment are assessed and cataloged for future use with other students. The staff at the OSB evaluates each student and determines which students would be best suited for the identified tasks. Some mentoring takes place as students with fewer skills are matched with students who possess greater skills in a particular area. Additionally, students are given the opportunity to receive a "promotion" into more challenging and rewarding tasks. Every student that graduates from OSB is equipped with a print résumé, and, in some cases, a video résumé which highlights his or her work history while in school. The employment documentation is the basis for the portfolio that students take with them into adult services. Because many deafblind students require personalized environmental and technological support, it is often better to use video footage to *show* adaptations in use rather than rely solely on written reports and recommendations.

New York

For three years, from 2000 to 2002, the vocational rehabilitation training program at Helen Keller National Center's (HKNC) headquarters operated the Community Services Program (CSP) which was a collaboration and demonstration program in cooperation with the New York State Commission for the Blind (CBVH). The CSP provided direct rehabilitation, vocational, and support services to persons who were deafblind, at their homes, work sites, and communities.

Services were provided to eligible residents throughout New York State. Included in this program was a three-year project that enabled high school students who were deafblind to experience employment in their home communities with appropriate support. The work settings were diverse and reflected those identified by students as areas of interest:

- Flower store or botanical gardens assistant
- Blood bank assistant
- Drug store clerk
- Computer center technical aide
- Fast food restaurant worker

- Clothing store stock worker
- Video store clerk
- Book store clerk

All positions continued for a minimum of four weeks and a maximum of eight weeks; the program supported up to 24 hours per week of paid, competitive employment.

Following the selection of teenagers for the program, the first major step in the process was to contact the families to schedule information-sharing and planning meetings. The program philosophy was to incorporate family-centered planning, and would involve other persons from the community who would support the student. Because this program provided the first work experience for these children, both participants and family members expressed common concerns and anxieties. Some students were required to travel using public or para-transit for the first time. Parents were concerned about their child's safety outside the school setting, and the youths expressed fear of the novel and unknown.

After the initial year concluded, students and parents involved in the pilot program were invited to speak to the new group of students and parents. Meetings were held on weekends when all students and most parents were free to participate. Agencies connected with the program also scheduled staff to attend these meetings. Listening to the past successes and concerns of others helped to foster understanding and commitment to the process. The benefit of earning a salary was a frequent topic of discussion and appeared to be a primary motivator for teen participants.

In order to properly develop jobs for each adolescent and plan for a successful experience, numerous strategies were followed. Each participant was interviewed to determine his or her general interests, personal goals, academic and life skills, and the make-up of the neighborhood (i.e., retail outlets, businesses, and transportation options). Using this information, the job developer was able to establish a clear and precise follow-up plan. It was essential to agree on a time schedule for critical steps in the process, including: mock interview(s), a mobility assessment, and neighborhood visits. This established concrete expectations of both the program and the youths.

Work adjustment training was also implemented. The teens were exposed to concepts such as appropriate work behavior (e.g., being on time for shifts); communication strategies for the work site (such as using high and low technology options); responsibility, independence and interdependence; and appropriate behaviors for the work environment. It was important that communication on all of these issues was clear and effective.

Summary

Long before students begin their transition journey from high school; it is in the best interest of parents to take a very active role in their educational needs, and in the identification of support services and educational challenges (Ingraham, 2001). For students who are deafblind, it is imperative that parents maintain updated records and resource information regarding special accommodation needs, community programs that can provide support during and after school hours, and recommendations for goals beyond the high school program. Any exposure to real life work situations where money can be earned for performing chores or tasks can be valuable. Likewise, opportunities to meet with mentors, peers, family members, and friends who are willing to share information about their own work experiences can help the deafblind student form a clear understanding of the world of work, employment related responsibilities, and the expectations employers have of their workers.

Situational work assessments are invariably the best indicators for determining what work environments or careers are best suited for deafblind students. Cooperation from the surrounding businesses and community programs can offer tremendous insights to the student who has never experienced the "real world" of work (Grossi, Schaaf, Steigerwald, & Thomas, 2004). Many school programs across the country have forged relationships with businesses in the local community as a way to expose deafblind students to authentic work settings, along with all the responsibilities, expectations, and rewards that go along with being employed. A framework of this nature can help to steer deafblind students into successful competitive employment situations as they prepare to journey from high school to the world of work and independence.

Appendix A: School To Work Rubric

AGE 14	AGE 15	AGE 16	AGE 17	AGE 18	AGE 19	AGE 20	AGE 21
Parent, teacher, student interviews	Parent, teacher, student interviews	Parent, teacher, student interviews	Parent, teacher, student interviews	Parent, teacher, student interviews	Parent, teacher, student interviews	Parent, teacher, student interviews	Parent, teacher, student interviews
Participate in IEP	Participate in IEP	Participate in IEP	Participate in IEP	Participate in IEP	Participate in IEP	Participate in IEP	Participate in IEP
Extra curricular school activities, community, church, mentorship programs	Extra curricular activities in school, community groups, church groups, mentorship programs Begin visits to college campuses, job sites, apartment communities and group home programs	Extra curricular activities in school, community groups, church groups, mentorship programs;	Extra curricular activities in school, community groups, church groups, mentorship programs; Continue visits to college campuses, job sites, apartment communities and group home programs	Extra curricular activities in school, community groups, church groups, mentorship programs;	Extra curricular activities in school, community groups, church groups, mentorship programs;	Extra curricular activities in school, community groups, church groups, mentorship programs; Continue visits to college campuses, job sites, apartment communities and group home programs	Extra curricular activities in school, community groups, church groups, mentorship programs; Continue visits to college campuses, job sites, apartment communities and group home programs
Begin ADL skills training (orientation mobility, banking, budgeting, shopping, conduct on line searches for resources, assign household chores, meal planning and preparation	Continue ADL skills training, assign household chores, meal planning and preparation	Continue ADL skills training, assign household chores, meal planning and preparation	Continue ADL skills training, assign household chores, meal planning and preparation	Continue ADL skills training, assign household chores, meal planning and preparation	Continue ADL skills training, assign household chores, meal planning and preparation	Continue ADL skills training, assign household chores, meal planning and preparation	Continue ADL skills training, assign household chores, meal planning and preparation
Draft personal vision statement	Review personal vision statement as part of IEP	Review personal vision statement as part of IEP	Review personal vision statement as part of IEP	Review personal vision statement as part of IEP	Review/Revise personal vision statement as part of IEP	Review/Revise personal vision statement as part of ITP	Review/Revise personal vision statement as part of ITP
Paper and pencil assessments	Paper and pencil assessments	Discuss potential job interests and goals	Job shadow activities on and off campus	Job shadow activities on and off campus; Paper and pencil or functional assessments	Job shadow activities on and off campus; Paper and pencil or functional assessments	Job shadow activities on and off campus; Discuss potential job interests and goals	Work experience off campus
Classroom exposure to work tasks	Classroom and community exposure to work tasks	Community work experience program during school hours	Community work experience during school hours; begin summer job	Community work experience program during school hours	Community work experience program during school hours; summer job	Community work experience program during school hours; summer job	Community work experience program during school hours; summer job

Because many of the essential skills for successful employment and independent living take time for deafblind students to master, it is recommended that many skill areas are addressed annually.

Chapter Twelve

Considering the Impact

Island Sunshine

"Oh, my island
 My beautiful Sunshine Island
Where the sun never ceases to shine
Its glory

Animals bountiful
Riding on elephants
Befriending rabbits
And wild animals

Trees overgrown
Grass up to your thighs
Special paths where grass
Is beaten under
By so many footfalls

Water abundant
Swimming in wild waters
Strengthens and refreshes

Walking sticks aplenty
Helping me walk the long miles
To my destination
Making bonds with birds
Who entrust me with their newborns

Sitting high on a grass top
Reading my books
Under the shade of huge trees
Small creatures
Come slowly up
To say their "hellos"

There's no communication barriers
No boundaries
Just me and the Sunshiny Island
And all my furry friends
Squirrels, monkeys, elephants, rabbits,
You name it, I have it!

My furry friends, big and small
Protect me from the fiercer breed
Warning me when one is close
Or elephant friends lift me
With their massive trunks
Onto their backs
And away we gooooo!

My Sunshine Island
Many places to explore
Caves, little niches
To keep me safe

I bathe in
The beautiful sun
Soaking up
All the Vitamin C
That one person can
Ever get off a SUNSHINY Island

Oh how, I love my Sunshine Island!
I feel such a belonging
With all my befriended animals galore!"

– Marcia McDermott, 2006

Considering the Impact of Recent Disability Legislation in Special Education and Vocational Rehabilitation on Future Employment Outcomes for DeafBlind Students

Jerome D. Schein
Glenn B. Anderson
Cynthia L. Ingraham

Without a doubt, the past quarter century has seen tremendous challenge and progress in the area of disability legislation. New advances in the area of telecommunications thanks to the leadership of the FCC, the telephone industry, particularly providers of state-operated relay services have helped. Without a doubt, consumer leadership within communities for individuals who are Deaf and those with partial sight or total blindness will continue to have significant impact on the quality of life for persons with combined vision and hearing loss for years to come. Compared to 25 years ago, deafblind people have many more choices, options, and opportunities for improved education, employment and living environments than ever before. However, to judge the true impact of these key pieces of education and employment legislation on the lives of deafblind students with disabilities is far too much to tackle within the margins of this closing chapter. Such a detailed analysis would require a more extensive review of these individual pieces of Civil Rights legislation for persons with disabilities and their broader impact on daily practices in local communities, corporate life and the classroom.

In short, the reality is that true impacts are difficult to measure objectively. The fact that a government passes laws such as those witnessed during the past quarter century shows its humanitarian side. *But passing laws and implementing them is not the same thing*. The former is far easier than the latter, especially in the case of legislation purported to assist students with disabilities. For example, there are the unintended consequences of academic integration in No Child Left Behind (NCLB) and the reauthorized IDEA, which for deafblind students may deprive them of teaching expertise and special facilities that can enhance their education. Too often 'inclusion' for students with extreme disabilities means they are in the hands of well-meaning teacher assistants and itinerant resource personnel who cannot provide necessary programming even for students with single disabilities let alone deafblind students. Not withstanding, it is clear that laws which mandate the education of *all* students, regardless of disabilities, can potentially have a positive influence on the educational outcomes for deafblind students.

However, over the past decade, the rehabilitation and special education fields have been forced to concentrate too much energy on the problems of the moment, and have neglected to assign the required attention to the potential crises looming on the horizon. Judging from the sampling of stories written by and about the numerous successful, bright students and adults who are deafblind shared in this monograph, it is clear that while the passage of key disability legislation like IDEA have impacted where students with disabilities receive education, the overall impact on quality of life for students has been nominal. Isolation during school years and self-imposed or forced segregation into communities with other similarly disabled persons upon completion of their secondary education programs is evidence that laws that are mandated can not affect attitudes or guarantee acceptance. Instead, if greater efforts are put forth to better educate intelligent and capable deafblind students, like those showcased in this monograph, and if the education system affords such intelligent deafblind students access to the qualified personnel and programming they deserve, it is likely that the future for the next generation of deafblind students will truly be limitless. Moreover, employment opportunities offering students with disabilities livable wages should be a top priority to combat the post-school temptation to rely on government funded services for survival.

Only time will tell if No Child Left Behind (NCLB) does the right thing for deafblind students. To date, the movement for education and employment standards brought forth by NCLB has yet to result in positive outcomes for a significant number of students with disabilities. The fear of many is that unfunded mandates such as NCLB could potentially tax our already overburdened service delivery system. It also could mean that more emphasis on academic achievement will overshadow the need for life-skills training to address daily needs, which may result in more students with disabilities becoming dependent on SSI and other related *safety net* programs. In recent years, every citizen has come to learn how such dependence on uncertain future resources can have the potential to create staggering burdens on the nation's entire social service system and other entitlement programs for the disadvantaged. Thus, the long-term prospects for students with disabilities, who do not receive a quality education or the skills to function independently, may be more adverse and at-risk than we may realize at this point in our history.

Because all the diverse segments of our nation's population are aging, there are certainly significant implications for the funding, planning, and provision of medical, social, and related human services for *all persons with disabilities* in the coming years. There is no question the correlation between aging and disability becomes stronger the older people become. One of the consequences of this strong correlation notably will be the increase in

the number of Americans with both difficulties with hearing and vision. This will have tremendous impact on numerous sectors of our public and privately operated post-school service delivery programs and agencies. The impact is potentially a negative one. There are increased risks that funding priorities for certain subgroups which are often depicted as *vulnerable* members of the community will be pushed further down on the government's priority list. For Americans with disabilities, including those who are deafblind, such marginalizing will call for increased self-advocacy to ensure that post-school programs and services remain a high priority within governmental appropriations. It is not practical or feasible to acquiesce to the idea of *inclusion* or *one size fits all*. There will always be a strong need for appropriate specialized programs and services. However, in order for students to receive exposure to advanced education or to develop the strong literacy skills needed to succeed in our global economy, options within integrated educational settings will also need to be a part of the continuation of instruction offered in segregated programs. Often the specialized skills training, upon which future independent-living skills are built, are only available within segregated programs but do not exist within integrated educational programs. As a result, deafblind students who are intellectually capable of performing on or above grade level in public school programs are habitually left with very minimal training in functional skills of daily living; or sadly exit the education system unable to independently carry out basic daily responsibilities. Any future consideration for education or training programs for deafblind students must consider the benefits associated with both segregated and integrated programs as opposed to the one size fits all approach.

Given the reduction in specialized personnel preparation programs in rehabilitation, special education and research for students with disabilities versus the increase in unfunded mandates from the federal government in relation to those areas of interest for students with disabilities, the degree to which this reduction will impact services available for adults with congenital and acquired vision and hearing loss is staggering. Unfunded mandates levy a burden on all programs; however, the greater demands for specialized services makes the lack of government support less justifiable for programs aimed to assist students who are disabled – particularly those who are deafblind.

After investing more than 25 years for research projects on behalf of the education and employment of deaf, hard of hearing and deafblind individuals, the federal government's reduction in funding for these research centers and personnel prep programs threatens to reverse the achievements that such training projects have brought forth for this population. The cutback and elimination of programs coming about at a time in our nation's history when economic indicators suggest that a more competitive and component

workforce is needed in order for the United States to effectively compete in the global market is worrisome.

The Future Is Now

Given the rapid increase in the number of adults over the age of 60 who are at risk for age-related vision and hearing loss, the repatriation of employment-aged veterans who have been severely wounded in wars, the current substandard quality of the education and social-service systems for persons with disabilities, our nation is ill-prepared to accommodate the intensifying demands from a community of persons with disabilities whose membership is steadily on the rise. Many within this group of newly disabled persons, specifically wounded veterans of working age, will find that the information technology which was once their lifeline to information, services and the community will present a mixed blessing. As the high price of assistive and adaptive technology, prescription medication and reasonable healthcare marginalizes more of these new members of the disability community from what remains of the American dream, it is hoped that the United States will make the adjustments that are needed. Specifically what is required by policy makers is the opening of doors to quality education and employment opportunities offering a livable wage, along with independent-living-skills training that all persons with disabilities will require to fully access the community of their choice. An important first step, of course, will be for our elected officials to revisit previously considered goals for the future. By using the lessons of the past shared by the bright students in this monograph, new avenues of education, employment and independent living for deafblind students can be paved.

A practical approach for law makers to consider is to begin with current personnel prep programs which focus on the education and employment of students with disabilities. Improving course offerings at graduate-level preparation programs – such as 1) literacy development, 2) technology-access options, 3) employment training, 4) basic independent-living skills, and 5) communication-access skills for a global economy -- are but a few of the indispensable skills identified by family members, professionals and students who have contributed to this monograph as being conducive to post-school success for deafblind students. Deafblind students who exit educational programs with these core skills will be better prepared to survive and thrive in the competitive market place of the future.

Outcomes Measurable Throughout the Life Span

Mere survival should not be the *only* goal of education, as most will certainly agree. Technology can deliver great aid to education and employment outcomes for deafblind

students. However, without proper instruction on how best to effectively provide individual students with access or adaptations for existing and future technology the full benefit of technological advances will not be realized. Cochlear implants and braille-access technology present established examples of critical technological advances that will impact education outcomes for deafblind students. Educators deserve the contributions of research into how to make best use of what is available now and of what will undoubtedly emerge in future years. Consumers, parents and educators should demand continuing education for all students as the Twentieth-First Century is likely to bring radical changes in all aspects of life. Education should be a continuous option to help deafblind students adapt to these changes. Primarily, this continuing education should include instruction and practice in the use of presently available technology, communication and literacy skills, and functional daily living skills.

Finally, educators and rehabilitation professionals must recognize that deafblind students may continue to need assistance with travel and socialization throughout their lives and that some may be unable to hold white-collar jobs, as is true among nondisabled students. These realities should serve to guide educators and substantiate the ongoing need for individualized programming. *The more disabilities students have, the more specialized should be their education*.

Breaking down the Barriers

Sally Hobart Alexander

Nearly forty years ago, like the students profiled in this monograph, I faced adulthood and the challenges of moving from the familiar to an unfamiliar world. At this time, I could still see and hear and took a job teaching elementary reading in southern California, three thousand miles away from my family. There, I found an apartment on the beach and a group of friends.

But then, my health played a trick. I began to lose my sight due to a mysterious retinal hemorrhages. At twenty-six I became totally blind.

With no skills to perform daily tasks, I entered an excellent training program in Pittsburgh, Pennsylvania that restored my ability to function independent and my self-confidence. I decided not to continue teaching, since my Braille skills were slow and my faith in my ability to control mischievous third graders weak. I completed graduate school in social work, took a job as a child therapist, and later married. After my children were born, I became a writer, publishing books that dealt primarily with blindness. Because of my success as a writer, I've found a career as a motivational speaker and once again -- a teacher.

1974; wedding photo of Sally holding the arm of new husband, Bob, bookend by her two siblings.

Soon after receiving personal adjustment to blindness training, I experienced hearing loss that also mystified doctors. At age twenty-eight in the middle of graduate school, I had to miss class due to appointments with the ear doctor and hospitalizations. In 1987 when my children were 11 and 8, I lost what I termed *significant* hearing in my left ear, making it hard to hear my children's voices. Soon I was forced to wear a hearing aid. In 1999, further hearing loss demanded that I wear a hearing aid in my right ear as well. Now at age sixty-three, I await new and even more powerful hearing aids that will enable me to continue my teaching career at Chatham College and duties for two writing groups which I facilitate. Fortunately, my speech remains intelligible and my residual hearing is sufficient enough for communication in most settings. However, my hearing continues to deteriorate. Even though I am totally blind and consider myself moderately deaf, I never self identified as a

deafblind person. I associated this group with the remarkable Laura Bridgman, whose biography I've just finished writing and have sold to a publisher. In fact, I have only recently come to realize that I am representative of one of the fastest growing segments of the deafblind population – adults over the age of sixty.

Sally preparing for a stroll through the neighborhood with dog guide, Marit (in the harness), son Joel (on the leash) and young daughter, Leslie (in backpack).

Interestingly enough, the stories in this monograph of these articulate students resonate with me. I understand the tedium of struggling to hear in crowded situations. I appreciate the experience of being the lone disabled person in a classroom or work place. Even the pressure of having to work harder to keep up with my non-disabled peers and the extra effort required to fulfill expectations imposed by those who think I represent all disabled people in the world. But I also enjoy the uniquely comical circumstances that result from having a disability. For instance, I sometimes hear more interesting dialogue than is actually spoken.

"I had a date last night," a friend began, and I interrupted.

"Did you and Gary split up?"

She laughed. "No. I said *debate*, not *date*."

But many interactions aren't humorous. I remember being the only blind graduate student with professors who didn't know how to administer tests to me. I explained that I'd bring a reader and typewriter and asked only one accommodation from them—a quiet room. Instead, my professors supplied me with access to the nearby lavatory with flushing toilets and gossiping coeds.

Thirty years later, federal laws and specialized technology have improved educational opportunities for many deafblind students. But there still seems to be too much social isolation of the kind experienced by Laura Bridgman and Helen Keller a century ago. Too many social barriers between deafblind students and the sighted and hearing public still exist today. Since I spent a bit less than half my life among the ranks of the hearing-sighted majority and am now functioning quite successfully as a deafblind adult, I offer a few ideas for how deafblind students might enhance their interactions in both social and educational settings.

Even though students with disabilities are no longer sequestered away from mainstream society, a deafblind student entering a room can still send as powerful an emotional charge as if he'd walked into that very room unclothed! By in large, people react

to deafblind students with anxiety, not hostility. The uneasy person is fearful he'll say or do the wrong thing, so he plays it safe and avoids interacting with the deafblind person altogether.

Personally, I understand this avoidance. During college, I had classes with a competent, intelligent man who was blind; however, I never spoke to him. He fascinated me, but I was afraid I'd goof and embarrass both him and myself. He needed readers to access his text books and other assigned materials; and two of my more self-confident pals volunteered and became good friends with him.

If people do react malevolently toward a deafblind person, more often than not they aren't just anxious, they're also frightened. Most people struggle to be in control. When they see someone who they perceive to be more dependent, they feel unsettled and may tease or taunt the individual.

I have witnessed this reaction particularly in children. Once after I'd spoken at an elementary school, the mother of a fourth grade girl who was blind phoned me in tears. The kids "were being so cruel," she said. The mother explained how the other children wouldn't let her daughter sit with them at lunch.

As the conversation continued, I learned that this little girl didn't know her way around the school building and waited for her classmates to guide her everywhere. At home, she had no chores and no ability to get herself a sandwich, snack, or even a glass of water. In contrast, I recall how my own children in fourth grade pushed at the boundaries to try their wings. It is typical for fourth graders to strive to be independent. The reality that this mother did not realize was that her daughter's apparent helplessness made her classmates uncomfortable.

We can calm fears by being as competent as possible, by arranging for a trained professional or trusted friend to orient us to new surroundings. We also might think of favors and help we can give others instead of feeling entitled to goodwill from each person we encounter.

Another way to reduce uneasiness is by sharing information. Whenever I visit schools to speak about writing, I always ask if any kids with sensory loss or a physical disability would like to come up and join me at the podium. I say a few words about disability issues, and these students who may have been formerly viewed as outcasts become my helpers. Students who are blind or deafblind demonstrate how to use their canes and their Braille watches. Once one of my little helpers stole the show. At the conclusion of my presentation, the kids in attendance asked my special helper, not me, all

their questions of curiosity regarding blindness. The principal never needed to pay me to return.

Another strategy is to explain the rules of engagement, so to speak. People usually try their best; they don't want to offend a person with a disability by offering too much help. One of my rules of thumb is: "If I need assistance, I'll ask."

No matter how independent we are – we each can use a helping hand sometimes. So, I jokingly tell my sighted friends that I may use them much the same way I use taxi cabs, taking hold of their arm as they guide me from location "A" on to location "B" and then I will disembark when I am able to travel again from location "B" to the next location independently.

Sally on a walk through her neighborhood with present dog guide, Handley.

Another tactic is to answer questions, or even to anticipate them and address them before being asked. The first thing people want to know is how I became blind. If we as deafblind people explain what caused our disabilities, we can help to alleviate any fears regarding possible *contamination*. Over the years, I have learned that even the smallest amount of information can break down barriers.

Paying attention to our appearance also helps. During my life as a sighted person, I learned how much people judge us by our looks. I may be more vain than most, but there is a real phenomenon called "lookism," which is simply defined as discrimination against those who don't meet a commonly accepted standard of beauty and symmetry. Individuals viewed

Cover of one of Sally's earlier literary works, Mom's Best Friend – a picture book about her first dog guide told from the perspective of her twelve year old daughter, Leslie. (MacMillan, 1992)

as overweight or obese are typically the targets of "lookism." But those of us with disabilities also suffer from this type of discrimination as well.

Most Americans are captivated by eye contact, which many blind and deafblind people are unable to accomplish. So the average person may speak not to us directly, but to our sighted companions. Whenever possible, I try to face the speaker to offer a response, and he usually catches on.

Some blind eyes, like mine, aren't attractive. Since I'm self-conscious about them, I wear sunglasses in the same way I wear make-up and jewelry – to improve my appearance. Other blind people may have *normal-looking* eyes or worry less about the physical appearance of their eyes. Because many deafblind individuals, like me, may lack complete sensory input, we may fill the void by developing unusual mannerisms to stimulate a remaining sense (i.e., rocking). When I was sighted, I remember seeing "blindisms" and thinking they

were strange. Now I too have developed my own set of "blindisms" such as playing with my fingernails and chewing gum. I hope these behaviors are less noticeable or odd.

Given that many of us who are deafblind don't see everything clearly or at all, we may use less facial expression or fewer gestures. I'm reluctant to reach out to strangers because I've often missed my intended target and have landed on forbidden territory. However with friends and loved ones, I gesture, use some manual communication and hug them mercilessly.

Cover of another of Sally's earlier literary works, Mom Can't See Me – a picture book about being the child of a blind mother told from the perspective of her nine year old daughter, Leslie. (MacMillan, 1990)

I've come to realize that the lack of nonverbal communication or gestures that are not understood, can give an unconscious suggestion to an unknowledgeable sighted person that we aren't kindred spirits. But by offering some communication attempts and good grooming, we can begin to close the gap between ourselves as deafblind people and those with whom we come into contact.

Finally, friends come from common interests. My friendships spring from work, church, community groups, and the classes I take. By joining clubs or organizations, we interact and get acquainted. Access to such functions may be a challenge; however, pitching in for gas or buying lunch for someone who offers you a lift is always appreciated.

I know deafblind teens that have made friends by becoming active members of their high school wrestling or swimming teams. By playing together, their teammates were able to overcome any fear, anxiety, or discomfort they may have had toward their deafblind teammate.

Cover of *On My Own: The Journey Continues* (1997) Sally's sequel to *Taking Hold: My Journey Into Blindness*. This volume chronicles Sally's new life as a legally blind adult who copes with the onset of hearing loss, complete vision loss and emotional setbacks.

Cover of Taking Hold: My Journey into Blindness, Sally's autobiography chronicling her adjustment to vision loss and quest to regain independence as a legally blind adult. (MacMillan, 1994)

As I, and many other deafblind students I've met over the years, can attest, barriers can and do crumble away. We've emerged from the veneer of our disabilities to become distinct individuals who, like the bright students in this monograph, have excelled despite great challenges. With initiative, self-awareness and support deafblind students can take better advantage of legislation and technological advances to enter the world with an improved balance of work, competence and meaningful relationships vital for a full life.

Today, Sally enjoys a full life of adventure and achievement. Here she is seen swimming with dolphins.

Resources

Information in this resource section was taken directly from the web sites for each programs listed. More specific information can be obtained by contacting the various programs directly.

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National Center for Education Statistics
The primary federal program for collecting, analyzing and reporting information related to education in the United States and other nations.

http://nces.ed.gov/pubs2003/2003164.pdf
http://nces.ed.gov/surveys/SurveyGroups.asp?Group=2

TransCen, Inc.
The NCES survey program at the postsecondary education level provides statistical information used by planners, policymakers, and educators in addressing a multitude of issues. One major source of this information is the annual Integrated Postsecondary Education Data System (IPEDS) Survey which provides a variety of data on the nation's 9,800 public and private postsecondary institutions. Special studies of students, financial aid, postsecondary faculty, and bachelor's degree recipients, doctoral degree recipients, transcript studies, and various longitudinal studies, complement IPEDS.
TransCen, Inc. is a nonprofit organization that, since 1986, has been developing creative and innovative projects in school to work transition, education systems change, and employment for people with disabilities. We were founded and named to be a "**Trans**ition **Cen**ter," convening parties involved in promoting the successful transition of youth with disabilities from school to work and adult life.
www.transcen.org

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National Standards & Quality Indicators: Transition Toolkit for Systems Improvement
This Web site offers the contents of NASET's National Standards and Quality Indicators: Transition Toolkit for Systems Improvement. This document contains information and tools to provide a common and shared framework to help school systems and communities identify what youth need in order to achieve successful participation in postsecondary education and training, civic engagement, meaningful employment, and adult life.
http://www.nasetalliance.org/docs/TransitionToolkit.pdf

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The Institute for Community Inclusion at UMass Boston supports the rights of children and adults with disabilities to participate in all aspects of the community. As practitioners, researchers, and teachers, we form partnerships with individuals, families, and communities. Together we advocate for personal choice, self-determination, and social and economic justice.
http://www.communityinclusion.org

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Small Business Administration Office (SBA)
The U.S. Small Business Administration (SBA) was created in 1953 as an independent agency of the federal government to aid, counsel, assist and protect the interests of small business concerns, to preserve free competitive enterprise and to maintain and strengthen the overall economy of our nation. We recognize that small business is critical to our economic recovery and strength, to building America's future, and to helping the United States compete in today's global marketplace. Although SBA has grown and evolved in the years since it was established in 1953, the bottom line mission remains the same. The SBA helps Americans start, build and grow businesses. Through an extensive network of field offices and partnerships with public and private organizations, SBA delivers its services to people throughout the United States, Puerto Rico, the U. S. Virgin Islands and Guam.
 http://www.sba.gov/teens/

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National Collaborative on Workforce and Disability
This PowerPoint Presentation provides information on using assessments tools to help facilitate career planning.
http://www.ncwd-youth.info/assets/staff_Presentations/Joe_Timmons-Assessment_RSA_Short_Version.ppt (PowerPoint Presentation)

This web site lists various disability specific legislation and the services covered for students with disabilities.
http://www.ncwd-youth.info/assets/disability_legislation/disability_legislation.pdf

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The National Longitudinal Study-2
Information Brief explains the results of a survey sent to parents of students with disabilities to inquire about post-secondary employment outcomes.

http://www.ncset.org/publications/nlts2/NCSETNLTS2Brief_2.2.pdf

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Funded Parent Resource Centers
http://www.taalliance.org/centers/pti_list_20070228.pdf

Listing of Summer Pre-College Programs for Students with Disabilities as compiled by the George Washington University and HEATH Resource Center.

   http://www.heath.gwu.edu/PDFs/2007_precollege_summer_programs.pdf

   http://www.thinkcollege.net/families/index.php?page=schedules

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Clerc Center at Gallaudet University - Publications on Transition

Why Student Portfolios?
Portfolios offer the opportunity to observe and document a wide range of student behaviors, skills, and learning over an extended period of time. When combined with our five clearly defined outcomes, they are a powerful tool for analyzing, assessing, and promoting academic progress and personal growth. The portfolio enables the student, educators and families to analyze capabilities, focus on strengths, and develop compensatory strategies for underdeveloped areas, and plan for the future. Portfolios serve as the hub for integrating the diverse experiences students have both in and out of the classroom. Using portfolios, students examine a broad range of their own work, collected over time, to assess their own progress. They then use that information to assist with decision making as they make those crucial choices concerning their future. In this way, students become actively involved in a process of taking responsibility for their own learning and life plan.

http://clerccenter.gallaudet.edu/Transition/Training.html#docs

http://clerccenter.gallaudet.edu/Transition/TravelTrainingDocs/CC-full-manual.pdf

http://clerccenter.gallaudet.edu/Priorities/PSG-guide.html

http://clerccenter.gallaudet.edu/Transition/VR_Galluadet_4pgr.pdf

http://clerccenter.gallaudet.edu/Transition/VR_Galluadet_Stringer.pdf

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The **National Standards and Quality Indicators: Transition Toolkit for Systems Improvement** (herein referred to as the Transition Toolkit) combines the findings of current research on effective schooling, career preparatory experiences, youth development and youth leadership, family involvement, and connecting activities with the expertise of numerous individuals who work in these fields.
The Transition Toolkit can be used to promote planning and continuous improvement for secondary education and transition. State and local communities are encouraged to use these tools to:

- better understand their current operations;

- identify areas of strength, weakness, and opportunity;

- create action for improving and scaling up systems; and

- assess progress.

The Transition Toolkit is an evolving document, requiring continual refinement as we learn more about what all youth need to achieve positive school and post-school results. Download Toolkit using link below.
http://www.nasetalliance.org/toolkit/index.htm

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The National Collaborative on Workforce and Disability - Guideposts for Success

Transition from youth to adulthood is an awkward period in life; it presents challenges for almost every young person today. Youth with disabilities, indeed all vulnerable youth, may need extra supports throughout their transition period in order to make informed choices and become self-sufficient adults.
http://www.ncwd-youth.info/resources_&_Publications/guideposts/index.html

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My Future My Plan is a curriculum designed to motivate and guide students with disabilities and their families as they begin early transition planning for life after high school. It promotes positive attitudes and self-advocacy, and assists students, parents, and professionals to make the transition planning process more effective. The curriculum package – which may be used in home, school, and community settings – includes a videotape and discussion guide, a workbook for students, and a guide for family members and teachers. All materials are available in English and Spanish.
To preview My Future My Plan materials, visit
http://www.stateart.com/campaigns/myfuturemyplan/

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Student Resources through US Dept. of Education
This web site contains information specifically for students. The site covers community service options, how to pay for college, information about military service and how to register to vote.
www.students.gov

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Disability Benefits 101
The School and Work Calculator is for youth with disabilities who are approaching their 18th birthday. This information is invaluable for students who desire to calculate their anticipated expenses and benefits.
http://www.disabilitybenefits101.org/planning/(S(apb5xx5555yt2h3xfn1ttvz0))/y2w_start.aspx?screen=start&l=y2w

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American Foundation for the Blind - CareerConnect
http://www.afb.org/Section.asp?SectionID=7&TopicID=323

This link from American Foundation for the Blind CareerConnect web site compiles stories by young adults with vision loss, blindness and deafblindness who share their experiences with their first jobs.

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A Guide to Deaf-Blind Students who are Considering College
This very useful resource offers students a step by step checklist of the accommodations necessary for effective classroom and community access while attending college.

http://www.hknc.org/images/guidebookd_for_students_considering_college.doc

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DB-Link offers information on Federally Funded State DeafBlind Projects and other resources for students, parents and professionals.
www.dblink.org

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Resource links from DeafBlind.com compiled by James Gallagher

www.deafblind.com

http://ca.geocities.com/psdb2002ca/Entering.html

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(206) 324-1133 - Sorenson Video Phone (If possible, e-mail the office first to make sure the VP is turned on)
CAPTEL: 1-888-801-7210 to connect to the Federal captioning
service (toll free), then dial 1 (206) 720- 4642.

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Use the link below to obtain a listing of current HKNC Affiliate Partners
http://www.hknc.org/FieldServicesAFFILIATECONTACT.htm

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References

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Disability Specific Glossary

AACC:
American Association of Community Colleges

ABAWD:
Able-bodied adults w/out dependents

ABE:
Adult Basic Education

Absorb:
1. To take something in, as through the skin or the intestine.
2. To react with radiation and reduce it in intensity, as with a dose of radiation or transmitted light.

Access:
1. In general, a means of approaching something.
2. In health care, the opportunity or right to receive health care.
3. In dialysis, the point on the body where a needle or catheter is inserted to gain entry to the bloodstream.

Access barrier:
Any obstruction that prevents people with disabilities from using standard facilities, equipment and resources.

Access Utilities:
Access utilities are software programs that modify various aspects of the standard keyboard to simplify operation of the keyboard, replace the mouse, substitute visual cues for sound signals, or add sound cues to keystroke.

Example: In the case of a young person with a mobility impairment an access utility is important because it can alter the way keys on a keyboard respond to touch. Say, for example, Jimmy, a young boy with muscular dystrophy has difficultly pressing keys quickly and lingers a bit longer on each key than necessary or inadvertently presses multiple keys on the way to the

Photo Courtesy of Freedom Scientific

intended key. Altering relay time on these keys can enable Jimmy to more effectively process information via a keyboard. Many basic modifications can be made through software that already exists on your computer. Altering font size, color contrast, and adding or modifying audio alerts all can be done without purchasing additional software. "Sticky keys" are another very useful modification that can be made through pre-existing software. Sticky keys allow one to type a key at a time, sequentially, and experience the same results as holding down multiple keys simultaneously. So instead of holding down CTRL-ALT-DELETE, one can select each key, one at a time.
Additional Resources: http://www.ataccess.org/resources/atabook/s02/s02-03b.html

Accessible:
Easy to approach, enter, operate, participate in, or use safely, independently and with dignity by a person with a disability (i.e., site, facility, work environment, service or program).

Accessible Web design:
Creating World Wide Web pages according to universal design principles to eliminate or reduce barriers, including those that affect people with disabilities.

Accommodation:
An adjustment to make a workstation, job, program, facility, or resource accessible to a person with a disability.

ACF:
Administration for Children and Families, a federal agency funding state, territory, local, and tribal organizations to provide family assistance (welfare), child support, child care, Head Start, child welfare, and other programs relating to children and families.

ACINET:
America's Career Information Network - CareerOneStop

ACRN:
America's Career Resource Network

Acronyms:
Abbreviations for programs, laws, conditions, etc. used among professionals and families in the industries. Here is a printable list of acronyms that are commonly used.

ACTE:
The Association for Career and Technical Education

Activities of Daily Living:
Frequently used in national surveys as a way to measure self-care abilities in daily life, the ADLs include basic tasks such as eating, bathing, dressing, toileting, getting in and out of a chair or bed, and getting around in the home.
National surveys also measure another level of self-care functioning, Instrumental Activities of Daily Living (IADLs), which include activities such as doing everyday household chores, preparing meals, doing necessary business, using the telephone, shopping, and getting around outside the home.

Photo courtesy of Bob Vila

Adaptive behavior:
The person has overall adaptive behavior which is significantly limited in two or more skill areas (communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work), as measured by an instrument which is standardized, appropriate to the person's living environment, and administered and clinically determined by a qualified professional.

Adaptive technology:
Hardware or software products that provide access to a computer that is otherwise inaccessible to an individual with a disability. They include customized systems that help individual students move about, communicate in, and control their environments. They are designed specifically for persons with disabilities; devices which would seldom be used by non-disabled persons. Examples include augmentative communication devices, powered wheel chairs and environmental control systems. These assistive technologies are not used exclusively for education purposes, but are used in all of the child's environments.

Adventitiously Deafblind:
Vision and hearing are present at birth but are lost to some degree later in life.

ADHD:
Attention deficit hyperactivity disorder

Administrative Hearing:
Formal judicial process where appeal is heard.

Administrative Officer/Hearing Officer:
Person in charge of and decision-maker for formal appeals hearing.

ADR (Alternate Dispute Resolution):
A variety of procedures for resolving disputes. ADR is a fair and efficient alternative to court adjudication that must be entered into voluntarily by all parties. Some of the more common ADR procedures are arbitration, mediation, and conciliation. The Americans with Disabilities Act encourages the use of ADR to resolve conflicts.

Advocacy:
1. Writing, speaking, or assisting in support of a consumer
2. Taking an active role in the education and care of an individual or the act or process of supporting a cause or person.

AFDC (Aid to Families with Dependent Children):
This is the name of the former federal welfare entitlement program. In some states, the term is still used to identify individuals who are transitioning into the new TANF program. See *Temporary Assistance to Needy Families.*

Agencies:
State or Federal government units which provide, or are approved to provide, assistive technology or technology related services (examples include: worker's compensation court, social services, school districts, rehabilitation services, etc.)

Aids for Activities for Daily Living (ADL):
Self-help aids for use in activities such as eating, bathing, shopping, home maintenance, etc.

Aids for Daily Living:
Self-help aids for activities such as eating, bathing, cooking, dressing, toileting, and home maintenance.
Example: A wide range of devices fall under the phrase Aids for Daily Living (ADLs). A low tech example would be a finger nail brush with two suction cups attached to the

bottom that could stick onto a flat surface in the bathroom. Such an ADL would allow a child with limited mobility to clean her nails without having to grip the brush. There are also "higher tech" ADLs. For more information on these devices, see *Environmental Control Units (ECUs).*

Photo courtesy of Dynamic Living

Photo courtesy of
Washington Assistive
Technology Alliance

Photo courtesy of Grip Advantage

AIME (Average Indexed Monthly Earnings):
The dollar amount used to calculate your Social Security benefit if you attained age 62 or became disabled (or died) after 1978. To arrive at your AIME, we adjust your actual past earnings using an "average wage index," so you won't lose the value of your past earnings (when money was worth more) in relation to your more recent earnings. If you attained age 62 or became disabled (or died) before 1978, we use Average Monthly Earnings (AME).

AJB:
America's Job Bank – Career One Stop

Alcohol:
An organic chemical in which one or more hydroxyl (OH) groups are attached to carbon (C) atoms in place of hydrogen (H) atoms. Common alcohols include ethyl alcohol or ethanol (found in alcoholic beverages), methyl alcohol or methanol (can cause blindness) and propyl alcohol or propanol (used as a solvent and antiseptic). Rubbing alcohol is a mixture of acetone, methyl isobutyl ketone, and ethyl alcohol. In everyday talk, alcohol usually refers to ethanol as, for example, in wine, beer, and liquor. It can cause changes in behavior and be addictive.

ALMIS:
America's Labor Market Information System

ALT attribute:
HTML code that works in combination with graphical tags to provide alternative text for graphical elements.

Alternate Formats:
Formats usable by people with disabilities. These may include, but are not limited to, Braille, ASCII text, large print, and recorded audio.

Alternate Methods:
Different means of providing information, including product documentation, to people with disabilities. Alternate methods may include, but are not limited to, voice, fax, relay service, TTY, Internet posting, captioning, text-to-speech synthesis, and audio description.

Alternative Access/Input Device:
A tool that allows individuals to control their computers through means other than a standard keyboard or pointing device. Examples include alternative keyboards, electronic pointing device, sip-and-puff systems, wants and sticks, joysticks, and trackballs.
Example: A "modified mouse" such as a joystick or trackball can make a world of difference to a child with limited mobility. Whereas using an ordinary mouse would be difficult for someone like, Leo, a child with limited refined motor skills, the design of a joystick would allow him to have more full control of his web surfing experience.

Photo courtesy of Don Johnston

Alternative Keyboard:
Alternative keyboards may be different from standard keyboards in size, shape, layout, or function. They offer individuals with special needs greater efficiency, control, and comfort.

Example: Alejandro is a child with cognitive disabilities. The traditional QWERTY keyboard is confusing, so his mom replaces it with a keyboard that lists letters A-Z in big, bold letters and doesn't contain a lot of "extra" keys. This makes focusing on spelling and typing words a lot easier for him.

Alva:
See Braille Display.

Photo courtesy of Big Keys

Alva Braille Carrier

Small portable face to face communication device using a Qwerty keyboard and LCD display on one side for sighted communicators and Braille display and keyboard for deafblind consumers. (See Screen Braille Communicator)

Ambulation Aids:
Devices that help people walk upright, including canes, crutches, and walkers.

AME (Average Monthly Earnings)
The dollar amount used in calculating your monthly Social Security benefit if you attained age 62 or became disabled (or died) before 1978. The AME is determined by dividing the total earnings in the "computation years" by the number of months in those same years. See *Retirement Insurance Benefits (RIB).*

Americans with Disabilities (ADA):
The American with Disabilities Act of 1990 (PL101-336) prohibits employers from discriminating against people with disabilities and makes such discrimination a civil rights violation. Providers of public services, schools, public building and public transportation services also must provide accessibility to people with disabilities.
AND
A federal civil rights law prohibiting discrimination on the basis of disability in (1) employment, (2) programs, services and activities of state and local government agencies and (3) goods, services, facilities, advantages, privileges and accommodation of places of public accommodation. To obtain a copy of the ADA you can call the ADA Hotline at 800-514-0301 (voice) 800-514-0383 (TDD).

Americans with Disabilities Act of 1990 (ADA):
A comprehensive Federal law that prohibits discrimination on the basis of disability in employment, telecommunications, public services, public accommodations and services.

American Standard Code for Information Interchange (ASCII):
Standard for unformatted text which enables transfer of data between platforms and computer systems.

Anger:
An emotional state that may range in intensity from mild irritation to intense fury and rage. Anger has physical effects including raising the heart rate and blood pressure and the levels of adrenaline and noradrenalin.

Annual Cost of Living Increase:
Social Security benefits and Supplemental Security Income payments may be automatically increased each year to keep pace with increases in the cost-of-living (inflation).

Aphasia:
An impairment of language, affecting the production or comprehension of speech and the ability to read or write. Aphasia is always due to injury to the brain, most commonly from a stroke, particularly in older individuals. Aphasia may also result from head trauma, brain tumors or infections.

Apnea:
Pause in breathing that lasts 20 seconds or longer.

Appeal:
This is the process which takes places when a request is denied. The consumer gives the funding agency additional information so they may reconsider the request.

Appeal (Appeal Rights):
Whenever Social Security makes a decision that affects your eligibility for Social Security or Supplemental Security Income benefits, we send you a letter explaining our decision. If you disagree with our decision, you have the right to appeal it (ask us to review your case). If our decision was wrong, we'll change it.

Application:
   Process by which the consumer formally requests a device or service from an organization.

Application for Benefits
   To receive Social Security or Black Lung benefits, Supplemental Security Income payments, or Medicare, you must complete and sign an application.

Apprenticeship:
   A structured approach for entering a skilled occupation in most of the major trade industries. Combines training on the job with related and supplemental instruction at school.

Arbitration:
   Process that is more formal than mediation but that also involves a neutral third party; after presentation of both sides a third person decides issue. Normally the third person has experience in the area.

Architectural Adaptations:
   Architectural adaptations are structural fabrications or remodeling in the home, work site, or other area (including ramps, lifts, lighting, kitchen remodeling, bathroom adaptations, etc.) that remove or reduce physical barriers for an individual with a disability.

Articulation:
   1. In speech, the production and use of speech sounds.
   2. In dentistry, the contact of the occlusal surfaces of the teeth.
   3. In anatomy, a joint where two bones are attached for the purpose of motion of body parts. An articulation, or joint, is usually formed of fibrous connective tissue and cartilage. Joints are grouped according to their motion: a ball and socket joint; a hinge joint; a condyloid joint (a joint that permits all forms of angular movement except axial rotation); a pivot joint; gliding joint; and a saddle joint. Joints can move in four and only four ways:
      · Gliding -- one bony surface glides on another without angular or rotatory movement;
      · Angular -- occurs only between long bones, increasing or decreasing the angle between the bones;
      · Circumduction -- occurs in joints composed of the head of a bone and an articular cavity, the long bone describing a series of circles, the whole forming a cone; and
      · Rotation -- a bone moves about a central axis without moving from this axis.

Arousal:
   Levels of activity from alertness to drowsiness.

ASET:
   Assistant Secretary of Employment and Training, U.S. Department of Labor

ASL:
America's Service Locator – CareerOneStop
OR
American Sign Language

Asperger's Syndrome (AS):
A developmental disorder that effects a person's ability to understand other people and socially interact with them. People with AS, while having trouble making eye contact, are unable to read and respond to social cues and body language. Persons with AS tend to repeat certain phrases or words repeatedly. Symptoms of the syndrome can include: clumsiness or lack of coordination, extreme self-absorption, limited interests, unusual preoccupations, ritual or repetitive routines, speech and language peculiarities and non-verbal communication difficulties. AS is a Spectrum Disorder which means that symptoms range greatly.

Assessment:
A systematic process of measuring the strengths and weaknesses of workforce development clients. A wide range of assessment instruments and methods is available, from structured interviews to computerized tests.

Assessment/Recommendation:
A professional opinion with regard to the types of aids, equipment, or other services within the field of assistive technology that might improve an individual's level of functioning.

Assistive Technology:
Any item, piece of equipment, or system, whether acquired commercially, modified, or customized, that is commonly used to increase, maintain, or improve functional capabilities of individuals with disabilities. Includes items such as communication devices, adapted appliances for accessible living, environmental control devices, modified housing, adapted computers, and specialized software.

Assistive Technology Device (as defined by ATP):
Devices that help individuals with disabilities to function more independently (devices may include: wheelchairs, communication devices, environmental controls, etc.).

Assistive Technology Device (as related to Special Education):
Any item, piece of equipment, or product system whether purchased off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities.

Assistive Technology Service:
A service related to an assistive technology device that may include evaluating, selecting, procuring, designing, fitting, customizing, applying, maintaining, repairing, replacing, coordinating, and training of individual, family, and others.

Assistive Technology Device:
Any item, piece of equipment, or product system that is used to increase, maintain, or improve functioning of individuals with disabilities.

Example: An AT device is almost everything set forth in this glossary! From low tech - a pen or pencil grip, to high tech - a computer that responds to touch and allows a child to communicate more effectively, all of these fall within the realm of AT devices.

LOW TECH

HIGH TECH

ASTD:
American Society for Training and Development

At-Risk Youth:
A young person (generally under the age of 22) who is perceived to be in danger of dropping out of school, being abused or neglected by a guardian, becoming involved in crime or gangs, getting pregnant or using drugs. Frequently, a young person must possess at least one "at-risk" characteristic before qualifying for workforce development programs.

Atresia:
Absence or closure of a natural passage of the body (e.g., ear canal).

Atrophy:
Decrease in size or wasting away of tissue.

Attention:
The ability to focus selectively on a selected stimulus, sustaining that focus and shifting it at will. The ability to concentrate.

Attention Deficit Disorder:
A neurobehavioral disorder that affects 3 to 5 percent of all American children. It interferes with a person's ability to sustain attention or focus on a task and some patients may be unable to control impulsive behavior.

Attention Deficit Disorder Hyperactivity Disorder:
A neurobiological disorder. Symptoms include hyperactivity, distractibility, impulsiveness, developmentally-inappropriate behavior and appear in early childhood, typically before seven years of age and usually lasting at least six months.

Audiologist:
A health care professional who is trained to evaluate hearing loss and related disorders, including balance (vestibular) disorders and tinnitus (ringing in the ears) and to rehabilitate individuals with hearing loss and related disorders.

Augmentative Communication:
Electronic and non-electronic devices that can be used to assist people with speech or writing difficulties to help them say what they want.

Augmentative Communication System:
   Any system that increases or improves communication of individuals with receptive or expressive communication impairments. The system can include speech, gestures, sign language, symbols, synthesized speech, dedicated communication devices, microcomputers, and other communication systems.

Autism:
   A developmental disorder of brain function. People with classical autism show three types of symptoms: impaired social interaction, problems with verbal and nonverbal communication and imagination and unusual or severely limited activities and interests.

American Manual Alphabet

Auxiliary Aids and Services:
   Under the **Americans With Disabilities Act** (see above), a wide range of devices and services that may be used by an entity to ensure that it communicates as effectively with people with disabilities as it does with others. Auxiliary aids may include taped texts, interpreters or other effective methods of making orally delivered materials available to students with hearing impairments, readers in libraries for students with visual impairments, classroom equipment adapted for use by students with manual impairments, and other similar services and actions.

AVA:
   American Vocational Association (now known as ACTE - the Association for Career and Technical Education)

Back Pay Award:
   Wages paid retroactively as a result of a determination by a judicial or quasi-judicial body. May be as a result of a wrongful discharge or the difference between wages already paid an employee and higher wages granted retroactively.

Baptismal Certificate:
   A religious record of a birth or baptism. In some situations we can use a baptismal certificate to establish your age. See *Birth Certificate.*

Base Years:
   A worker's (wage earner) base years for computing Social Security benefits are the years after 1950 up to the year of entitlement to retirement or disability insurance benefits. For a survivor's claim, the base years include the year of the worker's death. See *Retirement Insurance Benefits (RIB).*

Basic Skills Training:
   Training offered individually or in groups to help individuals improve fundamental academic skills, such as reading, writing and simple math.

BEA (Bureau of Economic Analysis):

The BEA is an agency of the U.S. Department of Commerce. The BEA is part of the Department's Economics and Statistics Administration. The BEA produces and disseminates economic account statistics that provide government, businesses, households, and individuals with a comprehensive, up-to-date picture of economic activity.

Behavior Disorders/Emotional Disturbance:

Many terms are used interchangeably to classify children who exhibit extreme or unacceptable chronic behavior problems. These children lag behind their peers in social development and are often isolated from others either because they withdraw from social contact or because they behave in an aggressive, hostile manner. Behavior disorders result from persistent negative social interactions between the child and the environment. Behavior disorders generally consist of four clusters of traits, including conduct disorders, anxiety-withdrawal, immaturity and socialized aggression.

Benchmark:

A point of reference (either an estimate or a count) from which measurements can be made or upon which adjustments to estimates are based.

Benefit Verification Letter (BEVE):

An official letter from Social Security that provides information on how much an individual receives in monthly Social Security benefits and/or Supplemental Security Income payments. These letters are normally issued following a request from a beneficiary or his/her authorized representative.

Benefits:

Social Security provides five major categories of benefits:
- Retirement,
- Disability,
- Family (dependents),
- Survivors and
- Medicare.

The retirement, family (dependents), survivor, and disability programs provide monthly cash benefits and Medicare provides medical coverage.

Benefits – Reduced:

You can get the following reduced monthly benefits before reaching full retirement age:
- Retirement insurance benefits at age 62 through the month before your reach Full Retirement Age (FRA);
- Husband's or wife's insurance benefits at age 62 through the month before you reach FRA, provided no child of your spouse either under age 18 or disabled and entitled to benefits is in your care;
- Widow's or widower's insurance benefits beginning at any time from age 50 through the month before you reach FRA;
- Widow's or widower's insurance benefits after your spouse has received a retirement insurance benefit reduced for age;
- Disability insurance benefits received after a reduced retirement insurance benefit; or
- Retirement or disability insurance benefit received after a reduced widow's or widower's insurance benefit.
- This applies only if you were born before 1928.

BETP:
  Bureau of Employment and Training programs (Pennsylvania Department of Public Welfare)

Birth Certificate (Original):
  The record maintained by a governmental entity such as a state, county, parish, city, or borough which documents your birth.

Block Grant:
  A method by which the federal government distributes funds to states and localities in "lump sums" for broadly defined purposes (such as job training). A block grant is the opposite of a "categorical program," which distributes funds for a narrowly defined purpose (such as job training for low-income, out-of-school youth). Generally, states and localities like block grants because they are easy to administer and spending can be tailored to local circumstances.

BLS (Bureau of Labor Statistics):
  Part of the U.S. Department of Labor. This Federal agency is the principal data-gathering agency of the Federal government in the field of economics. The BLS collects, processes, analyzes, and disseminates data relating to employment, unemployment, the labor force, productivity, prices, family expenditures, wages, industrial relations, and occupational safety and health. Well known data released by the BLS include: the Consumer Price Index, the Producer Price Index, the unemployment rate, and nonagricultural employment levels.

BOC (Bureau of the Census):
  Part of the U.S. Department of Commerce. This agency conducts the censuses of population and housing every 10 years and of agriculture, business, governments, manufacturers, mineral industries, and transportation at 5-year intervals. The Census Bureau also conducts the monthly Current Population Survey (CPS) in cooperation with the Bureau of Labor Statistics (BLS). Data from this survey are the source of unemployment statistics.

Braille:
  A raised dot printed language that is used by persons with visual impairments. Each raised dot configuration represents a letter or word combination.

Braille Embossers and Translators:
  A Braille embosser transfers computer-generated text into embossed Braille output. Translation programs convert text scanned in or generated via standard word processing programs into Braille that can be printed on the embosser.

  Photo of the Talking Tactile Atlas courtesy of Touch Graphics

National Geographic Talking Tactile Atlas of the World . Sheet AF1: Africa . copyright 2003 by Touch Graphics, USA
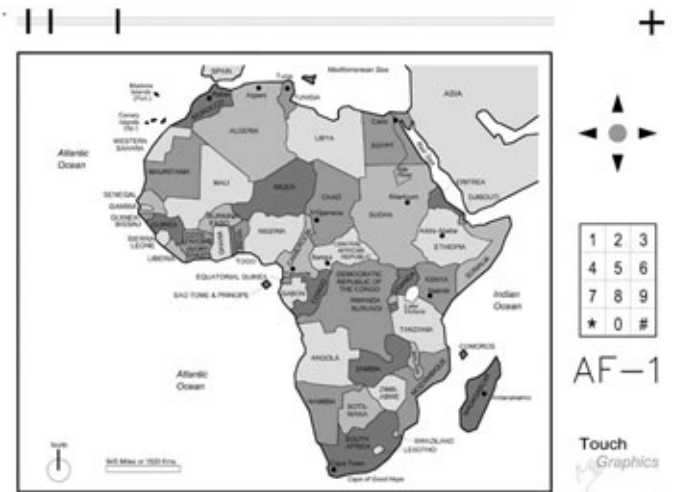
Braille Display:

A Braille display is a tactile device consisting of a row of special 'soft' cells. A soft cell has 6 or 8 pins made of metal or nylon; pins are controlled electronically to move up and down to display characters as they appear on the display of the source system - usually a computer or Braille note taker...They can also be used for advanced math work and for computer coding. A number of cells are placed next to each other to form a soft or refreshable Braille line. As the little pins of

each cell pop up and down they form a line of Braille text that can be read by touch.

Photo courtesy of Deaf Blind -- A-Z to Deaf Blindness

Braille Note Takers:

These portable "Personal Digital Assistant" (PDA) for blind and deafblind students are versatile and often practical solutions to jotting quick notes or accessing the Internet. Newer units have Braille displays, speech output and wireless features which can also include a GPS system. The Braille display on a note taker can contain 18 or 40 cells.

Brain:

That part of the central nervous system that is located within the cranium (skull). The brain functions as the primary receiver, organizer and distributor of information for the body. It has two (right and left) halves called "hemispheres."

Brain Injury:

Injury to the brain caused by a brain bleed in prematurely, trauma, infections, or other events that affect functioning in various ways.

Brain Stem:

The stem-like part of the brain that is connected to the spinal cord. Or conversely, the extension of the spinal cord up into the brain. The brain stem is small but important. It manages messages going between the brain and the rest of the body, and it also controls basic body functions such as breathing, swallowing, heart rate, and blood pressure. The brain stem also controls consciousness and determines whether one is awake or sleepy.

Breathing:

The process of respiration, during which air is inhaled into the lungs through the mouth or nose due to muscle contraction, and then exhaled due to muscle relaxation.

BRG:

Business Relations Group – U. S. Department. of Labor

Bright Line Reading Guide (See Reading Guides)

Browser:

A program that runs on an Internet-connected computer and provides access to the World Wide Web. Web browsers may be text-only, such as Lynx, or graphical, such as Internet Explorer and Netscape Navigator.

Cadmium:
A metallic element whose salts are toxic and cause cancer.

Cancer:
An abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize (spread).

CAO:
County Assistance Office

CASAS:
Comprehensive Adult Student Assessment System

Captioning:
A text transcript of the audio portion of multimedia products, such as video and television, that is synchronized to the visual events taking place on screen.
Example: For a child with a severe hearing impairment like Justine, captioning of TV, video and multimedia makes an enormous difference in the quality of her experience with a certain product. A CD-Rom that uses audio narration to tell a story, if captioned, will allow Justine to engage with the material to the same extent a child without a hearing impairment would.
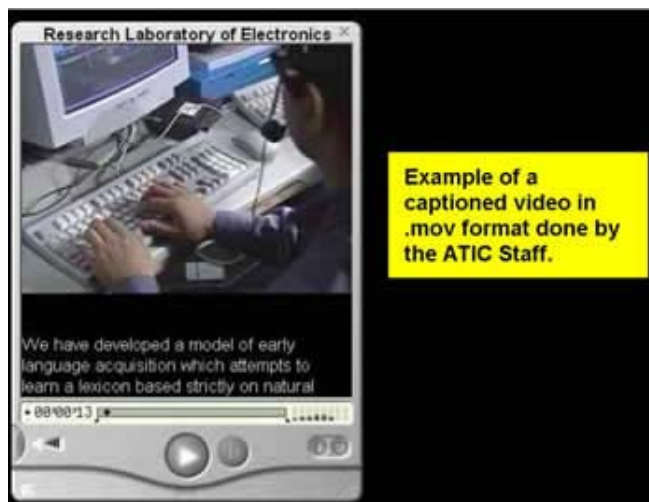
Photo courtesy of Adaptive Technology for Information and Computing at MIT

Captioned film or videos:
Transcription of the verbal portion of films or videos is displayed to make them accessible to people who have hearing impairments.

Care Management:
Any program through the Area Agency on Aging (AAA) offices that help consumers age 60 and over maintain their independence in their homes.

Career Development:
Career development refers to "the outcome of actions on career plans as viewed from both individuals and organizational perspectives". The outcomes desired by individuals range from status to job flexibility to monetary rewards, depending on the situation. Organizations' desired outcomes include achieving the best match between people and jobs.

Case Management:
A systematic process by which staff monitor the client's implementation of an employability development plan and intervene when necessary to remove barriers or solve problems. In many programs, case management staff may also *develop* the employability plan as well as provide personal and career counseling. Sometimes, case managers are also responsible for employer outreach.

Case Notes:
A written log documenting (in a systematic and consistent way) each client's progress in implementing his/her employability development plan. This includes the case manager's subjective views as well as any changes in programs or services.

CBO:
Community-Based Organization

CBT:
Computer-based Training

CCE:
Center for Credentialing and Education, a corporate affiliate of the National Board for Certified Counselors

CCTV: (See Video Magnifier)

CDF:
Career Development Facilitator

CDBG:
Community Development Block Grants. A method by which the federal government distributes funds to states and localities in "lump sums" for broadly defined purposes (such as community development). A block grant is the opposite of a "categorical program," which distributes funds for a narrowly defined purpose (such as job training for low-income, out-of-school youth). Generally, states and localities like block grants because they are easy to administer and spending can be tailored to local circumstances.

CEG:
The Council for Excellence in Government works to improve the performance of government at all levels. The Council helps to create stronger public sector leadership and management, driven by innovation and focused on results; and increased citizen confidence and participation in government, through better understanding of government and its role.

Cell:
The basic structural and functional unit in people and all living things. Each cell is a small container of chemicals and water wrapped in a membrane.

Census:
A complete count of a specified population or some measurable characteristics in a given area (e.g. housing, industry, etc.).

Census Data:
Data derived from a census, typically the U.S. Census of population.

Cerebral Palsy
A life-long condition caused by damage to the brain during pregnancy, labor or shortly following birth. "Cerebral" refers to the brain, and "palsy" to muscle weakness or poor control of movement or posture. It is not a disease; and it is neither progressive nor communicable. There is no single cause of cerebral palsy. It is characterized by the

inability to control motor functions and can result in involuntary movement, disturbance in gait and mobility and impairment of sight, hearing and speech.

Certification:
The process by which applicants must prove that they meet the eligibility criteria for a particular program. Typically, this involves submission of one or more official documents including wage reports, a Social Security card, proof of home address, etc. For many programs, certification is a long and tedious process that discourages many applicants.

CES (Current Employment Statistics):
Statistics based on a monthly survey of non-farm business establishments. The numbers include wage and salary employment, worker hours and payroll by industry and area statistics. Through a Federal/State cooperative effort, these data are used to compute current monthly employment, hours and earnings estimates, by industry, for the nation, the 50 states and the District of Columbia and over 250 Metropolitan Areas.

CEU:
Continuing Education Unit

CFR:
Code of Federal Regulations

Chemotherapy:
1. In the original sense, a chemical that binds to and specifically kills microbes or tumor cells. The term chemotherapy was coined in this regard by Paul Ehrlich (1854-1915).
2. In oncology, drug therapy for cancer. Also called "chemo" for short.

Child:
We use the term "Child" to include your biological child or any other child who can inherit your personal property under State law or who meets certain specific requirements under the Social Security Act; such as:
   · A legally adopted child,
   · An equitably adopted child,
   · A stepchild, or
   · A grandchild.

Childhood:
1. The time for a boy or girl from birth until he or she is an adult.
2. The more circumscribed period of time from infancy to the onset of puberty.

Civilian:
Not in the military.

Civilian Employment:
Civilian workers 16 years and older who (a) during the survey week did any work at all as paid employees or in their own businesses or profession on their own farm, or worked 15 hours or more as unpaid workers in a family enterprise; or (b) were not working but had jobs or business from which they were temporarily absent because of illness, bad weather, vacation, labor management disputes, personal reasons, whether or not they were paid for the time off.

Civilian Labor Force:
The sum of civilian individuals who are 16 years old or older and are either employed or counted as unemployed. This category does not include the military.

Civilian Unemployment:
All civilians 16 years and over who did not work during the survey week, who made specific efforts to find a job within the past four weeks, and who were available for work (except for temporary illness) during the survey week. Also included as unemployed are those who did not work at all, but were available for work, and (a) were waiting to be recalled to a job from which they had been laid off for a specific time; or (b) had a new job to go to within thirty days.

CJT:
Customized Job Training

Closed Circuit TV Magnifier (CCTV):
A camera used to magnify books or other materials on a monitor. Currently the term *Video Magnifier* is used to described the CCTV.

CMSA (Consolidated Metropolitan Statistical Area):
Adjoining Metropolitan Statistical Areas (MSAs) having a combined population of one million or more. When combined into a CMSA, each component metropolitan area is referred to as a Primary Metropolitan Statistical Area (PMSA).

COBRA:
The Consolidated Omnibus Budget Reconciliation Act (COBRA) gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances.

Cognitive Development:
Development of mental processes; can be adversely affected by sensory loss.

Cognitive Impairment/Mental Retardation:
Individuals with cognitive or learning disabilities who use aids or devices to improve learning, increase their ability to receive, understand, and give information.

Cognitive Skills:
Thinking, reasoning, and other intellectual abilities.

COLA (Cost of Living Adjustment):
Social Security benefits and Supplemental Security Income payments are increased each year to keep pace with increases in the cost-of-living (inflation).

Compensatory tools:
Adaptive computing systems that allow people with disabilities to use computers to complete tasks that would be difficult without a computer (e.g., reading, writing, communicating, accessing information).

Computation Years:
Computation years are the years with highest earnings selected from the "base years." We add total earnings in the computation years and divide by the number of months in those years to get the AME or the AIME.

Concept Development:
Developing concepts. A concept is something conceived in the mind (e.g., thought or notion), an abstract or generic idea, or a mental representation, image, or idea of concrete objects as well as of intangible ideas.

Condition:
The term "condition" has a number of biomedical meanings including the following:
- An unhealthy state, such as in "this is a progressive condition."
- A state of fitness, such as "getting into condition."
- Something that is essential to the occurrence of something else; essentially a "precondition."
- As a verb: to cause a change in something so that a response that was previously associated with a certain stimulus becomes associated with another stimulus; to condition a person, as in behavioral conditioning.

Conduct Disorder:
A persistent pattern of behavior that involved violation of the rights of others (disobedience, destructiveness, jealousy, boisterousness, inadequate feelings of guilt). The pattern is seen at home, school and in the community. Verbal and physical aggression are key features of conduct disorder. See also *Behavior Disorders/Emotional Disturbance* and *Oppositional Defiant Disorder.*

Congenital:
Originating from birth.

Congenitally Deaf/Adventitiously Blind:
Having a hearing impairment or being deaf from birth or early childhood and experiencing vision loss in adult life; the most common cause is Usher's Syndrome, the combination of congenital deafness and Retinitis Pigmentosa.

Congenitally Deafblind:
Having both visual and hearing impairment since birth or early childhood; a common cause is Congenital Rubella Syndrome as a result of maternal Rubella during pregnancy.

Consumer:
An individual with a disability who is requesting assistance from the Assistive Technology Project.

Consumer-Driven:
People with disabilities are the decision-makers in the design, implementation, and evaluation of the services and devices.

Consumer-Responsive:
To listen to feedback from people with disabilities and then changing the way services are provided based upon that information.

Contingent Workers:
Workers hired for a limited time or to work on a specific project lasting from a few days to many months.

Control Group Study:
The most rigorous (and, therefore, the most trustworthy) type of scientific study. In such studies, a group of people is recruited for a program. A lottery is held and half are selected for the program ("program group"). The other half, called the "control group," is not allowed to enroll. The purpose is to evaluate, over time, the effect that the program had upon participants, as compared with non-participants. Only a control group study accurately isolates and measures the specific effects of a workforce development or other program.

Cooperative education:
Programs that work with students, faculty, staff, and employers to help students clarify career and academic goals, and expand classroom study by allowing students to participate in paid, practical work experiences.

Cortex:
Outer layers of the cerebrum and cerebellum of the brain that contains most of the higher nervous centers such as those concerned with hearing and vision.

Cortical:
Relating to the cortex.

COS:
CareerOneStop is an integrated suite of national web sites that help businesses, job seekers, students, and workforce professionals find employment and career resources. CareerOneStop is sponsored by the U.S. Department of Labor

County:
The largest territorial division for local government.

Covered Employment and Wages (ES-202) Program:
This program produces employment and wage data for workers covered by State unemployment insurance laws and Federal workers covered by the Unemployment Compensation for Federal Employees Program.

CPI (Consumer Price Index):
A Bureau of Labor Statistics program which measures the average change in prices of a fixed set of goods and services purchased by households. It is the most commonly recognized measure of inflation.

CPI-W (Consumer Price Index):
An index prepared by the U. S. Department of Labor that charts the rise in costs for selected goods and services. This index is used to compute COLA increases.

CPS (Current Population Statistics):
Monthly household survey of the civilian non-institutional population of the United States. The survey provides monthly statistics on employment, unemployment, and related subjects. The data are analyzed and published each month by the Bureau of Labor Statistics.

CRC:
Civil Rights Center - U. S. Department of Labor, Employment & Training Administration

Creaming:
Refers to any of several methods by which workforce development programs select applicants for enrollment who possess the fewest or least serious barriers to employment. Creaming is often criticized because it gives programs better results than they might otherwise have achieved.

Credits (Social Security Credits):
Previously called "Quarters of Coverage." As you work and pay taxes, you earn credits that count toward your eligibility for future Social Security benefits. You can earn a maximum of four credits each year. Most people need 40 credits to qualify for benefits. Younger people need fewer credits to qualify for disability or survivors' benefits.

Crosswalk:
A method that provides a means of matching components of different system

CRT/CT:
Classroom Training

CSWE:
Community Service Work Experience

Customer Service:
A system of practice by which an organization seeks to meet or exceed the expectations of its customers.

CWDP:
Certified Workforce Development Professional

CWP:
Center for Workforce Preparation - U. S. Chamber of Commerce

Cyclical Unemployment:
Temporary downturn in the job market. The most common form of cyclical unemployment occurs when workers are temporarily laid off.

Data:
Factual information used as a basis for reasoning, discussion or calculation.

DBTAC (Disability and Technical Assistance Centers):
Ten regional centers established by the National Institute on Disability and Rehabilitation Research that provide information, training, and technical assistance to employers, people with disabilities and others on their rights and responsibilities under the Americans with Disabilities Act.

Deafblind/DeafBlind/Deaf-Blind:
Term applied to those who have a degree of both vision loss and hearing loss.

Decision Notice (Award Letter or Denial Letter):
When you file for Social Security, we decide if you will receive benefits. We send you an official letter explaining our decision and, if benefits are payable, we tell you the amount you will get each month.

Delayed Retirement Credits (DRC):
Social Security benefits are increased (by a certain percentage depending on a person's date of birth) if retirement is delayed beyond full retirement age (FRA). Increases based on delaying retirement no longer apply when people reach age 70, even if they continue to delay taking benefits.

Demand:
In labor market information this term is usually used in reference to the need for workers in a particular occupation, or workers with specific skills.

Demographics:
The characteristics of the population such as age, income, ethnicity, etc.

Denial:
A process by which the agency or organization informs the requesting party that the service or device requested will not be provided.

Dependent Benefits:
See *Family Benefits.*

Developmental Disabilities:
Manifest before the person reaches 22 years of age (or 18 in some states), which constitutes a substantial disability to the affected individual, and is attributable to mental retardation or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions when such conditions result in: Impairment of general intellectual functioning or adaptive behavior similar to that of a person with mental retardation. Unless otherwise specifically stated, the federal definition of "Developmental Disability" found in 42 U.S.C. 6000, et seq., shall not apply.

Developmental Delay:
The slowed or impaired development of a child who is under 5 years old and who is at risk of having a developmental disability because of the presence of one or more of the following: Chromosomal conditions, Congenital syndromes, Metabolic disorders, Prenatal and prenatal infections and significant medical problems, low birth weight, postnatal-acquired problems. **OR:** A child less than 5 years old who is delayed in development by 1.5 standard deviations or more in one or more of the following areas: communication, self-help, social-emotional, motor skills, sensory development or cognition. **OR:** A child less than 3 years of age who lives with one or both parents who have a developmental disability.

Di George Syndrome:
A rare but often complex genetic abnormality caused by a deletion of chromosome 22 with prevalence estimated at 1:4000 live births. The most common presentation in the neonatal period begins with the diagnoses of a cardiac defect. Late presentations of Di George Syndrome can occur in children between the ages of 3-6 who show developmental delays, moderate to severe behavioral problems and recurrent airway infection.

Diagnosis:
1. The nature of a disease; the identification of an illness.
2. A conclusion or decision reached by diagnosis. The diagnosis is rabies.
3. The identification of any problem. The diagnosis was a plugged IV.

Digitized Speech:
Human speech that is recorded onto an integrated circuit chip and which has the ability to be played back.

Direct Deposit:
The standard way to receive Social Security benefits and Supplemental Security Income payments. Your money is sent electronically to an account in a financial institution (a bank, trust company, savings and loan association, brokerage agency or credit union).

Direct Service:
Work directed at the achievement of the agency's primary mission which often involves the provision of services directly to agency clients.

Disability:
A physical or mental impairment that substantially limits one or more of that person's major life activities, has a record of such impairment, or who is regarded as having such an impairment.

Disability Benefits:
You can get disability benefits if you:
- Are under full retirement age
- Have enough Social Security credits and
- Have a severe medical impairment (physical or mental) that's expected to prevent you from doing "substantial" work for a year or more, or have a condition that is expected to result in death.

Discouraged Worker:
Persons who had no employment during the survey week, want a job, have looked for work during the past year, and are available to work, but did not look for work in the last four weeks because they believed that no jobs were available to them. Discouraged workers are classified as not in the labor force. They are not counted as unemployed because they have not made specific efforts to find work.

Discrimination:
The act of treating a person differently in a negative manner based on factors other than individual merit.

Dislocated Worker:
An employee who has been laid off from his/her job because of a business cutback or plant closure.

Dispute Resolution:
An umbrella term for processes people can utilize to address their problems or conflicts.

Documents (Proofs):
Forms and papers such as birth certificates, marriage certificates, W2 forms, tax returns, deeds, etc., submitted by individuals applying for benefits and services. We can accept

only originals or copies certified by the agency that has the original document. See *Evidence.*

DoEd (or ED):
U. S. Department of Education

DOJ:
U. S. Department of Justice

DOL (Department of Labor):
Cabinet-level U.S. agency that enforces laws protecting workers, promotes labor-management cooperation, sponsors employment and training placement services, oversees the unemployment insurance system, and produces statistics on the labor force and living conditions.

DOLETA:
U. S. Department of Labor, Employment & Training Administration

DOSO:
Division of One-Stop Operations or One-Stop Division – U. S. Department of Labor, Employment & Training Administration

DOT (Dictionary of Occupational Titles):
Occupational coding system established by the U.S. Department of Labor to classify occupations in a consistent manner.

Down Syndrome:
A genetic condition caused by extra genetic material (genes) from the 21st chromosome. The extra genes cause certain characteristics that we know as Down Syndrome. Individuals with Down Syndrome also have all the other genes given to them by their parents. As a result, they have a combination of features typical of Down Syndrome on top of the individual features from their parents. This can include some degree of mental retardation, cognitive disability and other developmental delays.

DPW:
Department of Public Welfare

DSS:
Department of Social Services

DST:
Direct Service Team

DUA:
Disaster Unemployment Assistance

Durable Medical Equipment:
Equipment which is most often used to serve a medical purpose, withstands repeated use, and is something that can be used in the consumer's home.

Duration of Unemployment:
The length of time during which a person classified as unemployed has been continuously looking for work.

Dymo Labeller:
A device used to create raised print or Braille labels.

Dysfunction:
Difficult function or abnormal function.

Dyslexia:
A specific reading disability due to a defect in the brain's processing of graphic symbols.
Dyslexia is a learning disability that alters the way the brain processes written material.

DWP:
Dislocated Worker Program

EAP:
Employee Assistance Program. Many companies provide EAP services for their
employees. The range of services include marriage and family problems, stress related
problems, financial and legal difficulties, and psychological and workplace conflict. EAP's
furnish professional counselors, who provide confidential assessment and short-term
counseling to employees and their families in order to assist in dealing with these, and
related, matters.

Ear:
The hearing organ. There are three sections of the ear, according to the anatomy
textbooks. They are the outer ear (the part we see along the sides of our head behind
the temples), the middle ear, and the inner ear. But in terms of function, the ear has
four parts: those three and the brain. Hearing thus involves all parts of the ear as well
as the auditory cortex of the brain. The external ear helps concentrate the vibrations of
air on the ear drum and make it vibrate. These vibrations are transmitted by a chain of
little bones in the middle ear to the inner ear. There they stimulate the fibers of the
auditory nerve to transmit impulses to the brain.

Early Retirement:
You can start getting Social Security retirement benefits as early as age 62, but your
benefit amount will be less than you would have gotten at full retirement age. If you
take retirement benefits early, your benefit will be permanently reduced, based on the
number of months you received checks before you reached full retirement age. See
Retirement Insurance Benefits (RIB).

Early Retirement Age:
Age 62.

Earned Income Disregards:
To encourage welfare recipients to move toward employment self-sufficiency, many
states allow TANF recipients to earn an income equal to their monthly cash assistance,
and retain both incomes. This allowance does not extend beyond the state's respective
time-limited deadline for moving off public assistance. This additional income is intended
to help TANF recipients make a gradual transition from assistance to self-sufficiency.

Earnings Record (lifetime record of earnings):
A chronological history of the amount you earn each year during your working lifetime.
The credits you earned remain on your Social Security record even when you change
jobs or have no earnings.

EBSA:
Employee Benefits Security Administration – U. S. Department of Labor

Economic Development 1:
An effort by government or community-based organizations to improve the economic health of an impoverished area through job creation. Typically, such programs aim to entice businesses to re-locate in the economic development zone, to improve the occupational and academic skills of local residents and to encourage formation of new businesses. A wide variety of tax credits, hiring subsidies and other incentives may be used.

Economic Development 2:
The entire array of activities, some conducted by government, and some by the private sector, often in partnership with government, which are intended to expand the economy of a designated area to increase the number of jobs available to the population of that area.

Economic Indicator:
A set of data that serves as a tool for analyzing current economic conditions and future prospects. Usually classified according to their timing in relationship to the ups and downs of the business cycle, that is, whether they anticipate (lead), coincide with, or lag behind general business conditions.

EDP:
Employment Development Plan

EEOC (Equal Employment Opportunity Commission):
Federal agency responsible for overseeing and enforcing nondiscrimination in hiring, firing, compensation, promotion, recruitment, training, and other terms and conditions of employment regardless of race, color, sex, age, religion, national origin or disability.

EFF:
Equipped for the Future

EITC (EARNED INCOME TAX CREDIT):
A federal program which helps to make work more attractive than welfare by offsetting or reducing the federal payroll and income tax burden for low- and moderate-income workers – primarily those with children. For families with incomes so low they do not pay taxes, EITC provides a wage supplement. For eligible families with very low earnings, EITC can increase a family's income from wages by 34 to 40 percent. Workers may either file for a tax refund at the tax filing deadline or select the EITC Advance Payment Option to have a portion of the credit added to each paycheck and receive the remaining lump sum (usually half or more of the credit) at the end of the year.

Electronic and Information Technology:
Technology and any equipment or interconnected system or subsystem of equipment that is used in the creation, conversion, or duplication of data or information. The term electronic and information technology includes, but is not limited to, telecommunications products (such as telephones), information kiosks and transaction machines, World Wide Web sites, multimedia, and office equipment such as copiers and fax machines.

Electronic Information:
Any digital data for use with computers or computer networks, including disks, CD-ROMs, and World Wide Web resources.

Electronic Pointing Devices:
Electronic pointing devices allow the user to control the cursor on the screen using ultrasound, an infrared beam, eye movements, nerve signals, or brains waves. When used with an on-screen keyboard, electronic pointing devices also allow the user to enter text or data.

Photo courtesy of Don Johnston

Eligible, Eligibility:
The process and result of transition through the course of action of taken to qualify for various programs.

Emerging Occupations:
1. Occupations newly created as a result of technological innovation, shifting markets or new regulations; or
2. Existing occupations that have undergone substantial modification in skill requirements; or
3. Existing occupations with new opportunities created by changes in legislation, social concerns, demographics, industry or the market place.

Employability Competencies:
As defined in the Job Training Partnership Act (JTPA), these are core work-readiness skills youth need to enter the workforce successfully. These competencies are the basis for one of the six "performance standards" agencies must meet annually in order to retain their JTPA funding.

Employability Plan:
A written plan devised by staff and/or setting forth an individualized mix of training programs and services leading to a specified career or personal goal. Also known as an "Employment Development Plan" or "Individual Service Strategy."

Employed:
A job whereby payment is provided for assigned tasks that are performed. Persons who are aged 16 years or older are eligible by law to work.

Employer Outreach:
An organized effort by a job placement service provider to place its clients in a job with a particular employer. This may be accomplished by the clients themselves or by staff who either encourage employers to list job openings with the employment agency or who advocate on behalf of individual clients. Also called "Job Development."

Employer Payroll Records:
Wage records employers submit quarterly to support the unemployment insurance program.. These records contain information on the number of workers, and the total wages paid.

Employment:
Jobs, or people who are working for pay.

Employment Tax Credit:
   Refers to any of several (mostly state) initiatives to entice employers to hire low-Income people by reducing corporate or other taxes.

Empowerment:
   The process by which an individual becomes enabled to make changes in his/her life.

Entry-Level:
   Jobs or occupations for which employers hire workers with little or no previous work experience or with relatively minimum training or education. Occupations that require more education or training may have specific entry-level classifications such as "apprenticeship" or "internship."

Environment:
   The sum of the total of the elements, factors and conditions in the surroundings which may have an impact on the development, action or survival of an organism or group of organisms.

Environmental Controls:
   Aids or devices (such as electronic equipment, switches and controls) used within an individuals surroundings in order to assist in independent living activities.

Environmental Adaptations:
   Changes or modifications (such as ramps, door widenings, tub seats, etc) to an individual's environment in order to assist in independent living activities.

Environmental Control Unit (ECU):
   A system that enables individuals to control various electronic devices in their environment through a variety of alternative access methods, such as switch or voice access. Target devices include lights, televisions, telephones, music players, door openers, security systems, and kitchen appliances. Also referred to as Electronic Aid to Daily Living (EADL).
   Example: Electronic pointing devices might look a bit space age but the technology is life changing for people with little or no mobility. Take the case of Vanya, a teenager with a traumatic brain injury. Vanya's ocular movement was tracked and registered and she is now able to use a device that lets her interact with her computer, and thereby control her environment, solely with eye movement.

Photo courtesy of EyeGaze

Equipment Fabrication:
   The design and construction of a device or piece of equipment that improves and individual's functioning level.

Equipment Fitting:
   The process of installing, adjusting, and testing a device, or other adaptation as it applies to benefiting an individual in some way.

Equipment Loan:
   To provide needed equipment to consumers free of charge for a specific period of time.

Equipment Modification:
   To change or alter the design and construction of an existing device or piece of equipment that improves an individual's functioning level.

Equipment Purchase:
   To obtain equipment by the consumer paying for it or by an agency/organization authorizing the purchase of the equipment.

Equipment Rental:
   To provide needed equipment to consumers for a fee.

Equipment Repair/Maintenance:
   A service that must be performed routinely or as needed to keep products, devices, or other equipment functioning at the maximum level.

Etiology:
   Cause or origin.

ERIC:
   Educational Resource Information Center

ERISA:
   Employee Retirement Income Security Act

ES-202 Program:
   Refers to Covered Employment and Wages Program.

ESA:
   Employment Standards Administration - U. S. Department of Labor

ESL:
   English as a Second Language

ESOL:
   English for Speakers of Other Languages

ESPL:
   Employment Service Program Letter

Essential Job Functions:
   Fundamental job duties of an employment position that an individual with a disability holds or desires

Establishment:
   The physical location of a certain economic activity, for example, a factory, store, or office. Generally a single establishment produces a single good or provides a single service.

Estimate:
Numerical data calculated from sample data, or from a model, and intended to provide information about a larger set of data.

ETA (Employment and Training Administration):
A part of the U.S. Department of Labor. This agency oversees the State Unemployment Insurance Programs and job training and placement services provided by the State Employment Security Agencies.

ETP:
Employment and Training Programs

Evaluation/Technical Assessment:
A hands-on, in-person evaluation whereby a disabled individual is tested, measured, observed, and questioned for the purpose of determining the most appropriate and beneficial technology for his/her individual situation.

Evidence (Proofs):
"Proofs." The documents you must submit to support a factor of entitlement or payment amount. The people in your Social Security office can explain what evidence is required to establish entitlement and help you to get it.

Evolution:
The continuing process of change, especially in reference to natural selection.

Extended Benefits:
Benefits payable for up to 13 additional weeks during periods of high unemployment. Extended benefits are payable to individuals who have exhausted their entitlement to regular benefits.

Eye:
The organ of sight. The eye has a number of components. These components Include but are not limited to the cornea, iris, pupil, lens, retina, macula, optic nerve, choroid and vitreous.

EZ:
Enterprise Zone

Facility:
All or any portion of a physical complex, including buildings, structures, equipment, grounds, roads, and parking lots.

Family:
1. A group of individuals related by blood or marriage or by a feeling of closeness.
2. A biological classification of related plants or animals that is a division below the order and above the genus.
3. A group of genes related in structure and in function that descended from an ancestral gene.
4. A group of gene products similarly related in structure and function and of shared genetic descent.
5. Parents and their children. The most fundamental social group in humans.

Family Benefits (Dependent Benefits):
When you're eligible for retirement or disability benefits, the following people may receive benefits on your record:
- Spouse if he or she is at least 62 years old (or any age but caring for an entitled child under age 16)
- Children if they are unmarried and under age 18, under age 19 and a full-time elementary or secondary student
- Children age 18 or older but disabled
- Divorced ex-spouse

Family Maximum:
The maximum amount of benefits payable to an entire family on any one worker's record.

FBO:
Faith-Based Organization

Fee For Service:
Refers to any of various efforts by nonprofit social services agencies to increase funding by charging fees. Fees might be charged for services often available without charge, such as a sliding scale for job training or for new services (such as leasing a computer learning lab to area businesses for training their own employees). Sometimes employers pay fees for screening, placement and/or retention services.

FEIN:
Federal Employer Identification Number. An Employer Identification Number (EIN) is also known as a federal tax identification number, and is used to identify a business entity.

FEMA:
Federal Emergency Management Agency

Fetal alcohol syndrome:
The sum total of the damage done to the child before birth as a result of the mother drinking alcohol during pregnancy. Fetal alcohol syndrome (FAS) always involves brain damage, impaired growth, and head and face abnormalities.

Fetus:
The unborn offspring from the end of the 8th week after conception (when the major structures have formed) until birth. Up until the eighth week, the developing offspring is called an embryo.

FICA Tax:
FICA stands for "Federal Insurance Contributions Act." It's the tax withheld from your salary or self-employment income that funds the Social Security and Medicare programs.

Fine Motor Skills:
Use of the hands to explore and manipulate objects in the environment.

Firm:
A business entity, either corporate or otherwise. May consist of one or several establishments.

FLSA:
Fair Labor Standards Act

FM sound amplification system:
An electronic amplification system consisting of three components: a microphone/transmitter, monaural FM receiver and a combination charger/carrying case. It provides wireless FM broadcasts from a speaker to a listener who has a hearing impairment.

Food Stamps (Food Stamp Program):
The U. S. Department of Agriculture program that helps needy families buy food.

Forecast:
To calculate or predict some future event or condition; usually as a result of study and analysis of available pertinent data.

FRA (Full Retirement Age):
The age at which a person may first become entitled to unreduced retirement benefits. Beginning with year 2000 for workers and spouses born 1938 or later and widows/widowers born 1940 or later, the retirement age increases gradually from age 65 until it reaches age 67 in the year 2022. This increase affects the amount of the reduction for persons who begin receiving reduced benefits.

Frame tags:
A means of displaying Web pages. The browser reads the frame tags and produces an output that subdivides output within a browser into discrete windows.

Frictional Unemployment:
Occurs when a person voluntarily leaves one job and has not yet begun another job. The worker is voluntarily unemployed and is utilizing his/her right to change jobs.

FSET:
Food Stamp Employment and Training Program

FTE:
Full-Time Equivalency

FTP:
Family Transition Program

Full-Time Employment:
A person employed 35 or more hours per week. (Bureau of Labor Statistics, Current Population Survey)

Funding Assistance/Consultation:
The consideration of funding a specific request. The provision of agency, program or organizational names, contact persons, addresses, and telephone numbers that may be available to financially assist an individual in the purchase of a device or service. Consultation is giving professional advice on funding strategies and correspondence.

Funding Coordinator:
A resource person responsible for funding assistance and guidance throughout the funding process.

FY:
Fiscal year

GAO:
General Accounting Office

GED (General Equivalency Diploma):
A nationally recognized high school equivalency certificate program administered by the Educational Testing Service. Testing is conducted locally and scored by ETS

Genes:
The basic biological units of heredity. Segments of deoxyribonucleic acid (DNA) needed to contribute to a function.

Genetic:
Having to do with genes and genetic information.

Graphical user interface (GUI):
Program interface that presents digital information and software programs in an image-based format as compared to a character-based format.

GPRA:
Government Performance and Results Act

GSA:
Government Service Administration

Handyman Unit:
Any program through care management or senior service centers that help consumers remain in their homes independently as long as possible through minor home repairs and homemaker services (examples: lawn mowing, snow removal, house cleaning, minor home modifications, etc.)

Hard-to-Employ:
Denotes a specific population of individuals with occupational, academic, personal and other barriers that make it particularly difficult for them to find jobs. Examples include people with very low reading skills, physical and mental disabilities, long-term welfare recipients, ex-offenders, the homeless, substance abusers and the long-term unemployed. Many workforce development programs are directly targeted at such individuals.

Hardware:
Physical equipment related to computers.

Hearing impairment:
Complete or partial loss of the ability to hear, caused by a variety of injuries or diseases, including congenital causes. Limitations, including difficulties in understanding language or other auditory messages and/or in production of understandable speech, are possible.

Health:
As officially defined by the World Health Organization, a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity.

Health Insurance (Medicare):
The federal health insurance program for:
- People 65 years of age or older
- Certain younger people with disabilities and
- People with permanent kidney failure with dialysis or a transplant, sometimes called ESRD (End-Stage Renal Disease).

Health Maintenance Organization (HMO):
One-stop healthcare organization which provides for all medical needs and makes referrals for any specialized care required but not available within the main structure of the organization. Most HMO's consists of a large group of healthcare professionals who can provide services in a variety of general areas. The overall operation is managed like a business and the emphasis is on preventive healthcare measures.

HHS:
U. S. Department of Health & Human Services

HIPAA:
Health Insurance Portability and Accountability Act

Home/Worksite/Modifications:
Structural adaptations and/or fabrications in the home, worksite, or other areas that remove or reduce physical barriers for an individual with a disability such as ramps, lifts, widened doorways, lowered desk, or counter tops.

Household:
People living in a single residence regardless of relationship.

Hyperactivity:
A higher than normal level of activity. An organ can be described as hyperactive if it is more active than usual. Behavior can also be hyperactive.

Hypertonic:
Stiff, increased tone, resistance to passive movement.

Hypoplasia:
Condition of arrested development in which an organ or other body part remains below the normal size or in an immature state.

IAWP:
International Association of Workforce Professionals

IDA (Individual Development Account):
A new policy tool directed toward enabling struggling families to build assets and achieve economic self-sufficiency. IDAs are matched savings accounts that are similar to individual retirement accounts (IRAs). Use of the assets accrued in IDAs is restricted to post-secondary education and training, business capitalization and home ownership. Sixteen states already have implemented IDA programs in different forms, and IDA provisions are also included in the new federal welfare reform law.

ILAB:
International Labor Affairs Bureau - U. S. Department of Labor

Immune:
　　Protected against infection. The Latin *immunis* means free, exempt.

Immune system:
　　A complex system that is responsible for distinguishing us from everything foreign to us, and for protecting us against infections and foreign substances. The immune system works to seek and kill invaders.

Impulsivity:
　　Inclined to act on impulse rather than thought. People who are overly impulsive, seem unable to curb their immediate reactions or think before they act. As a result, they may blurt out answers to questions or inappropriate comments, or run into the street without looking. Their impulsivity may make it hard for a child to wait for things they want or to take their turn in games. They may grab a toy from another child or hit when they are upset.

IMS:
　　Information Management System

INA:
　　Indian and Native American

Incidental Learning:
　　Learning that occurs unintentionally or by chance; often done through vision and hearing.

Independent study:
　　A student works one-on-one with individual faculty members to develop projects for credit.

Individual with a Disability:
　　Any individual who is considered to have a functional limitation in major life activities in which assistive technology devices or services would enable the individual to maintain or achieve a greater level of functioning.

Individuals with Disabilities Education Act (IDEA):
　　The Individuals with Disabilities Education Act (IDEA) requires public schools to make available to all eligible children with disabilities a free appropriate public education (FAPE) in the least restrictive environment appropriate to their individual needs. The law requires that public schools develop appropriate Individualized Education Programs (IEPs) for each child. The specific special education and related services, including assistive technology, that are outlined in each IEP should reflect the individualized needs of the student. IDEA also requires that particular procedures be followed in the development of the IEP. Each student's IEP must be developed by a team of knowledgeable persons and must be reviewed at least once a year. The team usually includes the child's teacher, the parents, the child, if appropriate, a school system representative who is qualified to provide or supervise the provision of special education, and other individuals at the parents' or school's request. If parents disagree with the proposed IEP, they can request a due process hearing and a review from the state educational agency if applicable in that state. They also can appeal the state agency's decision to state or federal court.
　　Additional Resources: http://www.ed.gov/offices/OSERS/Policy/IDEA/index.html

Individual Education Program (IEP):
A legal document developed by a team, the members of which include the student and his/her parents, that contains the student's present levels of educational performance, goals and objectives, special education and related services and placement for each school year. Discussion of assistive technology as it pertains to the student's ability to "receive a free and appropriate public education" is an important component of the IEP. See also *Individuals with Disabilities Education Act (Amendments of 1997). Additional Resources*: http://www.katsnet.org/fact4.html

Industry:
A group of firms that engage in similar activities. Every business is classified into a category according to what products or services account for the majority of revenue.

Industry Cluster:
Non-specific terms (such as tourism) used to group industries with similar economic activities, for instance linking a business with its suppliers. (An example might be a cluster representing growers, packing and shipping businesses, in an Agricultural cluster.)

Industry Employment:
Full-time and part-time workers (including employees on paid vacation or paid sick leave) who work or receive compensation from establishments for any part of the pay period including the 12th of the month. Those workers involved in labor-management disputes are excluded. This is a count of the number of jobs, and is available by industry.

Infant:
A child up to 2 years (24 months) of age.

Infection:
The growth of a parasitic organism within the body. A parasitic organism is one that lives on or in another organism and draws its nourishment therefrom. A person with an infection has another organism (a "germ") growing within him, drawing its nourishment from the person.

Information and Referral:
Knowledge provided to a consumer, family member, provider, or other advocate to aid the consumer in finding the right technology. Direction or otherwise linking someone to the correct professional program, service, or agency that will supply or play a major part in helping the consumer get assistive technology.

Information Technology:
Information technology includes any product used to acquire, store, manipulate, or transmit information, such as computers, multimedia, telecommunications, copy machines, and the Internet.

Informational interview:
An activity where students meet with people working in careers to ask questions about their jobs and companies, allowing students to gain personal perspectives on career interests.

Infrastructure:
The resources required for an activity. The underlying foundation or basic framework.

Input:
Any method by which information is entered into a computer.

Instructional Equipment:
Equipment, supplies, and publications necessary to aid the consumer in reaching the goals and objectives of the individual education program (IEP).

Insured Status:
If you earned enough Social Security credits to meet the eligibility requirement for retirement or disability benefits or enable your dependents to establish eligibility for benefits due to your retirement, disability, or death, you have insured status.

Intake:
The phase of a workforce development program during which applicants are oriented to the program and discuss their eligibility to participate. This phase also includes a client's personal assessment (e.g., family composition, income, marital status, educational achievement, health status); testing of math and reading ability; identification of employment barriers and formulation of an Individual Service Strategy. See *Employability Plan*.

Internet:
Computer network connecting governmental, educational, commercial, other organizations, and individual computer systems.

Internship:
A time-limited, intensive learning experience outside of the typical classroom.

Interpreter:
Professional person who assists a person who is deaf in communicating with hearing people.

Intervention:
The act of intervening, interfering or interceding with the intent of modifying the outcome. In medicine, an intervention is usually undertaken to help treat or cure a condition. For example, early intervention may help children with autism to speak. From the Latin *intervenire*, to come between.

IT:
Information Technology

ITA:
Individual Training Account

ITSC:
Information Technology Support Center

JAN:
Job Accommodation Network

JFF:
Jobs for the Future

Job Bank:
A list of currently available job openings.

Job Club:
A type of self-directed job search program in which clients meet regularly as a peer support group to learn job-search techniques and to telephone potential employers and arrange interviews. An employment program staff member often acts as an instructor and "cheerleader."

Job Coach:
Person hired by a placement agency or provided through an employer to assist an employee with a disability in learning and performing a job and adjusting to the work environment.

Job Search Assistance:
A category of employer outreach that includes (1) training to help clients find their own jobs (self-directed job search), (2) job leads for clients, and (3) on-the-job training.

Job shadowing:
A short work-based learning experience where students visit businesses to observe one or more specific jobs to provide them with a realistic view of occupations in a variety of settings.

Joysticks:
A joystick may be used as an alternate input device. Joysticks that can be plugged into the computer's mouse port can control the cursor on the screen. Other joysticks plug into game ports and depend on software that is designed to accept joystick control.
See *Alternative Access/Input Device.*

Photo courtesy of Aroga

JTPA (Job Training Partnership Act):
This was the primary federal employment-training program for disadvantaged adults, youth, Native Americans, veterans, dislocated workers, elderly and farm workers since enacted in 1982. It will be superseded by the Workforce Investment Act (WIA) of 1998 as of July 1, 2000.

Keyboards Additions:
A variety of accessories have been designed to make keyboards more accessible. *Keyguards* are hard plastic covers with holes for each key. Using a keyguard, someone with an unsteady finger or with a pointing device can avoid striking unwanted keys.
Moisture guards are thin sheets of plastic that protect keyboards from spills and drooling.
Alternative labels add visual clarity or tactile information to the keys.
Example: When John, a young man with muscular dystrophy, doesn't use the keyguard, he often clicks letters that he

Photo courtesy of AbilityNet

doesn't want. The clearly defined spaces between keys provided by the keyguards helps him more easily select the keys he wants.

Keyboard emulation:
Uses hardware and/or software in place of a standard keyboard.

Kinesthetic:
Refers to touch-based feedback.

Labor Dispute:
Any controversy concerning terms or conditions of employment, or concerning the association or representation of persons in negotiating, fixing, maintaining, changing, or seeking to arrange terms or conditions of employment, regardless of whether or not the disputants stand in the proximate relation of employer and employee.

Labor Force:
The sum of individuals who are 16 years old or older and either employed or counted as unemployed, including persons in the military.

Large-print:
Most ordinary print is six to ten points in height (about 1/16 to 1/8 of an inch). Large-print type is fourteen to eighteen points (about 1/8 to 1/4 of an inch) and sometimes larger.

LAUS (Local Area Unemployment Statistics):
A Federal/State cooperative program which produces employment, labor force and unemployment estimates for States and local areas.

Lawful Alien Status:
People admitted to the U.S. who are granted permanent authorization to work by the Immigration and Nationalization Service (INS) or admitted to the U.S. on a temporary basis with INS authorization to work.

LEA:
Local Education Agency

Learning Disability:
A disorder in one or more of the basic processes involved in understanding or in using language, spoken or written, which may be seen in the consumer's inability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term does not include children who have learning problems which are mainly the result of visual, hearing, or motor handicaps, mental retardation, emotional disturbance, of environmental, cultural, or economic disadvantage.

Learning problem:
See *Learning disability.*

LEO:
Local Elected Official

LEP:
Limited English Proficiency

Light Box:
A small lighted box used to help teach basic visual skills in children with vision loss. The box can also be used to assist with better viewing of certain types of photos, to highlight handwriting skills and increase visual memory.

Life Skills Training:
A form of pre-employment training that prepares job seekers who have few job skills or little workplace experience. It provides job seekers with information on what it takes to be hired and to keep a job. Typical components in this training include the importance of a strong work ethic, punctuality and reliability, a positive attitude, dressing for success, effective interview techniques, budgeting, conflict resolution and how to get along with supervisors and co-workers

Lifetime Earnings:
See *Earnings Record.*

Link:
A connection between two electronic files or data items.

LLSIL:
Lower Living Standard Income Level

LMA (Labor Market Area):
An economically integrated geographic area within which individuals can reside and find employment within a reasonable distance or can readily change employment without changing their place of residence. (U.S. Department of Labor, Bureau of Labor Statistics- January 2001)

LMC:
Local Management Committee

LMI (Labor Market Information):
Information about the market -where labor skills are exchanged for wages. Information can be descriptive (qualitative) or statistical (quantitative). The key elements in the labor market are the workers (labor resources) and jobs (employment opportunities).

Long-Term Unemployment:
Persons who have been unemployed for 15 or more consecutive weeks.

Low Vision Simulation Kit: (See Vision and Hearing Loss Simulation Kit)

Lump Sum Death Payment:
A one-time payment of $255 paid in addition to any monthly survivors insurance benefits that are due. This benefit is paid only to your widow/widower or minor children.

LWIA:
Local Workforce Investment Area

Lynx:
A text-based World Wide Web browser.

MA (Metropolitan Area):
A geographic area made up of a county containing a central city of 50,000 inhabitants or more, plus adjoining counties that are socially and economically integrated with the central city. There are three types of metropolitan areas: Metropolitan Statistical Area (MSA); Primary Metropolitan Statistical Area (PMSA); Consolidated Metropolitan Statistical Area (CMSA).

Macro:
A mini-program that, when run within an application, executes a series of predetermined keystrokes and commands to accomplish a specific task. Macros can automate tedious and often-repeated tasks or create special menus to speed data entry.

Major Life Activity:
The basic activities that the average person in the general population can perform with little or no difficulty. Examples include: caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working, etc.

Maximum Earnings:
The maximum earnings we can count for any calendar year when computing your Social Security benefit.

Mean:
The average value of a set of numbers.

Median:
The mid-point in a data set after the numbers are sorted. The median is the point where half of the numbers lie above and half lie below this value

Mediation:
Negotiation that involves a third party who is neutral on the conflict; "facilitated negotiation."

Medically Necessary:
Items that are needed by the consumer for medical reasons. These items need to be ordered by a doctor or other medical professionals.

Medication:
1. A drug or medicine.
2. The administration of a drug or medicine. (Note that "medication" does not have the dangerous double meaning of "drug.")

Medicaid:
A joint federal and state program that helps with medical costs for people with low incomes and limited resources. Medicaid programs vary from state to state, but most health care costs are covered if you qualify for both Medicare and Medicaid.

Memory:
1. The ability to recover information about past events or knowledge.
2. The process of recovering information about past events or knowledge.
3. Cognitive reconstruction. The brain engages in a remarkable reshuffling process in an attempt to extract what is general and what is particular about each passing moment.

Mental retardation:
A term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with mental retardation may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They will learn, but it will take them longer. There may be some things they cannot learn. As many as 3 out of every 100 people have mental retardation. In fact, 1 out of every 10 children who need special education has some form of mental retardation.

Mentors:
Mentoring is the deliberate pairing of a more skilled or experienced person with a lesser skilled or experienced one, with the agreed-upon goal of having the lesser skilled person grow and develop with specific life/work skills and competencies. Mentors may counsel new employees on any issue from managing time and stress to balancing work and home commitments or maintaining professional work habits and handling office relationships and conflicts appropriately. Length of commitment between mentor and mentee typically ranges from a few months to a year or more.

MIS:
Management Information System

MLS (Mass Layoff Statistics Program):
This is a Federal-State cooperative effort to identify, describe, and track the effects of major jobs cutbacks using each State's unemployment insurance database. The program has reports on mass layoff actions that result in workers being separated from their jobs.

MOA:
Methods of Administration

Mobility:
Denotes the ability to navigate from one's present fixed position to one's desired position in another part of the environment.

Mobility and Transportation Aids:
Products that help mobility impaired persons move within their environment and give them independence in personal transportation. Includes standing/walking aids, transfer

Photo of all-terrain wheelchair courtesy of Infintec

aids, stair lifts, walkers, scooters, wheelchairs and three-wheeled chairs, adapted bikes and Trikes, car seats/bed, stretchers, patient chairs, ramps, recliners, strollers, travel chairs, wheelchair trays, driving controls, seat belts, vehicle conversions, patient and wheelchair lifts, wheelchair loaders/carriers, wheelchair restraint systems, etc.

MOE (Month of Election):
This usually applies to retirement claims. In certain situations, you can choose the month in which your benefits will start. There are many different factors that can affect when you want to begin receiving your payments. Your local office can help you decide.

Mode:
The number in a distribution of numbers that appears most frequently.

Mother:
1. The female parent.
2. To produce offspring as a female. To attribute the maternity of.
3. A cell or other structure from which similar cells or structures are formed. Accordingly, such a cell might be referred to as the mother cell.
4. To provide maternal protection, guidance, and nurturing to children.

Motivation:
Desire to accomplish a goal or participate in an endeavor.

Motor:
In medicine, having to do with the movement of a part of the body. Something that produces motion or refers to motion. For example, a motor neuron is a nerve cell that conveys an impulse to a muscle causing it to contract. The term "motor" today is also applied to a nerve that signals a gland to secrete. Motor is as opposed to sensory.

Motor Planning:
Ability to automatically start, perform, and complete a series of movements to achieve a desired outcome.

MOU:
Memorandum of Understanding

MSA (Metropolitan Statistical Area):
A Metropolitan Statistical Area (MSA) is a relatively freestanding metropolitan area (MA) typically surrounded by non-metropolitan counties.

MSFW:
Migrant and Seasonal Farm Workers

Multimedia:
A computer-based method of presenting information by using more than one medium of communication, such as text, graphics, and sound.

Myriad:
A great number, a very large number, a huge number of something.

NACo:
National Association of Counties

NAFTA:
North American Free Trade Agreement Act

NAM:
National Association of Manufacturers

NASWA:
National Association of State Workforce Agencies

NASWBC:
National Association of State Workforce Board Chairs

Natural Supports:
Supports provided to an employee with a disability from supervisors and co-workers, such as mentoring, friendship, socializing at breaks or after work, providing feedback on job performance or learning a new skill together. These natural supports are particularly effective as they enhance the social integration of the employee with a disability with his or her co-workers and supervisor. In addition, natural supports are more permanent, part of the workplace and more readily available than paid job coaches, thereby facilitating long-term job retention.

NAWB:
National Association of Workforce Boards

NAWDP:
National Association of Workforce Development Professionals

NCDA:
National Career Development Association

NCWD:
National Collaborative on Workforce and Disability

NCWE:
National Council for Workforce Education

NECA:
National Employment Counseling Association

Negotiation:
A process which may be formal but involves at least two people who are on different sides of an issue; typically they discuss and give and take in order to reach a resolution that requires compromise on both sides.

Nerve:
A bundle of fibers that uses chemical and electrical signals to transmit sensory and motor information from one body part to another.

Neural:
Having to do with nerve cells.

Neurological:
Having to do with the nerves or the nervous system.

New Entrants:
Persons entering the labor force for the first time.

NIMH:
National Institute of Mental Health, one of the National Institutes of Health in the U.S., whose mission is to "provide national leadership dedicated to understanding, treating, and preventing mental illnesses through basic research on the brain and behavior, and through clinical, epidemiological, and services research."

NGA:
National Governors Association

NIFL:
National Institute for Literacy

NJCA:
National Job Corps Association

Non-Durable Goods:
Manufactured items that generally last three years or less. Food, beverages, clothing, shoes, and gasoline are common examples.

Non-institutional:
Persons not residing in penal or mental institutions, sanitariums, and homes for the aged, infirm, and needy.

Not in the Labor Force:
All persons in the civilian non-institutional population who are neither employed nor counted as unemployed are "not in the labor force."

NRA (Normal Retirement Age):
See *FRA (Full Retirement Age)*

NWA:
National Workforce Association

NYEC:
National Youth Employment Coalition

Number Holder (NH):
See *Wage Earner.*

OAS:
Office of Adult Services - U. S. Department of Labor, Employment & Training Administration

OASDI (Old Age Survivors and Disability Insurance):
The Social Security programs that provide monthly cash benefits to you and your dependents when you retire, to your surviving dependents, and to disabled worker beneficiaries and their dependents.

OASP:
Office of the Assistant Secretary for Policy - U. S. Department of Labor

OATEL:
Office of Apprenticeship Training, Employment & Labor Services - U. S. Department of Labor, Employment & Training Administration

Occupation:
A set of activities or tasks that employees perform. Employees that perform the same tasks are in the same occupation, whether or not they are in the same industry (from the Bureau of Labor Statistics).

Occupational Information:
Specific information about a particular occupation (e.g., wages, skills required, benefits, entrance requirements, etc.)

Occupational Skills:
Skills needed to practice a particular occupation or career. Typically these are "hard skills" (such as welding) rather than "soft skills" (such as punctuality). Also called "Vocational Skills."

ODEP:
Office of Disability Employment Policy - U. S. Department of Labor

OES (Occupational Employment Statistics Program):
A Federal/State cooperative program produces employment and wage estimates for over 700 occupations.

OGCM:
Office of Grants & Contracts Management - U. S. Department of Labor, Employment & Training Administration

OIS:
Occupational Information Systems

OJC:
Office of Job Corps - U. S. Department of Labor, Employment & Training Administration

OJT:
On-the-Job-Training

O*NET (Occupational Information Network):
The Occupational Information Network is a comprehensive database of worker attributes and job characteristics.

One-Stop Career Center:
One location within a geographical area in which people can obtain comprehensive information about training and job openings. They can also receive training for a self-directed job search as well as apply for additional social and supportive services, such as transportation and child care allowances. A movement that began in the mid-1990s, one-stop centers typically combine the efforts of the U.S. Employment Service, local Job Training Partnership Act (JTPA) agencies and other social services providers. A one-stop center may be an actual building or merely an electronic information system available to community social services agencies.

On-The-Job Training:
A type of vocational training in which the trainee learns skills at the work site while earning a wage. Often, employers are offered cash training reimbursements or other incentives to hire hard-to-employ people and train them on the job.

ONP:
   Office of National Programs - U. S. Department of Labor, Employment & Training Administration

Onscreen Keyboard:
   On-screen keyboards are software images of a standard or modified keyboard placed on the computer screen by software. The keys are selected by a mouse, touch screen, trackball, joystick, switch, or electronic pointing device.
   Example: Brad, a young boy with limited mobility and severe verbal impairments uses onscreen keyboards to communicate with those around him. Through accessing these keyboards (both pre-formatted keyboards and those designed by his parents to meet his specific needs) and selecting options on the screen he is able to relay concepts, needs and thoughts more easily.

OOH:
   Occupational Outlook Handbook

OPDER:
   Office of Policy, Development, Evaluation and Research - U. S. Department of Labor, Employment & Training Administration

Operation:
   Although there are many meanings to the word "operation," in medicine it refers to a surgical procedure.

Optical Character Recognition (OCR):
   Machine recognition of printed or typed text. Using OCR software with a scanner, a printed page can be scanned and the characters converted into text in an electronic format.

Organ:
   A relatively independent part of the body that carries out one or more special functions. The organs of the human body include the eye, ear, heart, lungs, and liver.

Organization:
   A consumer association or group of people having specific interests in the activities of persons with disabilities. This group may receive funding from both the public and private sectors (example: Cerebral Palsy, Easter Seal Society, etc.).

Orientation:
   Process through which an individual who is visually impaired uses his/her remaining senses to establish his/her position and relationship to all other significant objects in the environment

OSHA:
   Occupational Safety and Health Administration - U. S. Department of Labor

OST:
Occupational Skills Training

Outcomes:
Another term for performance measurement criteria used to evaluate the effectiveness of a job training or placement program. Traditional criteria used to measure employment and training programs include number of job placements and percentage of retained employees after six months or one year.

Output:
Any method of displaying or presenting electronic information to the user through a computer monitor or other device (e.g., speech synthesizer).

OWCP:
Office of Workers' Compensation Programs - U. S. Department of Labor

OWI:
Office of Workforce Investment - U. S. Department of Labor, Employment & Training Administration

Oxygen:
A colorless, odorless and tasteless gas that makes up about 20% of the air we breathe (and at least half the weight of the entire solid crust of the earth) and which combines with most of the other elements to form oxides. Oxygen is essential to human, animal and plant life.

OYS:
Office of Youth Services - U. S. Department of Labor, Employment & Training Administration

PBIF:
Performance Based Incentive Funding

Personal Assistance Services:
A range of services provided by one or more people. These services are designed to assist an individual with a disability to perform activities of daily living on or off the job that the individual would typically do if s/he did not have a disability.

Part-Time Employment:
A person employed less than 35 hours per week.

Pay Period:
Frequency with which worker's wages are calculated and paid; usually weekly, biweekly, semimonthly, or monthly

Payment Dates for Social Security Benefits:
If you filed for Social Security benefits before May 1, 1997, your payments usually are dated and delivered on the 3rd of the month following the month for which the payment is due. For example, payments for January are delivered on February 3rd.
If the 3rd of the month is a Saturday, Sunday or Federal holiday, your payments are dated and delivered on the first day before the 3rd of the month which is not a

Saturday, Sunday or Federal holiday. For example, if the 3rd is a Saturday or Sunday, payments are delivered on the preceding Friday.

If you filed for Social Security benefits May 1, 1997, or later, you are assigned one of three new payment days based on the date of birth of the insured person:

If you were born on the.	**Your payment will be delivered on the.**
1st through 10th of the month	Second Wednesday of the month
11th through 20th of the month	Third Wednesday of the month
21st through end of the month	Fourth Wednesday of the month

If your scheduled Wednesday payment day is a Federal holiday, we'll send your payment on the preceding day that is not a Federal legal holiday.

Payment Dates for Supplemental Security Income (SSI) Payments:
SSI payments are usually dated and delivered on the first day of the month for which they are due. However, if the first falls on a Saturday, Sunday or Federal holiday, they are dated and delivered on the first day preceding the first of the month which is not a Saturday, Sunday or Federal holiday.

Payroll:
Total wages paid by a business to its employees for work performed during the pay period (weekly, monthly, etc.)

Personal Counseling:
Advice, services and activities offered by a trained professional to help individuals overcome barriers to employment stemming from their personal lives. These may include issues such as physical abuse, depression, alcoholism, low self-esteem, procrastination and anxiety.

Performance Standards:
Numerical measures of program outcomes. Under the Job Training Partnership Act (JTPA), for example, programs must achieve six performance standards annually (mostly having to do with post-program wages and labor market retention) in order to receive funding. Performance standards are becoming increasingly common in the social services.

Physical or mental impairment:
Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more, but not necessarily limited to, the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genitourinary; hemic and lymphatic; skin and endocrine; or any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities (Americans with Disabilities Act of 1990).

Physical/Orthopedic Impairment:
A physical disability which limits the consumer's ability to walk or be mobile.

PIA (Primary Insurance Amount):
The monthly amount payable if you are a retired worker who begins receiving benefits at full retirement age or if you're disabled and have never received a retirement benefit reduced for age.

PIC (Private Industry Council):
A workforce development governing and advisory board required by agencies administering funds under the Job Training Partnership Act (JTPA). By law, a majority of PIC members must be from private business. PICs may receive funds, administer programs or entire Service Delivery Areas or simply act in an advisory capacity. In the mid 1990s, many PICs began evolving into Workforce Development Boards (WDBs) with expanded membership and duties but (generally) without the power to operate programs directly

Piece-Work:
Work paid for at a fixed rate (piece-rate) per piece of work done.

Plug-ins:
Programs that work within a browser to alter, enhance, or extend the browser,s operation. They are often used for viewing video, animation or listening to audio files.

PMSA (Primary Metropolitan Statistical Area):
If a metropolitan area (MA) has more than 1 million inhabitants it may be defined as a Primary Metropolitan Statistical Area (PMSA). PMSAs consist of a large urbanized county or cluster of counties that demonstrates very strong internal economic and social links, but are also linked to other portions of the larger area. This larger area is then called a PMSA.

Pointing and Typing Aids:
A pointing or typing aid is typically a wand or stick used to strike keys on the keyboard. They are most commonly worn on the head, held in the mouth, strapped to the chin, or held in the hand.

Example: For Kwame, a young man with severe spinal cord injury and no mobility from his head down, pointing and typing aids allows him to interface with his computer. His aid, a small patch, worn on his forehead allows him to navigate around his computer.

Photo courtesy of Madentec

When he moves his head this device substitutes as a mouse and allows him to perform standard activities such as playing games or taking tests and even more advanced activities like drawing.
Additional Resources: Alliance for Technology Access
http://www.ataccess.org/resources/atabook/s02/s02-03i.html

Portable Document Format (PDF):
The file format for representing documents in a manner that is independent of the original application software, hardware and operating system used to create the documents.

Population:
The total number of inhabitants occupying an area.

Post-Placement Follow Up:
An effort to increase client job retention and productivity by means of regular contact by staff and the provision of supportive services such as transportation and child care.

PRA:
Personal Reemployment Account

Pre-existing Condition:
A medical condition that was present before the consumer applied with the insurance company. Some insurance companies will deny funding of medical costs related to pre-existing conditions.

Preferred Provider Organization (PPO):
A network of individual healthcare providers brought together under one insurance plan. A consumer will be required to select only from this list to be covered under the insurance plan.

Pregnancy:
The state of carrying a developing embryo or fetus within the female body. This condition can be indicated by positive results on an over-the-counter urine test, and confirmed through a blood test, ultrasound, detection of fetal heartbeat, or an X-ray. Pregnancy lasts for about nine months, measured from the date of the woman's last menstrual period (LMP). It is conventionally divided into three trimesters, each roughly three months long.

Pregnant:
The state of carrying a developing fetus within the body.

Primary:
First or foremost in time or development. The primary teeth (the baby teeth) are those that come first. Primary may also refer to symptoms or a disease to which others are secondary.

Prior Approval/Authorization:
A written payment agreement from the funding agency based on their review of materials give to them explaining the consumer's need for a device or service. This process must take place BEFORE the device or service has been purchased.

PRO:
Performance and Results Office - U. S. Department of Labor, Employment & Training Administration

Projections:
An estimate of a future occurrence, event or activity based on historical evidence of past experience. Projections of employment are based on historical employment statistics, cyclical and structural factors, and estimates of economic growth, trends in the U.S, State, and regional characteristics that are likely to affect the region's economy.

Proofs:
See *Evidence*

Proprietary software:
Privately owned software based on trade secrets, privately developed technology, or specifications that the owner refuses to divulge, thus preventing others from duplicating a product or program unless an explicit license is purchased. The opposite of proprietary is open (publicly published and available for emulation by others).

Protective Filing Date:
The date you first contact us about filing for benefits. It may be used to establish an earlier application date than when we receive your signed application.

Prosthetic and Orthotics:
Replacement, substitution or augmentation of missing or malfunctioning body parts with artificial limbs or other orthotic aids. Includes splints, braces, foot orthosis, helmets, restraints, supports, etc.

PRWORA (Personal Responsibility and Work Opportunity Reconciliation Act of 1996):
The name of the new federal welfare reform law that replaced the entitlement to Aid to Families with Dependent Children (AFDC) with a block grant to the states. This block grant covers time-limited, cash assistance, employment and training activities for economically disadvantaged individuals until they can find employment and become self-sufficient.

Psychiatrist:
A physician (an M.D.) who specializes in the prevention, diagnosis, and treatment of mental illness. Psychiatrists must receive additional training and serve a supervised residency in their specialty. They may also have additional training in a psychiatric specialty, such as child psychiatry or neuropsychiatry. They can prescribe medication, which psychologists cannot do.

Psychological/Behavioral Disorder:
Severe conditions that produce intensive, frequent and long-term signs and symptoms diagnosed by a qualified mental health professional that are extremely limiting to one's ability to functionally live independently.

Psychology:
The study of the mind and mental processes, especially in relation to behavior. There are a number of fields of psychology. Clinical psychology is concerned with diagnosing and treating disorders of the brain, emotional disturbances, and behavior problems. Child psychology is the study of the mental and emotional development of children and is part of developmental psychology, the study of changes in behavior that occur through the life span. Cognitive psychology deals with how the human mind receives and interprets impressions and ideas. Social psychology looks at how the actions of others influence the behavior of an individual.

Puberty:
A complex biologic and psychologic process involving sexual development, accelerated growth, and adrenal maturation heralded by the secretion of hormones from a part of the brain called the hypothalamus. This event is the first known step in the reproductive cascade.

Public health:
   The approach to medicine that is concerned with the health of the community as a whole. Public health is community health. It has been said that: "Health care is vital to all of us some of the time, but public health is vital to all of us all of the time."

PY:
   Program Year

QC (Quarter of Coverage):
   Social Security "credits." As you work and pay taxes, you earn credits that count toward eligibility for future Social Security benefits. You can earn a maximum of four credits each year. Most people need 40 credits to qualify for benefits. Younger people need fewer credits to qualify for disability or for their spouse or children to qualify for survivors' benefits. During their working lifetime most workers earn more credits than needed to be eligible for Social Security. These extra credits do not increase eventual Social Security benefits. However, the income earned may increase the benefit amount. See *Credits, Social Security.*

Qualified Individual with a Disability:
   Individual with a disability who satisfies the requisite skill, experience, education and other job-related requirements of an employment position the individual holds or desires, and who, with or without reasonable accommodation, can perform the essential functions of such position.

Quackery:
   Deliberate misrepresentation of the ability of a substance or device for the prevention or treatment of disease. We may think that the day of patent medicines is gone but look around you and you will see them still. They appeal to our desire to believe that every disease is curable or at least treatable. Quackery also applies to persons who pretend to be able to diagnose or heal people but are unqualified and incompetent.

Quartile:
   One of four divisions of observations that have been grouped into four equal-sized sets based on their rank.

Radiation:
   1. Rays of energy. Gamma rays and X-rays are two of the types of energy waves often used in medicine.
   2. The use of energy waves to diagnose or treat disease.

Random Assignment:
   The important process during a control group study (q.v.) by which a group of program applicants is selected randomly (often using a computer) to become members of the "program group" or the "control group."

Range:
   In medicine and statistics, the difference between the lowest and highest numerical values. For example, if five premature infants are born weighing two, three, four, four, and five pounds respectively, the range of their birth weights is two to five pounds.

Rapid Response:
   An early intervention service that assists workers and employers affected by layoffs, plant closures, or natural disasters. It provides access to the Commonwealth's

CareerLink system of user-friendly resources and information to help transition workers into reemployment.

Reader:
Volunteer or employee of a blind or partially sighted individual who reads printed material in person or records to audiotape.

Reading Guides:
A tool often used by students with low vision to assist with reading. Some reading guides have illumination and are placed over text to reduce glare, increase contrast and to highlight the text. Other guides can be fashioned from sturdy card stock or card board that contrast with the paper and text.

Re-Entrants:
Persons who are re-entering the labor force after an absence.

Reasonable Accommodation:
1. Modification or adjustment to a job application process that enables a qualified applicant with a disability to be considered for the position;
2. modifications or adjustments to the work environment, or to the manner or circumstances under which a position held or desired is customarily performed, that enable qualified individuals with disabilities to perform the essential functions of that position; or
3. modifications or adjustments that enable an employee with a disability to enjoy the same benefits and privileges of employment as similarly situated employees without disabilities

Receptor:
1. In cell biology, a structure on the surface of a cell (or inside a cell) that selectively receives and binds a specific substance. There are many receptors. There is a receptor for (insulin; there is a receptor for low-density lipoproteins (LDL); etc. To take an example, the receptor for substance P, a molecule that acts as a messenger for the sensation of pain , is a unique harbor on the cell surface where substance P docks. Without this receptor, substance P cannot dock and cannot deliver its message of pain. Variant forms of nuclear hormone receptors mediate processes such as cholesterol metabolism and fatty acid production. Some hormone receptors are implicated in diseases such as diabetes and certain types of cancer. A receptor called PXR appears to jump-start the body's response to unfamiliar chemicals and may be involved in drug-drug interactions.
2. In neurology, a terminal of a sensory nerve that receives and responds to stimuli.

Reconciliation:
Comparing different data sources to establish accuracy.

Record of Earnings:
See *Earnings Record.*

Recruitment:
An organized effort to attract eligible and suitable people for participation in a workforce development program. Also called "Client Recruitment."

Reduction Months:
Months beginning with the first month you're entitled to reduced benefits up to, but not including, the month in which you reach full retirement age

Rehabilitation:
The process of restoration of skills by a person who has had an illness or injury so as to regain maximum self-sufficiency and function in a normal or as near normal manner as possible. For example, rehabilitation after a stroke may help the patient walk again and speak clearly again.

Rehabilitation Act of 1973:
Federal legislation that set up grant programs for vocational rehabilitation, supported employment, independent living and client assistance. The Rehabilitative Services Administration in the Department of Education oversees programs created by the Act.

Rehabilitation Engineering:
A service that uses technology to assist persons who have difficulty doing things independently. Rehabilitation engineers work as team members and may make custom-made devices, adapt existing devices, or make changes in work site, homes or other environments to increase access and independence for people with disabilities.

Rehabilitation Technology:
The use of technologies, engineering methods, or scientific principles by individuals with disabilities. The term includes rehabilitation engineering, assistive technology devices, and assistive technology services.

Related Services:
Transportation and such corrective developmental and other helping services as required to assist a handicapped child to benefit from special education.

Relay service:
A third-party service (usually free) that allows a hearing person without a TTY/TDD device to communicate over the telephone with a person who has a hearing impairment. The system also allows a person with a hearing impairment who has a TTY/TDD to communicate in voice through a third party, with a hearing person or business.

Remedy:
Something that consistently helps treat or cure a disease. From the Latin *remedium*, meaning that which heals again (and again).

Replacement:
Openings resulting from people leaving an occupation.

Representation:
Having another present or position; can take place within a variety of context including appeals, litigation, and alternative dispute resolution.

Representative Payee:
If you receive Social Security benefits or Supplemental Security Income and become unable to handle your own financial affairs, after a careful investigation, we appoint a relative, a friend, or an interested party to handle your Social Security matters. Representative payees are required to maintain complete accounting records and periodically provide reports to Social Security..

Retention:
Keeping clients involved in a program or employed with an agency over an appropriate period of time.

Retirement Age – Early:
Age 62. *See Retirement Age – Minimum*.

Retirement Age - Full Benefits:
Full retirement age was 65 for many years. However, beginning with the year 2000 (for workers and spouses born 1938 or later, or widow and widowers born 1940 or later), the retirement age increases gradually from age 65 until it reaches age 67 in the year 2022.

Retirement Age – Minimum:
The minimum age for retirement-age 62 for workers, and age 60 for widows or widowers. You can choose a reduced benefit anytime before you reach full retirement age.

Retirement Earnings Test:
If you get Social Security benefits, are under full retirement age, and work, your earnings from wages and/or self-employment that exceed a certain maximum will cause a deduction in your monthly benefits.

Retroactive Benefits (Back Pay):
"Back Pay." Monthly benefits that you may be entitled to before the month you actually file an application, if you meet the entitlement requirements.

Reverse Referral:
A common (but sometimes illegal) practice of workforce development agencies by which they encourage employers to refer job applicants to the agency to see if they are eligible for on-the-job training reimbursements or other hiring incentives. Critics say reverse referrals are just another form of "creaming."

RFB:
Request for Bid

RFP:
Request for Proposal

RFQ:
Request for Quotation

RIB (Retirement Insurance Benefit):
Money that's payable to you at full retirement age (you can get reduced benefits as early as age 62) if you have enough Social Security credits.

RRTC (Rehabilitation Research and Training Centers):
Centers nationwide that conduct research and offer training in improving rehabilitation methods and delivery systems, alleviating or stabilizing disabling conditions, or promoting maximum independence for people with disabilities.

RSA:
Resource Sharing Agreement

Rule out:
A term much used in medicine, meaning to eliminate or exclude something from consideration. The ACB (albumin cobalt binding) test helps rule out a heart attack in the differential diagnosis of severe chest pain.

Salary:
Fixed compensation paid for labor or services. Most salaries are paid for a fixed periods of working hours.

Sample:
A finite part of a statistical population whose properties are studied to gain information about the whole.

Screen Braille Communicator:
A small portable face to face communication device that enables deafblind people to communicate with people who are sighted. The communication works in both directions. The person who can see is able to type short text using a Qwerty keyboard and the deafblind person can read this text using the 8 cell Braille display via Braille keys. Information typed by the deafblind person can be read by the sighted person using a small LCD display.

Screen Enlargement Programs:
Screen enlargement programs magnify a portion of the screen, increasing the visibility for some users with limited vision. Most have variable magnification levels. Some screen enlargement programs offer text-to-speech.

Screen Reader:
A screen reader is a software program that uses synthesized speech to "speak" graphics and text out loud. This type of program is used by people with limited vision or blindness.
Example: Teri has been blind from birth. A screen reader allows her to access visual information on a computer screen. A piece of software installed in her computer goes "behind the scenes" and reads to her the text that exists behind, for example, the graphic webpages that sighted people read.

SCSEP:
Senior Community Service Employment Program - U. S. Department of Labor, Employment & Training Administration

SDA (Service Delivery Area):
A geographical area with a population of at least 275,000 people that is designated to receive funds and administer programs under the Job Training Partnership Act (JTPA). Typically, SDAs are administered by county or state government, cities or JTPA-mandated Private Industry Councils (PICs).

SEA:
Self-Employment Assistance Program

Seasonal Adjustment:
A process whereby normal seasonal changes are removed or discounted. In doing so, the underlying trends are easier to identify.

Seasonal Factors:
Seasonal factors are events that cause normal fluctuations in business activity within individual or combinations of industries. Seasonal factors include, but are not limited to, such events as: weather conditions, holidays, and school schedules.

Seasonal Unemployment:
A condition resulting from jobs being available for only a portion of the year. For example, migrant workers who follow the harvest of various crops, but have little chance of working when that crop is completed, are seasonally unemployed.

Seasonally Adjusted:
Seasonal changes have been removed or discounted.

Section 508:
Section of the amended Rehabilitation Act requiring all federal agencies to make their electronic and information technologies available to people with disabilities.

Self-Directed Job Search:
The process by which job training clients seek work on their own, without the direct intervention of staff. Clients are often, although not always, trained beforehand in such skills as interviewing and resume-writing.

Self-Employed:
Persons who work for profit or fees in their own business, profession or trade, or who operate a farm.

Sense:
In biology and medicine, the faculty of sensory reception. The ability to convey specific types of external or internal stimuli to the brain and perceive them. Sensory reception occurs through a process known as transduction in which stimuli are converted into nerve impulses which are relayed to the brain.

Sensory:
Relating to sensation, to the perception of a stimulus and the voyage made by incoming (afferent) nerve impulses from the sense organs to the nerve centers.

Separating Employer:
The worker's most recent employer prior to his filing a claim for benefits. The separating employer may or may not be a base period employer

Separations:
Job opening created due to workers permanently leaving one occupation to take a job in a different occupation, stay home, attend school, move out of the area, retire or die. This term is not the same as turnover.

Service Provider:
The person whose job and responsibility is to provide a valued service that is appropriate to and in the best interest of the person with a disability, their family members, and/or advocates. The service provider should be knowledgeable about his/her specialty area and an advocate for the rights of people with disabilities. This includes, but is not limited to; physical therapist, speech/language pathologist, occupational therapist, etc.

Seating and Positioning Aids:
Modifications to wheelchairs or other seating systems that provide greater body stability, upright posture or reduction of pressure on the skin surface. Equipment includes wheelchair cushions, trunk/head supports, modular seating, and seating lifts.

SEI (Self-employment/Self-employment Income):
You are self-employed if you operate a trade, business or profession, either individually or as a partner, and have net earnings of $400 or more in a taxable year.

Sensorimotor:
Related to functioning in both sensory and movement aspects of bodily activity.

Sensory Integration:
Organization of sensory information to enable the child to act on and interact with the environment.

Sensory Stimulation:
Rousing or invigoration of the senses - vision, audition, tactile, olfactory, gustatory, or kinesthetic.

SGA:
Solicitations for Grant Applications

Shaken Baby Syndrome:
Syndrome that results from shaking an infant.

Short Term Unemployment:
Persons who have been jobless for fewer than five weeks.

Shortage of Workers:
There are too few applicants with the required experience and abilities to fill openings within a reasonable amount of time.

Sibling:
A brother or sister.

SIC (Standard Industrial Classification):
The Standard Industrial Classification system is a hierarchical classification system that defines all establishments to a specific industry based on their primary output or product. The SIC is scheduled to be replaced by the North American Industrial Classification System (NAICS).

Sign language:
Manual communication commonly used by people who are deaf. Sign language is not universal; deaf people from different countries speak different sign languages. The gestures or symbols in sign language are organized in a linguistic way. Each individual gesture is called a sign. Each sign has three distinct parts: the hand shape, the position of the hands, and the movement of the hands. American Sign Language (ASL) is the most commonly used sign language in the United States.

Situational Barriers:
Barriers to employment caused by "situations" in an individual's personal life. These include such things as an ill child, an alcoholic spouse, homelessness, substance abuse or mental or emotional problems.

Skin:
The skin is the body's outer covering. It protects us against heat and light, injury, and infection. It regulates body temperature and stores water, fat, and vitamin D. Weighing about 6 pounds, the skin is the body's largest organ. It is made up of two main layers; the outer epidermis and the inner dermis.

Skull:
The skull is a collection of bones which encase the brain and give form to the head and face. The bones of the skull include the following: the frontal, parietal, occipital, temporal, sphenoid, ethmoid, zygomatic, maxilla, nasal, vomer, palatine, inferior concha, and mandible.

Smell:
A sense that can give information from a distance.

SOC (Standard Occupational Classification):
A numerical coding system that classifies occupational data for the purpose of collecting, calculating, or disseminating data. All workers are classified into one of over 820 occupations according to their occupational definition. To facilitate classification, occupations are combined to form 23 major groups, 96 minor groups, and 449 broad occupations. Each broad occupation includes detailed occupation(s) requiring similar skills, education, or experience.

Social Security:
Social Security is based on a simple concept: While you work, you pay taxes into the Social Security system, and when you retire or become disabled; you, your spouse and your dependent children receive monthly benefits that are based on your reported earnings. Also, your survivors can collect benefits if you die.

Social Security Number (Social Security Card):
Your first and continuous link with Social Security is your nine-digit Social Security Number (SSN). Your SSN helps us to maintain an accurate record of your wages or self-employment earnings that are covered under the Social Security Act, and to monitor your record once you start getting Social Security benefits.

Social Security Office:
Your local Social Security office is the place where you can:
- Apply for a Social Security number
- Check on your earnings record
- Apply for Social Security benefits, black lung benefits, Supplemental Security Income (SSI), and hospital insurance (Medicare) protection
- Enroll for medical insurance
- Get help applying for food stamps and
- Learn everything you need to know about your rights and obligations under the Social Security law

Specialized Program:
A program using assistive technology or technology related services in service delivery to people with disabilities.

Specific learning disability (SLD):
A disorder of one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in difficulties listening, thinking, speaking, reading, writing, spelling, or doing mathematical calculations. Limitations may include hyperactivity, distractibility, emotional instability, visual and/or auditory perception difficulties and/or motor limitations, depending on the type(s) of learning disability.

Speech/Communication Impairment:
Speech, language, or writing impaired persons who use devices, systems, or electronic aids which provide augmentative communication.

Speech impairment:
A problem in communication and related areas, such as oral motor function, ranging from simple sound substitutions to the inability to understand or use language or use the oral-motor mechanism for functional speech and feeding. Some causes of speech and language disorders include hearing loss; neurological disorders; brain injury; mental retardation; drug abuse; physical impairments, such as cleft lip or palate; and vocal abuse or misuse.

Speech input system:
A computer-based system that allows the operator to control the system using his/her voice.

Speech output system:
A system that provides the user with a voice alternative to the text presented on the computer screen.

Speech therapist:
An older term for a speech-language pathologist.

Speech therapy:
The treatment of speech and communication disorders. The approach used depends on the disorder. It may include physical exercises to strengthen the muscles used in speech (oral-motor work), speech drills to improve clarity, or sound production practice to improve articulation.

SPOC:
Single Point of Contact

Spouse:
You are the spouse of the worker if, when he or she applied for benefits:
- You and the worker were validly married or
- You would have the status of a husband or a wife for that person's personal property if they had no will or
- You went through a marriage ceremony in good faith, which would have been valid except for a legal impediment.

SS-5:
The application form you need to get a Social Security number, a replacement card, or a duplicate card.

SSI:
Supplemental Security Income

SSN:
Social Security number. See *Social Security Number (Social Security Card).*

Staffing Pattern:
Each business employs workers with different types of skills to produce a good or provide a service. A staffing pattern summarizes this array of workers for an industry. The costs of labor and equipment in a local area will largely determine the mix of workers that a business will employ to remain competitive. Industry staffing patterns are often used to determine the ability of a local area to support economic development by being able to provide a skilled workforce

Static Labor Market:
Unchanging labor market conditions resulting from the development of few openings coupled with a correspondingly low number of applicants.

Sticky keys:
Enables a computer user to do multiple key combinations on a keyboard using only one finger at a time. The sticky keys function is usually used with the Ctrl, Alt, and Shift keys. Simultaneous keystrokes can be entered sequentially.

Stress:
Forces from the outside world impinging on the individual. Stress is a normal part of life that can help us learn and grow. Conversely, stress can cause us significant problems.

Stroke:
Abnormal condition of the blood vessels of the brain characterized by a blockage from an embolus or cerebrovascular hemorrhage. Depending upon where the brain is affected and the extent of the decreased blood supply to the brain, paralysis, and weakness.

Structural Unemployment:
This type of unemployment occurs when the basic nature of the economy changes over time; when employers no longer demand skills that unemployed workers possess. Structural unemployment is involuntary unemployment and typically requires retraining or education of displaced workers to bring their skills in line with demand.

STW:
School-to-Work (Opportunities Act of 1994)

Substance:
1. Material with particular features, as a pressor substance.
2. The material that makes up an organ or structure. Also known in medicine as the *substantia*.
3. A psychoactive drug as, for example, in substance abuse.

Subsidized Employment:
Subsidized jobs or subsidized employment include paid work experience (including summer jobs for youth), internships, externships, and community service employment. States may use federal TANF and state funds for community service employment, i.e., publicly funded, wage-paying jobs designed to provide employment for individuals and to address unmet community needs.

Substance abuse:
The excessive use of a substance, especially alcohol or a drug. (There is no universally accepted definition of substance abuse.)

Supplemental Security Income (SSI):
A Federal supplemental income program funded by general tax revenues (not Social Security taxes). It helps aged, blind, and disabled people, who have little or no income by providing monthly cash payments to meet basic needs for food, clothing, and shelter.

Supply/Demand:
In labor market information this term usually refers to the supply of workers in relationship to the demand for workers.

Supported Employment:
Supports that help people with severe disabilities (e.g., psychiatric, mental retardation, significant learning disabilities, traumatic brain injury) find competitive work in an integrated setting where they might not otherwise be able to do so. The supports can include job coaches, transportation, assistive technology, specialized job training and individually tailored supervision.

Supportive Services:
Assistance provided by an agency other than academic or occupational skills training to help clients overcome barriers of employment. Common examples include providing bus tokens to reduce transportation costs or vouchers to cover child care expenses.

Surplus of Workers:
More applicants ready and willing to work than there are job openings.

Survey:
A study of all or a portion of the whole, conducted for purposes of making generalized statements about the whole.

Survey Week:
The week including the 12th of the month.

Survivor (Survivor Benefits):
Benefits based on your record (if you should die) are paid to:
· Your widow/widower age 60 or older, 50 or older if disabled, or any age if caring for a child under age 16 or who became disabled before age 22
· Your children, if they are unmarried and under age 18, under 19 but still in school, or 18 or older but disabled before age 22
· Your parents if you provided at least one-half of their support.
· A special one-time lump sum payment of $255 may be made to your spouse or minor children. An ex-spouse could also be eligible for a widow/widower's benefit on your record.

Switches and Switch Software:
Switches offer ways to provide input to a computer when a more direct access method, such as a standard keyboard or mouse, is not possible. Switches come in various sizes, shapes, colors, methods of activation, and placement options. An interface device and software are usually required to connect the switch to the computer and interpret the operation of the switch.

Some software programs have been developed specifically for use with a switch and can employ on-screen scanning. With on-screen scanning, the computer highlights (either by sound, visual cue, or both) options available to a user about what action he or she wants the computer to take. Using these specialized products, when a visual or auditory prompt indicates a desired keyboard or mouse function, the user activates the switch and the desired function occurs. Other programs have built-in options to allow switch use. Many standard software programs can be accessed through a switch with the use of additional software and devices.

Systems Change:
An adjustment to any policy, practice, or procedure that increases access to services, including assistive technology. These adjustments affect many people and have a permanent and lasting result.

TA:
Technical Assistance

TAA:
Trade Adjustment Assistance

TAG:
Technical Assistance Guide

Talking Word Processors:
Talking word processors (TWP) are writing software programs that provide speech feedback as the student writes, echoing each letter as it is typed and each word as the spacebar is pressed. Many of these inexpensive programs, typically used to assist with writing, also incorporate powerful tools for reading. Students with learning disabilities find that having written material read aloud assists them to better edit, comprehend and organize. Once any file (story from a book, assignment, article, typed information, etc.) is imported into a talking word processor, the text can be read aloud to the student. These TWP programs offer other adjustments such as enlarging the size of the text and changing the color of the foreground, background and highlighting box to assist students in following along as the text is read.

TANF (Temporary Assistance for Needy Families):
Refers to the new federal block grant program of time-limited cash assistance, training and job placement to welfare recipients.

Taste:
A sense. Distinguishes the sweet, sour, bitter, or salty quality of a dissolved substance.

Taxable Payroll:
All Taxable wages paid by an employer to all employees during a calendar year.

Technology User:
The person who uses the assistive technology device. Another word that is often used is consumer.

TEGL:
Training and Employment Guidance Letter

TEIN:
Training and Employment Information Notice

TeleBraille:
Telecommunication device for the deafblind which was also used for face to face communication. Unit consisted of TTY stacked on top of Braille display when used as a telecommunication device. When used as a face to face communication device, the unit is detached with Braille display used by deafblind consumers to receive and send messages and TTY device used by sighted individuals to receive and send messages.

Telecommunications Device for the Deaf (TDD) or Teletypewriter (TTY):
A device which enables someone who has a speech or hearing impairment to use a telephone when communicating with someone else who has a TDD/TTY. TDD/TTYs can be used with any telephone, and one needs only a basic typing ability to use them.

Temporary Workers:
Those workers who have no long-term attachment to an employer. They may work for several days, or several months, and often work for temporary help agencies.

TEN:
Training and Employment Notice.

Tension:
1. The pressure within a vessel, such as blood pressure: the pressure within the blood vessels. For example, elevated blood pressure is referred to as hypertension.
2. Stress, especially stress that is translated into clenched scalp muscles and bottled-up emotions or anxiety. This is the type of tension blamed for tension headaches.

Therapy:
The treatment of disease.

Throat:
The throat is the anterior (front) portion of the neck beginning at the back of the mouth, consisting anatomically of the pharynx and larynx. The throat contains the trachea and a portion of the esophagus.

Ticket-to-Work:
Social Security Administration (SSA) program designed to help individuals with disabilities who are receiving SSA benefits find and maintain employment.

Time Series:
A variable in which the values are successive observations over time. A key characteristic of a time series is that any 2 points in a time series can be compared.

TIN:
Tax Identification Number. An Employer Identification Number (EIN) is also known as a federal tax identification number, and is used to identify a business entity. Generally, businesses need an EIN

Title V of the Rehabilitation Act of 1973:
Title prohibiting discrimination on the basis of a disability by the federal government, federal contractors, recipients of federal financial assistance, and in federally conducted programs and activities.

Tobacco:
A South American herb, formally known as *Nicotiana tabacum*, whose leaves contain 2-8% nicotine and serve as the source of smoking and smokeless tobacco.

Toddler:
A young child who is learning to walk with short unsteady steps. The word toddle is of unknown origin.

Touch Screens:
A touch screen is a device placed on the computer monitor (or built into it) that allows direct selection or activation of the computer by a touch of the screen.

Trackball:
A pointing device consisting of a ball housed in a socket containing sensors to detect the rotation of the ball " like an upside down mouse. The user rolls the ball with his thumb or the palm of his hand to move the pointer.

Trainee:
An individual hired for a job, which may or may not require previous experience or education. A trainee could start in an entry-level, apprenticeship level, or internship level position.

Training:
A process whereby the individual with a disability, family members, or other personnel are taught how to use a piece of assistive technology, product, or service.

Transition Services:
A coordinated set of activities for a student, designed within an outcome-oriented process, that promotes movement from school to post school activities. These activities can include education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.

Transitional Employment:
Job seekers with few skills or little workplace experience, but with multiple barriers to employment are often placed in subsidized employment that allows them to gain life skills and confidence, combined with education and vocational skills training. This type of temporary employment environment can increase self-esteem and can often motivate individuals to achieve permanent employment and self-sufficiency.

Traumatic Brain Injury (TBI):
An open or closed head injury resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

Trend:
The persistent underlying movement that takes place over a period of time. It is the basic growth or decline that would occur if no variations in activity existed.

TTD or TTY :
A Telecommunication Device for the Deaf (TTY or TDD) is a device with a keyboard that sends and receives typed messages over a telephone line.

Photo courtesy of Ameriphone

TQM (Total Quality Management):
A process devised by the late W. Edwards Deming to improve the quality of goods and services. TQM focuses on "delighting the customer" by means of the statistical measurement and enhancement of the factors ("inputs") that determine the final quality of a good or service. TQM has been widely adopted in industry and is penetrating the social services as well.

TRS (Telecommunications Relay Services):
Service available in all states and territories that enables voice telephone users to talk to people who have deafness or hardness of hearing via trained Communications Assistants who relay the message in real time.

Turnover:
The rate of replacement of employees.

TWA:
The Workforce Alliance is a national coalition of community-based organizations, community colleges, unions, business leaders and local officials advocating for public policies that invest in the skills of America's workers, so they can better support their families and help American businesses better compete in today's economy.

UI (Unemployment Insurance) Program:
A national program administered by the U.S. Department of Labor under the Social Security Act. Provides temporary weekly payments to workers who lose their jobs through no fault of their own. The payments are financed by contributions from employers on the wages of their covered workers. Eligibility for benefits requires that the claimant be able to work, be seeking work and be willing to accept a suitable job.

UIPL:
Unemployment Insurance Program Letter

Umbilical cord:
The cord that connects the developing embryo or fetus with the placenta and through which run the umbilical arteries and vein.

Under-Employment/Employed:
A condition which exists when the full potential of labor is not being utilized. Measures of under-employment are not readily available.

Undue hardship:
An action that requires significant difficulty or expense in relation to the size of the employer, the resources available, and the nature of the operation (Americans with Disabilities Act of 1990).

Unemployed:
Persons, aged 16 years or older, who are not working but are able to work, available for work, and seeking either full-time or part-time work.

Unemployment:
Comprises all civilians 16 years and over who did not work during the survey week, who made specific efforts to find a job within the past four weeks, and who were available for work (except for temporary illness) during the survey week. Also included as unemployed are those who did not work at all, but were available for work, and (a) were waiting to be recalled to a job from which they had been laid off for a specific time; or (b) had a new job to go to within thirty days.

Unemployment Rate:
The unemployment rate is derived by dividing the number of unemployed by the labor force. The result is expressed as a percentage.

Universal Design:
Universal design is the design of products and environments to be usable by a wide range of people. Examples of universally designed environments include buildings with ramps, curb cuts, and automatic doors.

USCM:
U. S. Conference of Mayors

USES:
U. S. Employment Service - U. S. Department of Labor, Employment & Training Administration

VersaBraille:
Portable Braille notetaking equipment that contained a text processing system with Braille input and refreshable Braille output in a twenty-character long line. The VersaBraille could be connected to either a Braille or dot matrix printer to produce hardcopy of documents in print or Braille. A terminal program facilitated communication with other computer systems.

VETS:
Veterans' Employment and Training Service - U. S. Department of Labor

Video Magnifier:
Small camera and monitor unit that projects print or images onto the screen of the monitor for enhanced viewing. The image can be manipulated by using the tray upon which documents are placed for viewing. The image is captured by the camera and projected onto the monitor. The student can change the size, contrast and brightness of the image to suit their individual needs.   Video Magnifiers

were formerly called CCTVs (Closed Circuit Televisions) and were widely used by students in classrooms. Today, there are number of Video Magnifiers on the market that can be used in the classroom (desktop models) or can be carried in a pocket or small bag (portable Video Magnifiers).

Vision impairments:
A complete or partial loss of the ability to see, caused by a variety of injuries or diseases including congenital causes. Legal blindness is defined as visual acuity of 20/200 or less in the better eye with correcting lenses, on the widest diameter of the visual field subtending an angular distance no greater than 20 degrees.

Vision and Hearing Loss Simulation Kit:
Portable kit containing several different types of goggles used to simulate various degrees of vision loss. The kit is often used with professionals, peers and family members to increase sensitivity and awareness related to the needs of a student who is deafblind. The kit includes, vision simulation goggles, ear plugs, photos and instructional booklet.

Visual Impairment/Blindness:
Blind and visually impaired individuals who require sensory aids or devices to improve functioning.

Vocational Counseling:
Assistance provided by a trained professional to help clients select appropriate careers and training. May include vocational assessment and testing, visits to schools and to job sites. Also called "Career Counseling."

Vocational Rehabilitation:
Programs designed to help individuals with disabilities enter or reenter gainful employment.

Vocational Rehabilitation Act of 1973:
An act prohibiting discrimination on the basis of disability which applies to any program that receives federal financial assistance. Section 504 of the act is aimed at making educational programs and facilities accessible to all people with disabilities. Section 508 of the act requires that electronic office equipment purchased through federal procurement meets disability access guidelines.

Voice input system:
A computer-based system that allows the operator to control the system using his/her voice.

Voice Recognition:
Different types of voice recognition systems (also called speech recognition) are available. Voice recognition allows the user to speak to the computer instead of using a keyboard or mouse to input data or control computer functions. Voice recognition systems can be used to create text documents such as letters or email, to browse the Internet, and to navigate among applications and menus by voice.

Wage and Salary Employment:
Full-time and part-time workers (including employees on paid vacation or paid sick leave) who work or receive compensation from establishments for any part of the pay period including the 12th of the month. Those workers involved in labor-management disputes are excluded. This is a count of the number of jobs, and is available by industry.

Wage Earner:
A person who earns Social Security credits while working for wages or self-employment income. Sometimes referred to as the "Number Holder" or "Worker."

Wages:
All payment for services performed for an employer. Wages do not have to be cash. The cash value of all compensation paid to an employee in any form other than cash is also considered wages (unless the form of payment is specifically not covered under the Social Security Act).

WARN:
Worker Adjustment and Retraining Notification Act

WB:
Women's Bureau - U. S. Department of Labor

WDA:
Workforce Development Areas (WDA's) are geographic areas defined by the Workforce Development Council for implementation of the Workforce Investment Act.

WDB:
Workforce Development Board

Web Accessibility
Universal accessibility to the Web means that all people, regardless of their physical or developmental abilities or impairments, have access to Web-based information and services. Making Web pages accessible is accomplished by designing Web pages that allow the effective use of adaptive technologies to access their content. See also *Screen Reader.*

WEN:
Workforce Excellence Network - National Association of Workforce Boards

WFD:
Workforce Development

WIA (Workforce Investment Act) Of 1998:
This is the first major reform of the nation's job training system in more than 15 years. Key components include: streamlining services through a "one-stop" service delivery center; empowering individuals by providing information and access to training resources though Individual Training Accounts (ITAs); providing universal access to core services; increasing accountability for outcomes; ensuring a strong role for local boards and the private sector in the workforce investment system; and improving youth programs.

WIB:
Workforce Investment Board

Widow:
You are the widow/widower of the insured person if, at the time the insured person died:
- · You and the insured person were validly married or
- · You would have the status of a husband or a wife for that person's personal property if they had no will or
- · You went through a marriage ceremony in good faith that would have been valid except for a legal impediment.

The minimum age for
- · Disabled widows benefits is age 50.
- · Retirement for widows is age 60.

Widower:
See *Widow.*

WIN:
Welfare Information Network

Word Prediction Programs:
Word prediction programs enable the user to select a desired word from an on-screen list located in the prediction window. This list, generated by the computer, predicts words from the first one or two letters typed by the user. The word may then be selected from the list and inserted into the text by typing a number, clicking the mouse, or scanning with a switch.

Photo courtesy of NanoPac

Example: Word prediction programs speed up the time it takes, Johanna, a young woman with quadriplegia, to communicate her needs to her personal assistant (PA). Instead of typing out full words, a drop down list of common words beginning with the initial letters entered appears and an entire word can be simply clicked in lieu of typed out in full. Word prediction programs also help Chad, a 6th grader with learning disabilities, in writing papers for school. Often he can only recall parts of a word or can spell a word phonetically but can not correctly spell the word. Word prediction programs allow him to type in a few letters or type in a word's phonetic spelling and then present him with correctly spelled alternatives.
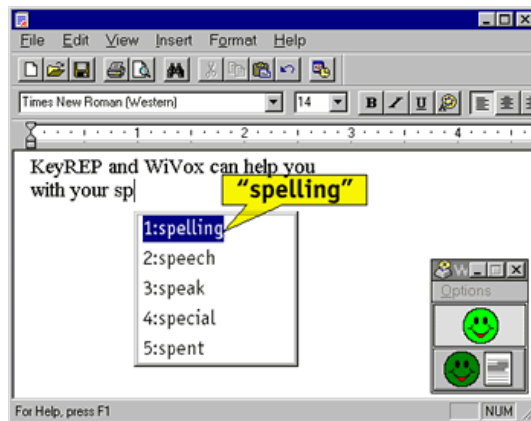
"Work First":
This term refers to the philosophy and operating concept of the new federal welfare reform initiative and also to the restrictions on the use of welfare-to-work funds. These funds can only be used for activities that directly promote, encourage and place welfare recipients into jobs (as opposed to classroom training). The concept is based on the ideas that the best way for individuals to succeed in the labor market is to join it first. New workers develop strong work habits, marketable skills and essential workplace experience on the job, not in the classroom.

Work Credits:
See *Credits or Quarters of Coverage*.

Work-Readiness Training:
Training provided to help clients get and keep jobs. "Job-getting" skills include such things as interviewing, grooming and resume-writing. "Job-keeping" skills include attendance, punctuality, getting along with others and resolving conflicts.

Worker:
See *Wage Earner*.

Workforce Development:
A general term to describe various efforts to improve the academic and occupational skills of all citizens. This term became popular in the mid-1990s, eclipsing "employment and training programs," which usually refers only to government programs benefiting laid-off workers and the poor. Workforce development efforts are still often referred to generically as "Job Training" or "Jobs" programs.

Workforce Preparation:
All job training and employment programs. This term is used interchangeably with workforce development. Working Age Population: All individuals 16 years or older in the United States. The lower limit of 16 years reflects the age at which most students can leave school voluntarily in most states. There is no upper age limit.

World Wide Web (WWW, W3, or Web):
Hypertext and multimedia gateway to the Internet.

WOTC:
Work Opportunity Tax Credit

WRIS:
Wage Record Interchange System

WTP:
Welfare Transition Program

WTT:
Workforce Tools of the Trade

WTW:
Welfare to Work

Youth:
The time between childhood and maturity. (Unfortunately, as the songwriter Sammy Cahn noted, "youth is wasted on the young.")

Resources

The Family Center on Technology and Disability (FCTD) Assistive Technology Glossary
http://www.fctd.info/resources/glossary.php

Social Security Disability Glossary of Terms
http://www.socialsecurityhome.com/glossary.htm

Assistive Technology Definitions: Glossary of Terms –Tools for Life
http://www.gatfl.org/ldguide/terms2.htm

MedicineNet.com Learning Disability Glossary of Terms
http://www.medicinenet.com/learning_disability/glossary.htm

Sparkle Deafblindness Glossary http://www.sparkle.usu.edu/glossary/index.asp?cat=db

Pittsburgh Partnership Glossary of Workforce Development Terms and Acronyms
http://www.pittsburghpartnership.org/documents/Workforce%20Development%20Glossary.
doc

The Alliance for Access to Science, Technology, Engineering, and Mathematics (AccessSTEM)
Glossary http://www.washington.edu/doit/Stem/glossary.html

Helen Keller Services for the Blind, Common Eye Problems Glossary
http://www.helenkeller.org/graphicversion/eyeproblems.html