

DIVERSE POPULATIONS

Teaching Your Colleagues and Community About Adults Who Are Deaf and Low Functioning*

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Abstract

Individuals who are deaf and low functioning frequently receive inadequate attention and service delivery. This is particularly true in education, rehabilitation, and independent living settings. Typically, professionals lack knowledge, resources, and experience with this population. To begin to address these problems, this paper identifies current needs and barriers to service delivery and then provides strategies for successfully working with these individuals, family members, and the broader community. Three levels for potential change are highlighted. The first level includes individual professionals and related service providers who have little deafness background. The second level includes programs and agencies designed to serve individuals who have disabilities. The third level focuses on advocacy for systems change.

** The authors would like to note that terminology used to describe these individuals (i.e., “low functioning”) is unnecessarily negative. We use it, however, in deference to state and federal trends.*



Barriers to Appropriate Service Delivery

Individuals who are deaf and low functioning face a myriad of obstacles in their quest for appropriate service delivery. According to Long and Clark (1993), these individuals are characterized as having limited language and communication skills. These language deficits impact multiple area of life including social and interpersonal skills, decision-making, independence, and employment. The 25th Institute on Rehabilitation Issues (Dew, 1999) described the communication characteristic of persons who are deaf and low functioning as follows:

Presenting poor skills in interpersonal and social communication interactions, many of these individuals experience difficulty expressing themselves and understanding others, whether through sign language, speech and speech reading, or reading and writing (p. 2).

Frequently, supports and necessary accommodations are not available. Barriers to service delivery increase when children leave school and enter the world of adulthood. The “helping system” is complex, fragmented, and based on eligibility, rather than entitlement. There is typically no case manager or other professional to help the family navigate this system. In addition, many families

hesitate to seek employment services for their child, as they do not want to risk their child's Medicaid coverage or Social Security income if the child becomes employed.

Professionals face multiple barriers to providing appropriate services to individuals who are deaf and low functioning. For example, there are few training opportunities to learn about this population. Most graduate training programs in psychology, social work, counseling, and education do not mention the unique needs of these individuals. In addition, there is limited literature about this population. Research into "best practices" to use when working with these individuals is particularly absent. Overall, there is dearth of literature on assessment, intervention, and teaching strategies known to be effective with these individuals.

Finally, the needs of this population are not on the national radar in terms of special populations or funding priorities. Since the 1960s, there has been a sporadic pattern of federal funding, resulting in a history of fragmented and disjointed services, or no services at all. As of July 2008, no federal dollars were specifically directed toward this population. The only source of federally sponsored support for these individuals is Social Security Subsistence funding, such as SSI/SSDI.

Strategies for Service Delivery—Basic Information for Generalists

Training and Education DVD: Collaboration between Region 4 Education Service Center in Texas and PEPNet-West resulted in the creation of a DVD entitled *Unrealized Dreams...Stories of Deaf Individuals With Unique Needs*. This DVD addresses a number of issues related to services and program needs. A companion booklet provides a wealth of information and resources pertaining to communication, assessment, existing programs, internet resources, and more.

The DVD includes three versions of the story (8-, 18-, and 30-minutes long) and may be used in multiple ways. The short version provides a quick synopsis of the population, their needs, and suggested actions to address these needs. This version is helpful when meeting people who may be potential donors or others with a limited amount of time. It provides a concise summary of these individuals, the barriers they face, and related service delivery issues. The two other versions of the DVD provide more in-depth information. The longer versions can also be combined with ideas, topics, and discussion points included in the accompanying training booklet. It would seem particularly helpful to use this approach with professionals who do not have experience or knowledge regarding this population. Overall, the intent of the developers was to provide a product that is versatile in its use.

To obtain a copy of the DVD, contact PEPNet at www.pepnet.org or Region 4 Education Service Center at www.esc4.net.

Strategies for Service Delivery—Programs and Agencies

As noted earlier, providing appropriate and effective services to this population is a complex task. A coordinated and collaborative approach to service delivery is the best strategy. The authors identified three programs that currently provide excellent service delivery with individuals who are deaf and low functioning: Lexington Vocational Services Center, Jackson Heights; Community Outreach Program for the Deaf, Tucson, Arizona; and the Kentucky Office of Vocational Rehabilitation. Contact information for all three programs is included in Appendix A. In addition, the following states have programmatic efforts underway to serve individuals who are deaf and low functioning: Alabama, New York, Texas, and Pennsylvania.

The Lexington Vocational Service Center provides a variety of services and is well known for its job coaching program. A job coach or communication specialist is an important support to ensure barrier free communication. While job coaching can serve as the link to effective communication

there are few people trained to work in this capacity. In addition, almost no programs offer job coach training to work with this population. One notable exception is the San Antonio College Interpreter Training Program. It offers an Associate in Applied Science in American sign language/deaf support specialist.

As a state-wide program, the Kentucky model is an exciting new development. The Division of Deaf and Hard of Hearing Branch of the Kentucky Office of Vocational Rehabilitation designed the program. Staffing includes four state coordinators, as well as coordinators for interpreting services; hard of hearing, late-deafened services; deaf services; and deaf-blind/“deaf at-risk” services. A special intake form has been designed for the deaf “at-risk” consumer which is global and attempts to identify community supports. The four state coordinators meet administratively to plan, develop resources, and identify future needs. In the future, a case manager will be hired to work with each RCD and the at-risk consumers. A combination of life skills, job clubs, and support services is being developed. Kentucky will become a model for a uniform, state-wide service system created and administered by a vocational rehabilitation agency.

Strategies for Service Delivery—Advocacy for Systems Change

In order to address the needs of persons considered deaf and low functioning, we must advocate for systematic change. One issue that should be addressed is effective service provision. Too often, gaps in service lead to poor vocational outcomes. When thinking about effective service provision several important concerns need to be considered: qualified service providers, barrier free communication, presence of secondary disabilities, effective transition planning, and individualized services.

Qualified Service Providers: The Committee on Deaf, Deaf Blind, Hard of Hearing, and Late Deafened under the Council of State Administrators of Vocational Rehabilitation (CSAVR) developed a model state plan. This plan includes a detailed explanation of what constitutes a qualified service provider. Although this document focused on the profession of vocational rehabilitation, the general principles have applicability to service provides in many other professions as well. A copy of the plan can be downloaded from CSAVR (http://www.rehabnetwork.org/committees/committee_deaf&deafblind.htm).

Barrier Free Communication: Inadequate communication skills are one of six key characteristics of persons who are LFD (Hurwitz, 1989; Long & Clark, 1993; Watson, 1997; Watson, 1998a, 1998b). Enhanced service provision with persons who are LFD requires an effective and appropriate communication assessment. Long and Alvares (1995) described an ecologically-based, functional communication assessment model for use with these individuals. This model emphasizes the person’s communicative competence in relationship to environmental demands and available supports. Building upon this work, Long (1996) developed an evaluation tool entitled, “Assessing workplace communication skills with traditionally underserved persons who are deaf.” This measure uses a four-step approach to (a) describe the individual and his/her communication skills, (b) evaluate the communicative demands of a particular work environment, (c) compare the individual’s skills to critical communication requirements in the work environment, and (d) identify and/or develop supports and interventions to make a better fit between consumers and their communication skills and environmental demands.

In 2005, Long collaborated with the Midwest Center for Postsecondary Outreach (now known as PEPNet-Midwest) to develop a website entitled *Communication Accommodations for Postsecondary Students Who Are Deaf or Hard of Hearing* (<http://pdcorder.pepnet.org/media/greglog/>). It targets Disabled Student Services (DSS) coordinators, students, families, and faculty. The website provides specific suggestions for

communication accommodations based on the type of environment (e.g., lectures, group discussions, labs) coupled with a consideration of the individual's hearing loss (i.e., deaf, late-deafened, hard of hearing), communication preference (i.e., oral, signing, cueing), and literacy skills (i.e., low literacy, literate). Because individuals who are deaf and low functioning have limited literacy skills, many of the accommodations suggested in the website would be appropriate for this population.

Presence of Secondary Disabilities: Many people identified as deaf and low functioning have secondary disabilities. One way to enhance service provision is to tap into alternative sources of funding. Developmental Disabilities Councils typically have funds to provide extended supported employment services for consumers with cognitive disabilities. Often there is a waiting list for these services. As such, consumers are encouraged to sign up for services several years before they are of employment age. People who are also legally blind may be able to receive additional services from the Services for the Blind. Additional resources and information for community rehabilitation programs who serve consumers who are deaf and low functioning can be found at: <http://www.pepnetnortheast.rit.edu/publication/tipsheet/commrehab.html>.

Effective Transition Planning: A key to career attainment is effective transition services that include family, social, environmental and academic support. Under federal law, secondary schools are required to develop transition plans with students and their parents, as well as a plan for employment after graduation. Although the concept of developing a plan of transition is good in theory, it often does not lead to job attainment.

Effective transition planning should include participation in career development programs. Unfortunately, career development programs designed for people who are deaf or hard of hearing are scarce. Furthermore, career development programs for persons who are deaf and low functioning are non-existent. PEPNet's new *iTransition* (<http://pepnet.org/itransition.asp>) program offers a comprehensive approach to career planning that could serve as a model for developing similar career development tools for persons who are LFD. Another PEPNet product that provides career stories of individuals who are deaf and hard of hearing is the series *Achieving Goals* (<http://www.netac.rit.edu/goals/menu.html>). *Achieving Goals* has a video series component as well as online videos of deaf professionals who can serve as career mentors.

Individualized Services: A strategy for implementing a program of individualized services is person-centered planning (PCP). Person-centered planning requires multi-agency coordination and collaboration. It also provides consumers with equal opportunity and access to services. In addition, it also creates an optimal system of social and environmental supports. Implementing PCP ensures non-duplication of resources and services. This model of service is consumer directed, person-centered and emphasizes consumer choice. The National Association of the Deaf proposed implementing PCP into the creation of their plan, *A Model for a National Collaborative Service Delivery System Serving Individuals who are Low Functioning Deaf* (National Association of the Deaf, 2004).

Conclusion

The primary goal for this document was to share resources that could be used to teach about the issues faced by the people who are deaf and low functioning. These issues are not new. The problems and barriers faced by this population remain the same. In fact, the same group of people has been advocating for systematic change for many years. As already stated, our field has had many advocates who have pushed for funding, resources, and ongoing programs and services for this population. We have created many position papers, written many articles in journals, and presented on the needs of persons who are deaf and low functioning at numerous conferences.

Effective and appropriate service delivery should lead to a true and positive impact on successful outcomes. To achieve this goal requires continued funding. In addition, multidisciplinary research should be supported to develop, assess, and implement proven assessment strategies, interventions, and accommodations.

At this point and time, the hope of federal support has diminished along with support for many other community services. It is incumbent upon each of us to find creative ways to seek funding and support, either on a local or state level. One avenue to find like-minded professionals is to attend a conference. For the past several years, Theresa Johnson has coordinated a conference in Houston, Texas on the needs of students who are deaf and low functioning. This year's conference is scheduled November 20-22, 2008. We plan to use this conference (and others) to continue our dialog about this population. Help us share information and resources. Use the links provided in the article to learn more. For additional information, please check the PEPNet website (www.PEPNet.org). Also, feel free to contact any of the authors directly via e-mail. Your interest in service provision for this population is critical. We invite you to help us build an interdisciplinary cadre of professionals committed to appropriate and effective service delivery for individuals who are deaf and low functioning. Please let us know if you have additional information or links you feel may be helpful. We look forward to ongoing collaboration with you.

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Watson, D. (1998b). A national network for postsecondary training of students who are LFD. In Kolvitz, M. (Ed.), *Empowerment through partnerships: PEPNet '98* (pp. 301-305). Knoxville, TN: University of Tennessee.

Appendix A

Lexington Vocational Services Center
30th Ave. and 75th St.
Jackson Heights, NY 11370
www.lex.nyc.com

Community Outreach Program for the Deaf
268 West Adams St.
Tucson, Arizona 85705
<http://www.angelfire.com/az2/valleyctrofdeaf/copd.html>

Kentucky Office of Vocational Rehabilitation
Deaf and Hard of Hearing Services Branch
209 St. Clair
Frankfort, Kentucky 40601
Contact: Janis Friend
More information about the Kentucky Model State Program can be found at:
www.dvr.ky.gov/programs_services/publications/Merged%20Monograph%20of%20LFD%20Presentation1.pdf.