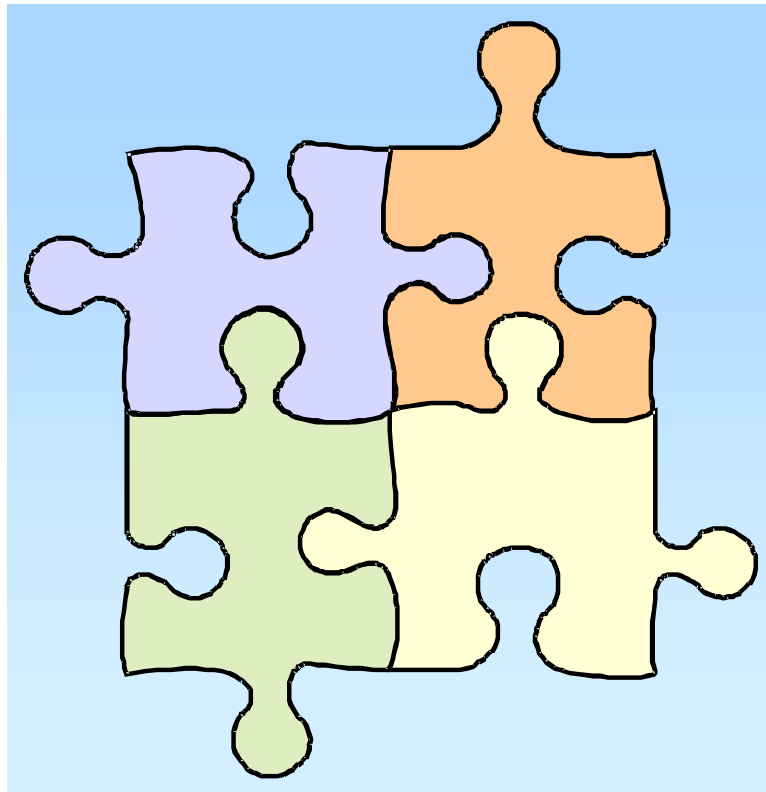


A Model for a National Collaborative Service Delivery System

*Serving low functioning deaf youth and adults to assist them
to be meaningfully employed and function independently at
home and in the community*



Position Paper
May 17, 2004

Foreword

This position paper: **A Model for a Nationwide Collaborative Service Delivery System**, provides the framework for a national approach to address the unmet needs of deaf and hard of hearing individuals that are most at risk, those individuals traditionally identified as low functioning deaf (LFD). The paper is intended to expand the ongoing discussion between service programs, educational programs, schools, advocates, research centers and federal program representatives regarding the challenges that individuals who are labeled LFD present to the public education and rehabilitation systems. More importantly, this paper should result in a call for action to mobilize the deaf community, policy makers and federal program professionals toward the establishment of a national approach that will assist at risk LFD individuals to become meaningfully employed through traditional and non-traditional means, and to function independently at home and in the community.

The paper is the product of the LFD Strategic Work Group, a group convened by the Postsecondary Education Programs Network (PEPNet) through their grant with the Office of Special Education Programs (OSEP) and endorsed by the Rehabilitation Services Administration (RSA), both components of the Office of Special Education and Rehabilitative Services, U.S. Department of Education. The Work Group includes federal program managers, national consumer leaders, researchers and professionals from the field.

A Model for a National Collaborative Service Delivery System Serving Individuals who are Low Functioning Deaf

Executive Summary

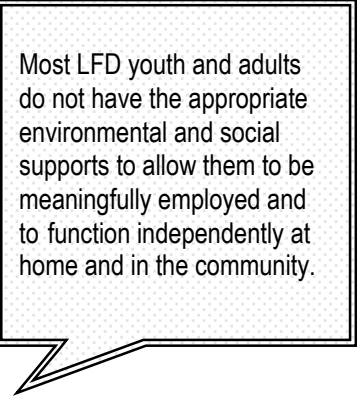
Current population estimates indicate that there are approximately 54 million Americans with disabilities (U.S. Civil Rights Commission, 1998). A report by Holt and Holto (1994) estimated that nearly 43 percent of these individuals are deaf or hard of hearing. In fact, individuals with hearing loss comprise the largest chronic disability group in the United States today. Within the population of individuals who are deaf or hard of hearing are a group of individuals with inadequate or no environmental supports whose functional skills and competencies are considered to be significantly below average making them the most at risk and underserved portion of the overall deaf population. These individuals, over the years, have been given a variety of labels, including underachieving, multiply handicapped, severely disabled, minimal language skilled and traditionally underserved, in addition to the current label of low functioning deaf (LFD). None of these labels adequately describe the population.

The LFD population is estimated between 125,000 to 165,000 individuals. While all members of the LFD population share the common characteristic of hearing loss, this population is also presumed to experience a number of risk factors, mostly environmental, that can affect their academic, social and vocational competence. These risk factors can include any one or combination of the following: the presence of secondary disabilities, being foreign born or having English as a second language, a lack of family support, inappropriate diagnosis, substance abuse, discrimination, inappropriate education and residence in a rural or low income urban setting.

As a consequence of these risk factors and lack of appropriate environmental and social supports, LFD individuals often have limited communication abilities, experience difficulty maintaining employment, demonstrate poor social and emotional skills and cannot live independently without transitional assistance. Most LFD adults read below the second grade level with academic achievements below the fourth grade. These individuals are not likely to have high school diplomas and are typically unable to participate in college and other post secondary vocational programs.

In contrast, today the majority of social supports and services available to deaf and hard of hearing youth and adults are targeted to those individuals who are able to participate in post secondary training and education programs. These programs are not able to effectively serve individuals who are not college bound, who are most at risk, or who have been identified as 'low functioning'. Unfortunately, there is no parallel system of financing from federal, state and local governments for post secondary training at non-college or vocational programs.

The LFD population is one of the most underserved components of the nation's disability population. There are no federally-funded rehabilitation centers and few state and local resources that can effectively address the needs of these individuals. State-to-state differences with regard to policy, resources, funding mechanisms and the role of the state agencies have limited access to appropriate services for the population. Federal funding for direct services targeted to the population has been without consistent intent, continuity or clearly defined expectations. The 'musical' grants (time-limited pilot projects) for programs serving the LFD population have lead to restricted eligibility and services.



Most LFD youth and adults do not have the appropriate environmental and social supports to allow them to be meaningfully employed and to function independently at home and in the community.

In addition, fees for services from state vocational rehabilitation (VR) agencies are not sufficient to address the long-term comprehensive needs of the LFD individual, and few Centers for Independent Living provide services to individuals who are deaf or hard of hearing, and, among those that do, fewer provide services to this population most at risk. The problem is compounded by differences in the levels of skill and expertise of professionals working with the population and the availability of those professionals across the country.

Federal and state efforts to serve this population have been further hindered by the lack of consistent and clear criteria for identifying LFD individuals, resulting in unreliable demographics and estimates of the population. Yet federal resources have not been available for a coordinated study of population characteristics, and service delivery methods and outcomes. Research efforts related to the LFD individual have been limited to a single five-year project.

Changes in federal direction over recent years put the population even further at risk. Today's legislative policies emphasize quick results and competitive outcomes. The focus of Congress, the current Administration and the federal government continues to move away from national service delivery systems that offer specialized direct services toward decentralized generic systems that shift service provision responsibility to the state and local level.

The Workforce Investment Act (WIA) of 1998, which reauthorized the Rehabilitation Act for another five years, creates demands at the state and local levels for partner programs, such as the state VR program, to provide core services, coordinate common functions and share costs. While the one-stop model is designed to offer a wide range of service options to the general population, the system lacks the capacity to provide the kind of specialized services required by the LFD individual.

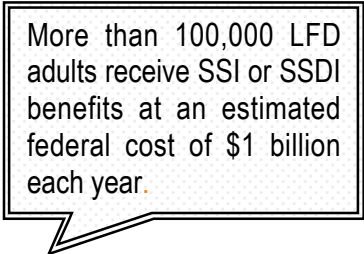
As another example, the Ticket to Work and Work Incentives Improvement Act (TWWIIA) makes it possible for millions of Americans with disabilities to join the workforce without fear of losing their Medicare and Medicaid coverage. The legislation does this by creating new options and incentives for states to offer a Medicaid buy-in for workers with disabilities and extending Medicare coverage for an additional four and one-half years for individuals on disability insurance who return to work.

The legislation includes a Ticket-to-Work program, which enables individuals receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits to obtain VR and employment services from their choice of participating public or private providers. However, the average cost of services to the individual, identified as LFD, is much greater than the outcome payments offered by the Social Security Administration (SSA) to the service provider participating in the Employment Network system.

The LFD student will also be disadvantaged by the 'high stakes testing' option that many states are implementing under the 2002 No Child Left Behind Act. Secondary schools already face significant challenges in reconciling the needs of the LFD student with the need to fulfill certain academic requirements. High stakes testing poses additional challenges by requiring schools that receive federal funds to achieve certain academic standards, including the requirement that students achieve 10th to 12th grade literacy to receive a high school diploma. In the past, deaf and hard of hearing individuals with fourth grade literacy achievements generally received a diploma. Under the new mandate, those individuals will now receive a certificate of completion, further limiting the post secondary training and employment options available to them. No new curriculum has been developed to enhance academic achievement of these students.

These legislative actions, while intended to improve quality of services and enhance the outcomes of federal programs, do not address the specific supports and services needed by individuals identified as LFD.

The challenges LFD youth and adults face in their daily lives result from the failure of national service delivery systems to provide access to appropriate services and environmental supports that will assist these individuals to become meaningfully employed and to function independently at home and in the community. Consequently, most LFD adults are dependent on welfare and do not work. Research indicates that more than 100,000 LFD adults are dependent on federal programs, notably SSI and SSDI. In addition, the number of LFD adults is projected to increase by 2,000 individuals each year due to the influx of new immigrants and high stakes testing requirements in public schools.



More than 100,000 LFD adults receive SSI or SSDI benefits at an estimated federal cost of \$1 billion each year.

National consumer groups, federal policy makers, researchers and concerned professionals have struggled with how to best provide services and social supports to this population since the 1940s. The consensus of these groups is clear – the needs of the LFD population will continue to go unmet through existing service delivery systems.

Now is the time to mobilize the deaf community, policy makers and federal program professionals toward the establishment of a coordinated, national approach that will assist LFD individuals who are most at risk to achieve optimal personal functioning and an enhanced quality of life through both meaningful employment at the workplace and independence in the community.

A Model for a National Collaborative Service Delivery System

When person-centered, comprehensive, specialized services are provided by skilled professionals in conjunction with appropriate environmental and social supports, LFD youth and adults can become economically and socially self-sufficient and lead full and productive lives. The below model for a National Collaborative Service Delivery System outlined here provides the framework for meeting that goal.

The National Collaborative Service Delivery System will build upon the expertise of service providers and programs already in the field as well as establish additional service components where necessary to ensure a full range of comprehensive services are available to the LFD population nationwide. The design for the proposed system will take into account existing programs, such as the Helen Keller National Center and the Postsecondary Education Programs Network (PEPNet), to maximize lessons learned, replicate effective practices and build upon already established linkages.

Mission

Every low functioning deaf youth & adult will be able to live & to work in the community of his or her choice, through ready access to optimal environmental supports & services.

Core Values

- Equal Opportunity
- Equal Access
- Optimal social and environmental supports
- Non-duplication of resources
- Fluent and direct communication that is defined by the consumer
- Services that are consumer directed, person-centered and emphasize consumer choice
- Multi-agency coordination and collaboration

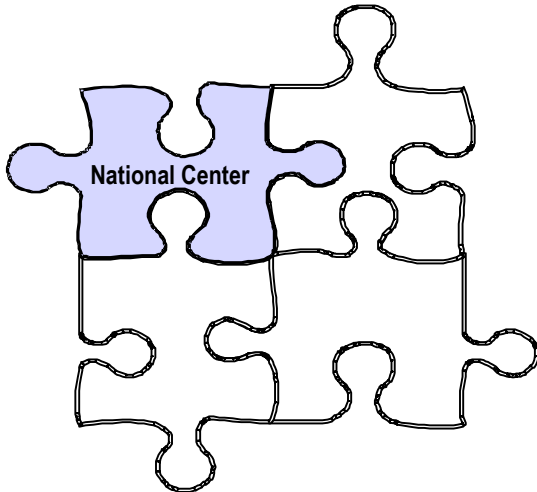
The proposed system is based on the establishment of a National Center, which will provide national leadership and operate an on-site training and rehabilitation facility where LFD individuals and service providers can receive intensive specialized services; a network of Regional Centers which will provide referral and counseling assistance to LFD individuals and technical assistance to service providers; and development of an Affiliate Network of public and private agencies that provide services to LFD individuals at the state and local level.

Linking the activities of the National Center, the Regional Centers and the Affiliate Network through the national system will maximize efforts, reduce duplication, facilitate information sharing and improve overall consistency in the provision of services to the LFD population.

This important linkage will ensure that capacity building occurs at all levels – nationally, regionally, state-by-state and in the local community.

Through services provided at the National Center, through the Regional Centers and at the Affiliate Network level, the national system will work one on one to teach, educate and rehabilitate LFD individuals according to their specific and unique needs. If this model is fully funded, for the first time LFD youth and adults will have access to a full range of appropriate and effective services that will lead to constructive participation in the home and community, increased employability and other development pertinent to their rehabilitation.

The National Center



The proposed National Center will serve as the headquarters and the primary point of coordination and collaboration for the National Collaborative Service Delivery System. The center will be responsible for establishing a national technical assistance delivery system; promoting research and data collection to identify population characteristics and service delivery methods and outcomes; providing technical assistance, training and outreach to service providers; and coordinating a nationwide system of direct services and supports for LFD youth and adults.

Responsibilities of the National Center include convening national consumer groups, experts from the field, policy makers, federal program managers and LFD individuals and their families to establish service delivery priorities at the national, regional, state and local level. The National Center will also establish an LFD Advisory Board comprised of leaders in the field of deafness, service providers, national consumer groups and LFD individuals and their families. Representatives from the National Center, Regional Centers and Affiliate Network will also participate on the LFD Advisory Board. The LFD Advisory Board will work to build consensus among the deaf community and key stakeholder groups in order to advocate with one voice to local, state and national legislators on issues related to the LFD population, including the need for a permanent stable funding base.

Through its national leadership role, the National Center will establish linkages and partnerships at the federal, state and local levels to maximize efforts, reduce duplication of effort, facilitate information sharing and improve overall consistency in the provision of services to the population. This will include promotion and establishment of formal, collaborative, interagency agreements aimed at improving the provision of appropriate services. The National Center will also develop policies and standards, along with procedural guidelines to ensure that the best services are available and accessible across the entire National Collaborative Service Delivery System.

The National Center, in coordination with the LFD Advisory Board, will also have responsibility for developing a national research agenda that identifies research priorities and will lead to the development of up-to-date information and statistics

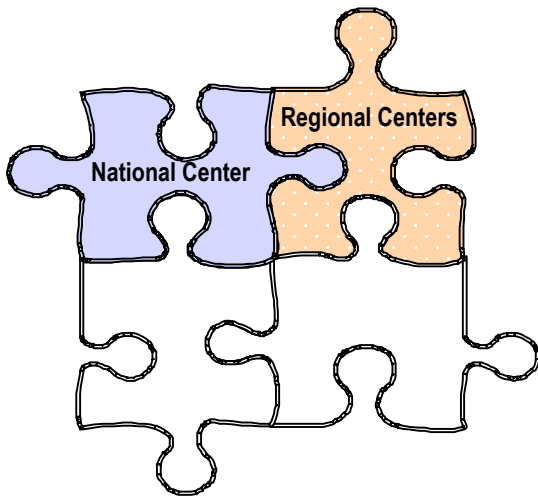
on the LFD population and its needs. The center will select evaluation methods to measure the effectiveness of direct services, training and technical assistance offered through the National Center, the Regional Centers and the Affiliate Network to ensure that services are responsive to the population's needs. A national database will have to be developed and implemented to capture information related to individuals served, their characteristics, types of services provided and future needs. The National Center will also institute evaluation techniques to ensure processes of continuous quality improvement are implemented at all levels of the National Service Delivery System.

Some direct services will be offered through an on-site program established at the National Center's residential program. While the objective is to ensure direct services are available at the local level, the National Center will serve as a testing ground for new techniques in order to establish "best practices" and model service delivery standards through direct services to a small group of consumers. Those techniques and practices can then be adopted at the regional, state and local level. Highly skilled professionals competent in linguistic and communication skills will provide direct services.

The National Center will offer technical assistance and training to the range of individuals and organizations that provide services to LFD individuals in the field. These professionals and para-professionals will learn new techniques and effective service practices through the program at the National Center that they can then take back to their local service delivery systems. The center will also provide consultation and training to consumer and parent groups, advisory boards, affiliate organizations and other private and public agencies.

To further facilitate the dissemination of relevant information, the National Center will establish and maintain a national clearinghouse of information. In addition, the Center may initiate special projects and conduct grant writing and fundraising to build a permanent funding base for the national system.

Regional Centers



Regional Centers will be established across the nation based on geography and population characteristics. These centers will work directly with the National Center to establish policy and set national priorities as well as coordinate efforts at the state and local level to ensure access to effective services for the LFD population within their region. The primary responsibility of each Regional Center will be to establish a regionally-based Affiliate Network of public and private service providers.

Each Regional Center will establish a Regional Advisory Board comprised of representatives from its Affiliate Network and other key stakeholders in the region. In conjunction with its Regional Advisory Board, each Regional Center will conduct ongoing assessments of the specific needs of individuals, communities, and states within their region, and developing strategies of collaboration, coordination, and cooperation to meet those needs.

Each Regional Center will use funds appropriated by the National Center to establish and support its Affiliate Network, including providing seed money to state and private agencies to establish or expand programs for LFD individuals within the region. Since the geography, population of LFD individuals and existing levels of service will vary from region to region, the manner in which each Regional Center establishes its Affiliate Network, and the composition of organizations participating in that network, will differ.

Another primary role of the Regional Centers will be the establishment of partnerships at the regional, state and local levels, including partnerships with state VR agencies, independent living centers, state education agencies, local education agencies, community service providers and State Coordinators for the Deaf (SCDs). In particular, each Regional Center will be responsible for developing memorandums of understanding with State VR agencies in the region to link the activities, pertaining to serving the LFD population, between Regional Center and the State VR agency.

The most important responsibility of the Regional Centers will be to build the capacity of its Affiliate Network. To that end, Regional Centers will provide training, technical assistance and outreach to the management and staff of its affiliates. This will include consultative assistance in the administration of programs providing direct services, and the promotion of collaborative,

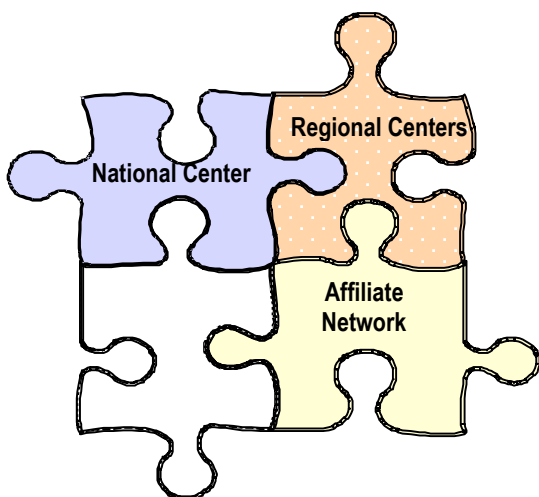
interagency efforts aimed at increasing the range of services available. Regional Center staff will also provide consultation and training to employers, state VR programs, mental health workers and special education programs in developing direct service plans for LFD individuals served by those programs.

To facilitate the national systems approach, each Regional Center will network within and among the regions through the conduct of forums, conferences and other mechanisms designed to share information and identify effective practices. The Regional Centers will also conduct ongoing resource development activities, including assisting the National Center with grant writing and fundraising.

Regional Centers will offer some specialized services provided by skilled professionals with the language and technical skills necessary to effectively train and communicate with LFD individuals. Regional staff will also provide counseling, information and referral for LFD individuals and their families. In addition, the centers will work with family members and target activities to build parent advocacy skills. In addition, each Regional Center will collect and report information to the National Center to assist in the identification of individuals served, their characteristics, types of services provided and future needs.

All of these activities, including developing a “menu” of services and expanding available resources, will be based upon the needs within the particular region and focus on developing appropriate environmental and social supports for the at risk LFD population in that region.

The Affiliate Network



The Affiliate Network will build the capacity of the state and local levels to better serve LFD youth and adults in their communities. Affiliate organizations may include local community service providers, independent living centers, state VR agencies, state and local education agencies and residential schools for the deaf. The primary role of the range of public and private agencies participating in the Affiliate Network will be the delivery of comprehensive, specialized services to LFD youth and adults.

Public and private service providers will enter the Affiliate Network through a funding process established by each Regional Center. Applicants may be rated by a panel comprised of individuals from the National Center, the Regional Center and experts in the field of deafness and services to the LFD population. Criteria for funding may include ongoing coordination with other service providers, parents, consumers and educators, and the applicant's ability to continue the services as the funding stream changes within the agency.

Examples of direct services available at the local level through the Affiliate Network may include: communication skills, emotional and behavioral modification, health and mental health services, physical therapy, independent living skills training, adaptive technology, work experience and transitional programs to prepare LFD youth and adults for the workforce and to live independently.

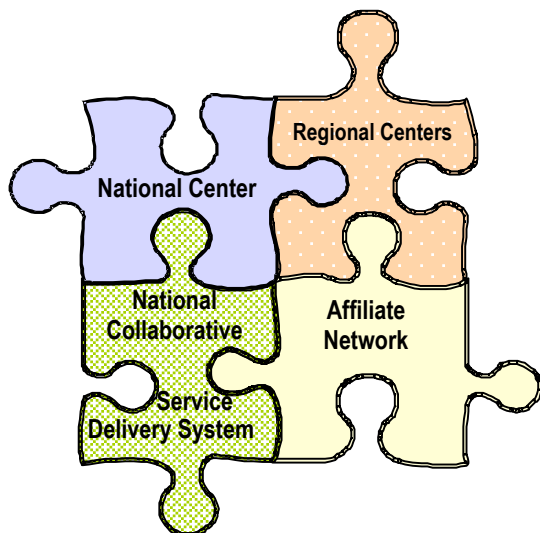
Another important aspect of the affiliate role will be the provision of employment related services. Each affiliate organization will develop a plan for working closely with local VR counselors to identify employment opportunities and services that can be provided through the VR program. Affiliates will also be responsible for securing long-term consumer support both in employment settings and within the community.

Each affiliate provider will be expected to identify the LFD population in their area and develop appropriate services and environmental supports to meet the particular needs of that population. Each affiliate will also be charged with case finding, consumer evaluations and assessments, screening and overall case management.

Because the majority of services will be provided through the Affiliate Network, affiliate members will be responsible for providing skilled professionals with the language and technical skills necessary to effectively train and communicate with LFD individuals.

Members of the Affiliate Network will be required to maintain communication and collaboration with the National Center, their designated Regional Center and the other affiliates in the region. Affiliates will also be responsible for collecting and reporting information to the Regional Center with regard to number of individuals served, their characteristics, types of services provided and future needs.

Envisioning the Future



The needs of this population of deaf and hard of hearing individuals most at risk have not been appropriately addressed for decades. It is time to mobilize the deaf community, policy makers and federal program professionals toward the establishment of a National Collaborative Service Delivery System. Through the National Center, Regional Centers and an extensive Affiliate Network of public and private service providers, the national system will provide LFD individuals with access to a full range of appropriate supports and effective services that can and will lead to increased employment, independence at home and in community, and an enhanced quality of life.

Envisioning the National Collaborative Service Delivery System is only the first step toward realizing this goal. Much still needs to be done to educate Congressional decision-makers and to achieve the buy-in and support of the deaf community. In addition, federal program managers across multiple agencies will also need to work together to discuss how best to collaborate and coordinate programs so that LFD individuals stop falling through the cracks.

It is worth the journey. Experience and research have demonstrated that when comprehensive, specialized services are provided by skilled professionals with the language and technical skills for effective training and communication, LFD youth and adults can become economically and socially self-sufficient and lead full and productive lives. The “vision” of the National Collaborative Service Delivery System provides the framework for meeting that goal.

LFD Strategic Work Group

The LFD Strategic Work Group was convened by the Postsecondary Education Programs Network (PEPNet) and sponsored by the Rehabilitation Services Administration, a component of the Office of Special Education and Rehabilitative Services in the U.S. Department of Education.

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