

ADULT SERVICES: PRESENTATION

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Abstract: First, the adult service system needs to be more accessible. To achieve this, we need (a) a reliable data base on the size, distribution, and characteristics of adults who are deaf-blind; (b) better interpreter training programs; (c) technical assistance centers; and (d) improved personnel preparation programs. Second, adults should have expanded options for choice and control of services and supports. To achieve this, they must be represented on adult service advisory councils; they must participate in Individualized Written Rehabilitation Program options for choice and control; and we must develop voucher or certificate demonstration programs. Third, in order to achieve a broad systemic and holistic model of community-based services, we must facilitate inter-agency planning and cooperation. Finally, we need to develop a consumer-driven system by promoting consumer self-advocacy and involving consumers and their families in the planning and organizing of adult services.

Fundamental changes are sweeping across America, breaking the chains of public ignorance and indifference toward people with disabilities. We are experiencing the coming-of-age of the disability rights movement in America. More and more agree that people with disabilities should have equal opportunities for full participation in all aspects of society (Thayer & Rice, 1990). Enactment of the Americans With Disabilities Act of 1990 (ADA) empowered consumers by helping people with disabilities gain control over their lives.

In P.L. 102-973, the Rehabilitation Act Amendment of 1992, Congress mandated fundamental changes that reflect values consistent with those of the ADA. The program of services authorized by the Act "empowers persons with disabilities with choice and meaningful employment, and promotes independence, productivity and full integration into the workforce and community—critical

components of participation in the fabric of life in our nation" (Button, 1992, p. 3). These two powerful commitments to building a society which supports efforts to live productively challenge us to reexamine our nation's approach to education and rehabilitation services for people who are deaf-blind.

Appropriately, this planning conference has targeted 10 key areas for reexamination. Numerous issues are readily evident for each of the key areas. Our charge, in turn, is to articulate a vision that involves a fundamental restructuring of programs and services and that will enable persons who are deaf-blind to gain power over their futures.

A Population in Search of Accessible Services

Various estimates suggest there are somewhere between 30 and 45 thousand individuals who are deaf-blind in the United States (Baldwin & Bullis, in press; Ouellette, 1983; Wolf, Delk & Schein, 1982). Lacking an accurate census of this low-incidence population, the adult service system in this country rarely considers the special needs of this group for purposes of program planning and resource allocation. As a result, most programs are ill prepared to serve the occasional request for services by a person who is deaf-blind. Appropriate services are often available only for the fortunate few who happen to live in an area that has skilled local professionals and/or programs.

Over the past two decades, major initiatives have directed the nation's adult service program staff to develop the knowledge and skills needed to serve these individuals. Considerable resources were dedicated to this objective through the development of a national "safety net" of specialized services, supplemented by technical assistance and support centers in the 10 geographical regions. The Helen Keller National Center (HKNC) and its regional affiliates exemplify the extensive investments made to implement a comprehensive nationwide program that is dedicated to enabling adults who are deaf-blind to access the adult service system. As a group, this system serves almost 2000 clients per year with several hundred placed into employment annually (HKNC, 1991). State and multi-state projects under Section

307.11 represent our national efforts on behalf of children and youth served by the educational system. Baldwin and Bullis (in press) report these centers annually serve over 7000 children and youth. These twin programmatic investments by Congress have had a significant impact on the lives of thousands. However, due to limited resources, the programs do not reach all those in need.

In an effort to patch the gaping holes in this "safety net," a continuing series of local, state, regional, and national "state-of-the-art" training and technical assistance programs have been conducted. Face-to-face and hands-on training for service personnel has been supplemented with the publication and dissemination of numerous guidelines and/or recommendations for practice, research, and programmatic approaches. Several of these merit mention. A conference on planning for the future, *1980 is Now* (Sherrick, 1974), presented recommendations for meeting the needs of children affected by the 1964-1965 rubella epidemic, as they matured. Another report, *Needs Assessment of Services to Deaf-Blind Individuals* (Wolf, Delk, & Schein, 1982), provided the field with population estimates and data on service needs. The following year, *A Model Service Delivery System for Deaf-Blind Persons* (Watson, Barrett, & Brown, 1983), provided guidelines for the planning and implementation of statewide service delivery systems. The *Eleventh IRI: Vocational Rehabilitation of Deaf-Blind Persons*

(Konar & Rice, 1984), recommended guidelines for improving state vocational rehabilitation services. Another national conference, *State of the Art: Research Priorities in Deaf-Blindness* (Stahlecker, Glass, & Machalow, 1985), articulated priority concerns for future research in the field. A 1986 national conference on transition issues generated a series of papers and recommendations, *Transition For Persons with Deaf-Blindness and Other Profound Handicaps: State of the Art* (Covert & Fredericks, 1987). More recently, developing concerns with the special needs of the elderly have been expressed in publications by HKNC such as, *Identifying Vision and Hearing Problems Among Older Persons: Strategies and Resources* (Bagley, 1989) and *Beyond Refuge: Coping with Losses of Vision and Hearing in Late Life* (Luey, Belser, & Glass, undated). Collectively, these and numerous other such published guidelines, priority recommendations, and "state-of-the-art" training and technical assistance packages have generated a vast body of knowledge to guide efforts to serve persons who are deaf-blind.

As a nation, we have obviously taken some significant steps toward constructing the broad outline of an adult service delivery system. The task ahead is to fill in that broad outline with a broad systemic and holistic community-based system of comprehensive services for adults who are deaf-blind. Given the very real restraints of finite personnel, program, and fiscal resources that are available to us, what critical

issues merit priority for the next decade?

Critical Issues in the Adult Service System

My charge from the planning committee is to address critical issues related to the topic of adult services. The original list of 15 issues generated by the planning committee has been reorganized into four priority areas. These include the following: (a) improving access to the adult service system, (b) expanding options for choice and control of services and supports, (c) facilitating inter-agency program planning, implementation, and coordination, and (d) encouraging consumer participation and leadership to ensure a more consumer-driven system. This review will focus on the task of relating current practices to critical issues that need to be addressed within the Federal-State Vocational Rehabilitation Services Program and the programs associated with it such as independent living, independent living centers, supported employment, rehabilitation facilities, and related vendors. Time and space constraints dictate that only selected issues can be considered here; however, the format also provides for a follow-up reactor and focus group discussion which should allow for a wider discussion.

Improving Access to the Adult Service System

Many persons who are deaf-blind have historically found it difficult to gain entry into the adult service system due to the assumption that the severity of their dual disability precluded the ability to obtain employment and live independently (Konar & Rice, 1984). Denials of service were based on concepts of feasibility of successful outcomes, concepts which were embedded in the eligibility process for most service systems.

The 1990 enactment of the ADA, combined with the passage of the Rehabilitation Act Amendment of 1992, effectively eliminates such standards of feasibility and eligibility and replaces them with the requirement that individuals be presumed eligible for services. Specifically, the Act creates "a presumption of eligibility" for all applicants for vocational rehabilitation services who have been determined to be disabled. The presumption is that a person with a disability who applies to vocational rehabilitation services is capable of benefiting from such services. In addition, a person is presumed to have a disability if she or he has been determined to be disabled under another program. To deny eligibility the *agency must show that a person cannot benefit from its services*. If the agency cannot show this, it is obligated to develop a plan and provide services. Consistent with the values articulated by ADA, these presumptions of feasibility, eligibility, and reasonable accommodation extend into all areas of the nation's

public and private adult service system.

However, a number of critical issues face persons who are deaf-blind and those who provide adult services to them.

1. Population data base. Our nation lacks a reliable data base on the size, distribution, and characteristics of adults within the population who are deaf-blind (Baldwin & Bullis, in press). The adult service system needs access to timely data on the number and needs of these individuals in order to plan and provide appropriate services. Recognizing this problem, the Rehabilitation Services Administration (RSA) issued Policy Directive 93-02 on November 10, 1992, introducing a series of new statistical codes to be used by state vocational rehabilitation agencies in reporting case service data (RSA-911 data system) to RSA on the major and secondary disabling conditions of clients who are deaf-blind (RSA-PD-93-02). Other adult service system programs need to implement similar mechanisms to enhance the utility of their client data base systems. Even the current "guesstimates" totally omit the growing numbers of elderly individuals experiencing progressive loss of hearing and sight. Federally sponsored population censuses, studies, data bases on people served, and related programs must be mandated to collect and report reliable information related to the size and characteristics of low-incidence populations.

2. Interpreter education/training.

Good communication is essential to ensure access to the adult service system, employment, and independent living. Persons who are deaf-blind must have access to skilled interpreters (Konar & Rice, 1984; Watson, Barrett, & Brown, 1983). Yet, interpreter training projects (ITP) funded by the RSA and the Office of Special Education Programs (OSEP) are not mandated to include in their curricula an emphasis on interpreting for persons who are deaf-blind. The 1992 Act added language expanding the number of ITPs that the Office of Special Rehabilitative Services (OSERS) can fund and requires that the mission of the ITPs include training in interpreting with people who are deaf-blind (P.L. 102-973). Many ITPs already have excellent curricula in place; the grant program should require these materials be pooled and shared, with funds earmarked for additional pre- and in-service education and training activities by both OSEP and RSA ITPs. The field also needs to address the lack of a career path for new interpreters and the inadequate levels of compensation (Watson, 1990).

3. ADA technical assistance centers.

Adult service system personnel and employers need access to training and technical assistance as they make reasonable accommodations for persons who are deaf-blind. NIDRR (National Institute on Disability Research and Rehabilitation) has funded 10 Regional Disability and Business

Accommodations Centers (RDBACs) to assist consumers, employers, and service systems. To provide these centers with state-of-the-art materials on how to make communication accommodations, NIDRR has twice issued requests for proposals from the field. Not receiving any proposals that merited funding, no grant has yet been awarded (Richard Johnson, NIDRR, personal communication, September, 1992). Consumer and professional leaders must insist that NIDRR issue another call for proposals and form a coalition of experts to jointly apply for and conduct this project. The RDBACs represent one of this nation's first major initiatives toward implementing the reasonable accommodations mandated by ADA. In the 1990 Rehabilitation Act, Congress added language that also authorizes the state agencies to train employers regarding the ADA. In order to assist employers and others to make reasonable accommodations for persons who are deaf-blind or have other communicative needs, the RDBACs and state agency ADA training units will need effective materials for consumers, employers, and service personnel.

4. Personnel training in "best practices."

Adult service system personnel preparation programs such as the RSA- and OSEP-sponsored pre- and inservice education and training grant programs are not providing adequate preparation to prepare general or specialty personnel in "best practices" with persons who are deaf-blind. This omission persists in spite

of the fact that state vocational rehabilitation and other adult service programs identified such training as a priority almost five years ago (Pelavin, Pelavin, & Celebuski, 1987). RSA and OSEP each year allocate millions of dollars to fund training grant programs for staff development, Regional Rehabilitation Continuing Education Programs (RCEPs), degree programs, and related training activities. We need to require that these grant programs include provisions for covering "best practices" for low-incidence populations. Perhaps the assessment and training models used by the deafness rehabilitation field as described by Watson (1990) could serve as a viable model for use with people who are deaf-blind. HKNC and other specialty programs have the materials already in place and could help training programs integrate "best practices" materials and instructional techniques into pre- and inservice curricula.

Expanding Options for Choice and Control of Services and Supports

Both the ADA and Rehabilitation Act Amendment of 1992 are predicated on the assumption that persons with disabilities be empowered with choice and control in all aspects of their lives. Title I of the Act (the Basic Program of Vocational Rehabilitation Services) specifies that individuals must be active participants in their own rehabilitation programs, making meaningful and informed choices about the selection of their vocational goals, objectives, and services (P.L. 102-973). The Act further

requires the State Plan to describe the choices given and control over the determination of goals and objectives. ADA, of course, extends the assurance of empowerment through choice and control into most aspects of life.

A number of critical issues face persons who are deaf-blind as they seek options in the adult service system.

1. Representation on adult service advisory councils. Persons who are deaf-blind must participate and be represented on advisory councils so they can shape and monitor adult service programs regardless of whether or not the programs are specifically directed to serving persons who are deaf-blind (Konar & Rice, 1984; Watson, Barrett, & Brown, 1983; Wolf, Delk, & Schein, 1982). Although no data exist on which to base a definitive declaration, it would be fair to estimate that few, if any, general adult service programs make it a practice to include consumers who are deaf-blind on their advisory councils. Yet, most of these programs are funded with a mandate to serve *all* persons with disabilities, including persons who are deaf-blind. No wonder low-incidence groups are so poorly served by our nation's general service delivery system, they are too often denied the opportunity to determine the way in which those services are organized and provided. Congress mandated that the composition of various advisory councils established to guide and monitor the programs

authorized by the Rehabilitation Act Amendment of 1992 must include a cross-section of representatives of disability advocacy groups (P.L. 102-973). Consumer organizations of people who are deaf-blind, their families, advocates, and professionals in the field must vigorously advocate for their rights to be represented in a meaningful way on the advisory councils of our nation's adult service system. This advocacy should be for across-the-board representation: State Rehabilitation Advisory Councils, Independent Living Councils, Supported Employment Councils, Projects With Industry Councils, Research Advisory Councils, Rehabilitation Technology Councils, Training and Demonstration Project Councils, the National Advisory Council on Disability, and numerous other groups operating on the local, state, and national level. They also need to work for representation in the OSEP and RSA peer-review process and related activities in order to significantly affect the planning, selection, and award of funding grants designed to improve the ways in which education and rehabilitation services are organized and provided for adults with disabilities.

2. Individualized Written Rehabilitation Program (IWRP): Options for choice and control.

Individual options for choice and control of services and supports were significantly expanded by Section 113 in the Act, reauthorizing the IWRP. Specifically, the IWRP must be designed to achieve the employment objective of the

individual, consistent with his or her unique strengths, priorities, abilities, and capabilities. The IWRP requires a statement by the individual in his or her own words describing how he or she was informed about and involved in choosing among alternative goals, objectives, services, entities providing services, and methods used to provide or procure such services. IWRPs must be jointly developed, agreed upon, and signed by the Agency and the client or significant others (P.L. 102-973). This amendment assumes increased control for individuals in developing their own plans of services. It also promotes individual choice for a range of living options, vocational/career options, ongoing support services (personal assistance, transportation, interpreting, etc.), and empowers the individual to look beyond entry level jobs to careers. Consumers and their families or advocates must insist that the intent of Congress be fully implemented on their behalf.

As with the requirements of the existing IWRP process, the key issue here is access to information. Service providers will need to make information available through interpreting, braille or large print materials, and related accommodations to ensure that consumers know about all the service and support options they are entitled to (Konar & Rice, 1984; Watson, Barrett, & Brown, 1983; Watson & Taff-Watson, in press). The Act also stipulates that state education and rehabilitation agencies are to establish interagency

IEP/IWRP plans for service. RSA and OSEP should be mandated to support programs of information, training, and technical assistance designed to educate consumers, their families, advocates, and service providers about the extent and scope of the client's right to make informed choices under the revised IWRP regulations. HKNC and NIDRR should likewise be mandated to conduct evaluative research and related monitoring programs in order to assess implementation and outcomes.

3. Client choice: Voucher or certificate demonstration programs.

Research has shown that when people feel powerless, they tend to cope by trying to control others, creating defensive, oppositional, and unresponsive behaviors in others, and fueling a negative cycle that Schlesinger (1987) describes as the cycle of powerlessness. Under Title VIII of the Act, Congress has added an amendment that calls for "Demonstration Projects to Increase Client Choice." This demonstration authority would permit state agencies to apply for vouchers or certificates to be used by people with disabilities to purchase their own services. The amendment calls for strategies to increase client choice, including choice among qualified service providers (P.L. 102-973). Participation in this program would give the consumer who is deaf-blind the ultimate control in exercising personal empowerment. Consumers, along with their parents and advocates, need to encourage their state agencies to participate in

alternative ways to make adult services options available. The information gained through this kind of participation of consumers who are deaf-blind could lead to a more responsive and effective adult service delivery system.

Facilitating Inter-agency Program Planning, Implementation, and Coordination

The needs of consumers who are deaf-blind are clearly diverse; these people require the resources of multiple adult service agencies. Probably the most effective approach to construction of a network of effective services has been through inter-agency planning and collaboration (Everson, Rachal, & Michael, 1992; Gottula, 1983; Konar & Rice, 1984). Although the composition of these inter-agency teams varies considerably, the agencies and individuals most often involved include representatives of the adult deaf-blind community, families, state vocational rehabilitation agencies, secondary and postsecondary education and training programs, mental health and developmental disabilities agencies, vocational education, and other allied service programs. The literature shows that inter-agency collaboration is the most productive way to improve the planning and delivery of services to persons who are deaf-blind. A national program, the HKNC Technical Assistance Center (TAC), has emerged in recent years as the leading force in assisting states or

communities to plan, train, and implement inter-agency teams. Since its inception in 1984, TAC has trained 18 state inter-agency teams (Everson, Rachal, & Michael, 1992). A primary goal of these inter-agency team efforts has been to make "best practices" more readily available within the existing adult service system. TAC findings show that these collaborative efforts have consistently produced positive community-integrated outcomes for persons who are deaf-blind.

Inter-agency collaboration networks can be expanded and improved. A number of issues need to be addressed.

1. Inter-agency adult service collaboration. Although originally pioneered by HKNC and various statewide inter-agency adult service collaboration efforts (Gottula, 1983; Konar & Rice, 1984), much of the recent literature has focused on services for children and youth in transition. To their credit, it appears that efforts such as the TAC program have significantly improved upon the original concept through the years. Further, the literature implies that these activities have encompassed the needs of adults as well as youth in transition. Yet, a careful reading of this body of literature fails to provide substantial evidence that adult services have received equal attention and resources. Whatever the case, the HKNC TAC project and various other inter-agency collaboration teams have successfully demonstrated that such programs can be highly effective; in

fact, these programs are perhaps the most productive approach available to the field. Priority should be given to the twin task of exporting the model to more states and expanding the scope of these efforts to include an equal emphasis on services for adults. For instance, some of the "best practices" in inter-agency collaboration programming are targeted to young adults in transition; these "best practices" need to be extended to adult services for all ages, including the growing number of senior citizens with late-onset dual loss of hearing and vision. Additional funding would obviously be needed; RSA and other related adult service funding sources should be made aware of the success of the TAC program and encouraged to allocate the funding needed to replicate and otherwise expand the program into the adult service system.

2. Broad systemic and holistic community-based approach needed. A detailed description and discussion of the numerous issues associated with the scope, mix, and quality of services most often included in inter-agency collaborations is not possible within the context of this paper. However, various combinations of the following adult service systems are most often represented in the literature:

- Inter-agency coordination and planning between education and rehabilitation programs
- Centralized case management arrangements

- Coordinated transition from school to adult services, work, and independent living
- A wide range of state vocational rehabilitation services
- Community-based independent living centers and independent living services
- Supported and competitive employment services
- Housing and transportation assistance
- Recreation and leisure services
- Postsecondary training and continuing education
- Interpreter training, information and referral
- Assistive technology and supports
- Personal assistance services
- Services for families and parents, including respite care
- Personal futures planning

Seiler, Everson, & Carr (1992) completed a national survey of agencies that reported they provided services for persons who are deaf-blind. They received usable responses from 719 agencies distributed across the nation which provided a mix of the kinds of services listed above. When asked if they needed technical assistance to help them improve their ability to

serve persons who are deaf-blind, most asked for help in a large number of areas. This great need for technical assistance suggests both that agencies are actively trying to serve these individuals and that they are aware of the need to improve their knowledge and skills to do so. However encouraging it was to find so many agencies involved in service delivery, the authors were disturbed to find that a vast majority of these programs continue to use an isolated skills training approach instead of a broad systemic and holistic model of community-based services for these individuals. In concluding their report, the authors recommended the following:

Future funding priorities and technical assistance activities must aggressively promote holistic and visionary client planning (e.g., personal futures planning, supported living, supported employment, home school initiatives) along with broad systemic and administrative inter-agency change supports. (pp. 50-51)

Is the field prepared to take a broad systemic and holistic approach to community-based inter-agency service delivery for persons who are deaf-blind? That is clearly the direction that Congress has mapped out in the Rehabilitation Act Amendment of 1992. The broad systemic and holistic approach proposed by the Act will require a careful reading, followed by an equally fundamental restructuring of how we conceptualize and approach

the delivery of services to adults who are deaf-blind. The current approach used by the TAC model for training inter-agency teams may be a good starting point. The TAC model has developed extensive networks that have demonstrated its effective implementation. How we perform this task may well be one of the most critical issues we face in the near future.

Encouraging Consumer Participation and Leadership

Tracing the roots of the development of the adult service system for people with disabilities in the United States, Thayer and Rice (1990) noted it should not be assessed in isolation from the broader disability rights movement. Reviewing this movement, they described it as follows:

The historic and long-term drive by people with disabilities to be empowered with the rights of self-determination and control of their own lives, to become integrated as active, productive, and respected members of their families and communities . . . making cultural and life style choices among options that minimize reliance on others in decision-making and in performance of everyday activities, limited only in the same ways that people without disabilities are limited. It means exercising the greatest possible degree of choice

about where you live, with whom you live, how to live, and how to use time. This includes taking risks and having the right to succeed or fail. It also includes taking responsibility for one's decisions and actions. (pp. 10-11)

The achievements of the disability rights movement in the United States are self-evident in the enactment of ADA and the current language Congress is using in the Rehabilitation Act Amendment of 1992. These achievements were hard earned, products of a drive by grassroots consumer advocates whose self-advocacy sparked the disability rights movement. However, we must not lose sight of the responsibilities that these new rights bring. First, the right to control one's own life requires assuming the responsibility for self-advocacy. Second, it assumes active involvement in general adult service system advisory councils and planning groups.

Issues related to each of these interrelated responsibilities for consumers who are deaf-blind and their families (or advocates) need to be addressed:

1. Consumer self-advocacy. Self-advocacy as used here, refers to the concept of individual and group self-advocacy which "underlies the basic philosophical and political tenets of American society: self-reliance; freedom to make choices on how to best meet one's own needs; freedom to pursue one's own interests in social, political, and economic areas .

. . . The key to success in any social movement always has been and still is self-advocacy" (Funk, 1986, p. 3). If the history of the disabilities rights movement in this country has taught us anything, it is that programmatic reform can be enacted and sustained only with the active participation of the beneficiaries of that reform. We need to be sure that, whether on the individual level or in organized groups, consumers who are deaf-blind and families with members who are deaf-blind are ultimately the ones who make their own choices and define their own needs. Many are concerned with a broad range of issues, but few know how to take effective action. Too often persons who are deaf-blind have not acquired advocacy skills nor have they learned how to influence decision makers. The same observation holds for many families with members who are deaf-blind. Three of the more recent programs developed by HKNC have addressed this need in part by providing technical assistance and training workshops for consumers and families through programs such as TAC, National Parent Network, and the HKNC program for Older Persons with Deaf-Blindness (Barrett, in press). These are important resources; however, we also need to empower entire groups to assume lead roles in self-advocacy. In our field, these consumer groups are the American Association of the Deaf-Blind (AADB), and numerous local and state consumer and parent advocacy groups. Programs and materials developed by the independent living field over the past

two decades have proven highly effective and would be easily adaptable for use by consumers who are deaf-blind. A self-help manual, *Consumer Involvement in Advocacy Organizations: Rehabilitating Communities for Independent Living* (Balcazar & Seekins, 1986), provides materials in easy-to-use form to help organize advocacy groups and teach advocacy procedures. This and other training packages have been widely used in cross-disability training efforts that, unfortunately, rarely included adults who were deaf-blind. The leadership of the field needs to correct this gross disservice and give priority to establishing a continuing program of self-advocacy training for adults who are deaf-blind. Federal agencies such as OSEP and RSA should more closely monitor federal grant projects that are supposedly "cross-disability," to ensure that federal funds to such consumer groups do in fact make a concerted effort to include persons who are deaf-blind.

2. Involvement in planning and organizing adult services. If consumers and families wish to control the services and supports they need or desire, they must be actively involved in the planning and organization of those services. This basic tenet has been stressed repeatedly in the preceding review and is presented yet one more time in order to reemphasize the central importance of consumer leadership. Moreover, we perhaps need to borrow from the independent living movement by speaking out in favor of majority representation on the

advisory councils of programs established specifically to serve adults who are deaf-blind. This would also include a call for strong adult consumer representation on inter-agency team efforts targeted to children and youth; surely those teams could benefit greatly from such adult input! The issue of representation is real; the field must recognize the importance of this issue. The adult service system for persons who are deaf-blind should be fully consumer-driven. By the same token, their representation on general adult service system advisory councils and planning groups also merits priority.

As a nation, we cannot afford to overlook the vast talents, motivation, experiences, and insights that only consumers can provide. Making the adult service system accessible to persons who are deaf-blind demands our best efforts. Until the adult service system is consumer-driven, we have not put the best team players on the field. In the decade ahead, if we change nothing else in the way we plan and organize adult services for persons who are deaf-blind, let that one change be to ensure that consumers and families are leading us forward.

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ADULT SERVICES: REACTION

Stephen Perreault

Abstract: Services for adults who are deaf-blind need to be more accessible as well as provide more continuity. A 1984 task force in Massachusetts examined the service needs of those who are deaf-blind and how those needs were being met. The resulting program used a system of centralized case management within a lead agency that was able to provide centralized information and referral, coordinated case management, utilization of specialty support services, and coordination of inter-agency resources. On a national level, leadership in achieving coordinated services might be provided through the Rehabilitation Services Administration (RSA). Other recommendations include improved personnel training, more choices and control of services by those who will receive them, and more inter-agency program planning and coordination. Recommendations presented in the position paper of the National Coalition on Deaf-Blindness are cited and RSA is urged to collaborate with the writers of that position paper.

I congratulate Doug Watson for his paper and comprehensive summary of current literature and practices in the provision of rehabilitation services to individuals who are deaf-blind. I was especially thankful for his analysis of legislative changes brought about through the Rehabilitation Act Amendment of 1992 and the potential benefits for persons who are deaf-blind. I will attempt to react to and supplement Doug's paper by drawing from three aspects of my personal experience (a) as a teacher of children who are deaf-blind, (b) as an administrator of an adult service program for individuals who are deaf-blind, and (c) from information gained through work with the National Parent Network and state organizations of parents of children who are deaf-blind.

Limitations in Adult Services

Much of the literature that Doug cited in his paper emanated from efforts to plan and advocate for the transition from education to adult services of the approximately 5 thousand young adults who were deaf-blind as a result of the rubella epidemic of 1964-65. This same literature detailed ranges of supported employment and living options along with social, health, and ancillary services important to the successful transition of this population. The majority of these people entered the adult service system in the years 1986-88. What happened? Giving myself the license to react both from personal experience and from experiences

related by a number of parents, I would like to offer the following statements: (a) For the majority of these young adults and their families the experience was a disaster; (b) programs were not and are not in place in adult service systems, which provide for the expansion of capacities learned in education programs; and (c) services which assist in obtaining basic quality-of-life goals such as personal housing, productivity, friendships and recreation have not been accessible to these individuals due to inadequate resources, inappropriate program planning, and untrained personnel.

In addition, a working group of the National Coalition on Deaf-Blindness, in an analysis of adult services in preparation for the reauthorization of the Rehabilitation Act, arrived at a consensus on the following issues:

- There are currently no programs that prepare rehabilitation personnel to provide services to individuals who are deaf-blind.
- Rehabilitation programs often do not include components that address the specific service needs of individuals who are deaf-blind. Time-limited and current case-closure standards are inappropriate service techniques for persons with progressive sensory loss.
- Services for individuals who are deaf-blind require comprehensive planning in order to be effective.

- Supported employment has been an underutilized resource in providing vocational services to individuals who are deaf-blind.
- There is no consistent method for collecting data and tracking the experience of individuals who are deaf-blind who are receiving rehabilitation services.
- Individuals who are deaf-blind could obtain community participation through supports provided through independent living centers, yet often these services are not developed or available.
- Early planning and inter-agency coordination is essential for the successful transition of youth who are deaf-blind from education to adult services. Parent/family member involvement is necessary to formulate an individualized plan that reflects the appropriate choices and abilities.
- Persons over age 65 with dual sensory loss make up a growing population in need of services.

We must acknowledge some wonderful examples of individual successes and innovative programs. Helen Keller National Center, its regional offices and affiliate programs and Technical Assistance Centers (TAC) have done an outstanding job of providing training and technical assistance to a number of individuals who are deaf-blind, their families, and service providers. Yet I believe they would be the first to agree that

we are only at the initial stages in addressing the adult service needs of individuals who are deaf-blind on a comprehensive, coordinated, and national basis.

To begin to address this as an issue that can be affected by policy statements and recommendations requires that we ask, "What is unique about the population of adults who are deaf-blind?" "What are the barriers in the adult service system that prevent the obtainment of eligible services?" and "How do we remove barriers in order to allow services to be accessible?" I agree that the passage of the Americans With Disabilities Act and congressional intent in the reauthorization process give us a mandate to proceed; however, I believe we need to be proactive in definition of service needs of all adults who are deaf-blind if they are to be included in new planning and changes.

The Population

I support Doug's call for the need for a federally sponsored database in assessing the size and characteristics of the population of adults who are deaf-blind. I would supplement this recommendation by suggesting that currently we do have a database of children who are deaf-blind and that this is a source of future information on adult service needs and experiences. This could be done by adding a five-year follow-up study mandated through state and multi-

state projects under Section 307.11. These data should be available to the National Register at Helen Keller National Center.

Before proceeding with an examination of barriers within the adult service system, there are some common characteristics that will give us a basis for discussion of accessibility for adults who are deaf-blind:

- The population of persons who are deaf-blind is heterogeneous with regard to the effects that combined sensory loss has on an individual's educational, functional, and vocational capacities. A large number of persons who are deaf-blind may have additional disabilities. Systematic programming for this population must address individual needs and capacities. Often, services need to be coordinated from a variety of sources and disciplines.
- The most common effect on people of all ages who are deaf-blind is impairment of communication. Development of communication capacities through individualized intervention is essential. Individual learning and access needs may vary, yet if persons who are deaf-blind are to benefit from services, communication accessibility and enhancement must be at the center of program planning whether it is for supported employment, independent living, or college attendance.

- Etiology may be present at birth as in rubella syndrome or later in life as with Usher syndrome or aging. In both cases sensory capacities may vary and change over time so that services which support living, work, and social goals may need to be modified.

In returning to the themes of Doug's paper, access, choices, and empowerment, I would offer communication accessibility, coordination of multiple services, and flexibility in service delivery as the means for achieving these goals through systems change and modification. I would like to illustrate this point by presenting a process of identifying and removing barriers to services for adults who are deaf-blind.

The Massachusetts Plan

I will draw from our experiences in Massachusetts, not to offer a model for replication, but to examine issues which I feel are critical if we are to comprehensively approach a service system design that is responsive to the unique needs of this population. Time does not permit a complete accounting of our efforts and this is available in other sources (Barrett, Carr, & Covert, 1987; Covert & Carr, 1988).

In 1984 a task force was commissioned within the state of Massachusetts to examine the service needs of individuals who are deaf-blind and how those needs were

currently being met by state agencies. The task force consisted of consumers, parents, educators, and representatives from key state agencies. The impetus for this effort came from multiple sources: (a) anticipation of the transition from education to adult services of approximately 75 young adults who were deaf-blind during the years of 1987-90; (b) advocacy from consumers frustrated by case management systems that were inaccessible due to lack of expertise in communication and service needs; (c) parents who complained of being shuttled from agency to agency when seeking to identify adult service responsibility; and (d) a follow-up study of individuals who had previously transitioned from state and multi-state projects under Section 307.11 (formerly VI-C programs) which found that many of these individuals were confined to their homes without services and supports.

The task force examined more than a dozen services including residential, vocational, recreational, transportation, interpreter, independent living, medical, social, and so on, requested by individuals who are deaf-blind and their families. Various aspects of these services could be accessed from at least nine different state agencies. As was expected, there existed huge gaps in the continuity of services needed by the range of persons who were deaf-blind.

A report issued by the task force identified service gaps in the

aforementioned areas and developed numerous recommendations to address these gaps. Central to the outcome of the report was the realization of the need for change in the system of service delivery for individuals who are deaf-blind. I believe these recommendations are crucial in developing accessible systems of adult services. These include the following:

- The assignment of a lead agency, with responsibility as a point of entry into the adult service system, to coordinate all the resources of that system.
- A system of case management by personnel with background and expertise in assessment, communication, and development of comprehensive plans of service to meet the unique needs of individuals who are deaf-blind.
- Capacity to provide technical assistance and training to state and community agencies to promote accessibility for individuals who are deaf-blind.
- Coordination of program development to meet identified service gaps within the system.

Through coordinated advocacy and lobbying by parents, consumers, and professionals, the above recommendations were implemented by the state legislature through appropriation of funds. The State Commission for the Blind accepted responsibility as lead agency and utilized both new and prior funding

sources to create a Program of Services for individuals who are deaf-blind. The program consisted of a director, supervisor, six case managers, and three persons with responsibility for program development, technical assistance, and training. The staff of this program functioned primarily as a team and consisted of persons with a broad spectrum of experiences in providing services to individuals who are deaf-blind and who are of differing ages and capacities.

The initial task of the program was to coordinate and develop a range of vocational and residential services for the population of individuals who are deaf-blind and transitioning from education to adult service programs. There were significant resources appropriated for this task and these services were developed for more than 75 people in a three-year period. Again, time and space do not permit me the opportunity to relate the full details of this accomplishment. I would like to highlight some key points:

- There is no one model of residential or vocational programs that we can prescribe for persons who are deaf-blind. A continuity of service options is needed that is responsive to and developed from individual needs, choices, and capacities.
- Communication and access to information from a variety of modes are essential for the achievement of quality of life goals in residential, vocational, and

community domains and yet are often the most difficult to achieve.

- Resources for increased staff and availability for personal interaction need to be examined and included in program development. Along with the lack of funding, the lack of experienced persons and training options is the primary barrier to comprehensive program development.

I realize that the amount of resources available for the development of this program was unique. It is probably not realistic to expect a similar level of funds across all other state systems. Yet I believe there were also a number of benefits that centralization of case management within a lead agency had in improving accessibility of services for individuals who are deaf-blind. The majority of examples I will offer here were achieved without additional funding; instead they were achieved by examination of how existing resources could be coordinated and adapted for enhanced accessibility.

Centralized Information and Referral

The creation of this program provided consumers, families, and other agencies a single access point for information on resources available through state agencies for individuals who are deaf-blind. Given the communication needs of this population, I believe this is essential for system accessibility and

individual empowerment through informed choices.

Coordinated Case Management

Case managers within the program had access to the social, vocational, and independent resources of the agency. This was crucial in the development of plans which supported the personal, living, and employment goals of individuals. Issues of communication, transportation, and acquisition of other supports were integrated across this planning and implementation.

Utilization of Specialty Support Services

Training and technical assistance were provided to other agency programs whose services were utilized by individuals who are deaf-blind. Examples include the integration of adaptive communication techniques within instruction in orientation and mobility, the inclusion of provision and training in use of hearing devices, and communication training within the agency program for individuals who are blind and over age 65.

Coordination of Inter-Agency Resources

During my time as director of this program, I cannot think of a single state agency's resources that were not utilized in some way in the development of a comprehensive service system. This ranged from minimal to major collaboration, but

illustrates the continuum of services needed and the enormous task in providing accessibility for all individuals who are deaf-blind. Initially, we worked most closely with the Commission for the Deaf in enhancing the availability of interpreter resources and technology. We also assisted the Department of Elder Affairs in identifying and providing services to individuals with dual sensory impairment in nursing homes. We advocated within the Department of Mental Retardation for community placements for individuals who were deaf-blind and in state institutions. We collaborated with the Department of Mental Health to identify resources for out-patient and in-patient services.

Finally, do I believe we approached full accessibility and optimal individualization of services for all adults who are deaf? The answer is no. We struggled to obtain funds that would have replicated services such as those offered by the Deaf-Blind Service Center in Seattle, to be offered on a regional basis throughout the state. We were able to fund expansion of the programs of the Deaf-Blind Contact Center from Boston to include the central region of the state. We made inroads on accessing services through Independent Living Centers for the Deaf. We struggled with the state contracting system to provide flexibility to provide in-home residential supports. What I do believe was important is that we were working within a system to remove the barriers of that system and gain improvements in service delivery.

I realize I have spent time illustrating state systems within a forum designed to examine federal systems and services. Yet I believe this was necessary to lay the groundwork for how Office of Special Education Rehabilitation Services (OSERS) directives can lead the way in initiating accessible systems of services for adults who are deaf-blind. It should be remembered that provision of adult services in state systems involves multiple agencies and community programs, of which rehabilitation is one aspect. I believe that leadership through the Rehabilitation Services Administration (RSA) could provide great benefit in the coordination of adult services for individuals who are deaf-blind.

I would like to return to some recommendations offered by Doug in his paper and then supplement with recently proposed recommendations by the National Coalition on Deaf-Blindness.

Recommendations

Personnel Training

Doug spoke to the integration of competencies in the pre-service and inservice curricula personnel preparation grants awarded by the Office of Special Education Programs (OSEP). I believe this recommendation should receive a strong endorsement and would like to add some additional details:

Targeted training programs. I believe this recommendation would be most beneficial if those programs are targeted that prepare professionals most likely to be involved in service provision to adults who are deaf-blind. Specifically these include preparation programs for rehabilitation counselors for individuals who are blind and individuals who are deaf, orientation and mobility specialists, and rehabilitation teachers.

Pre-service programs in education. In developing a system of community-based services for individuals who are deaf-blind in Massachusetts, our biggest obstacle, once funding was secured, was hiring staff with any expertise in working with individuals who are deaf-blind. Often contracts would go unbid or undeveloped. Our strategy was to fund at least one position in each program with a salary competitive with those offered in education programs and to recruit directly from those programs. The lack of funding of personnel preparation programs for education of individuals who are deaf-blind is compounded by the needs in adult services. With limited resources we must look to those programs to include competencies and expertise to cover both areas.

Agency staff development. In recent years RSA has cited deaf-blindness as a priority in agency staff development plans. It is imperative that this be supplemented by training materials and targeted competencies in service delivery. Too often, I fear this priority is translated

into a sign language course rather than strategies for coordination of services. Also this development should be extended to community agencies receiving federal funds particularly in the areas of employment and independent living.

Choices and Control of Services

I would supplement Doug's discussion here by adding two points. First I think we need to speak to informed choices and choices of services that truly meet the needs of individuals who are deaf-blind. Services that are fractured and uncoordinated without planning or discussion of the unique needs of this diverse population do not present choices to consumers and families. They simply offer frustration and struggle. We, as a collection of persons concerned about high quality services for individuals who are deaf-blind, have much work to do in examining options of services within adult services and translating those options into understandable choices for other consumers, families, and professionals. Creative plans developed through personal futures planning can identify individual capacities and needs for supports. Systems modification such as those offered through enhanced Individualized Written Rehabilitation Programs (IWRP) and model Medicaid Supported Living programs can offer those supports. Yet I believe there is an information and advocacy link that needs to be made if those services are to be accessible for adults who are deaf-blind. I will

return to this point at the end of this paper.

Second, we must also remember that there are a large number of persons who are deaf-blind in state institutions and nursing homes. Without identification, advocacy, and assistance those persons are without choices, not just in service needs, but often in basic needs such as choices of food or clothing.

Inter-Agency Program Planning and Coordination

Doug has admirably articulated both a need and a vision for inter-agency coordination and service delivery for individuals who are deaf-blind. This is crucial if we are to approach true accessibility of services. I hope I have illustrated this need with some of our work and experiences in Massachusetts. I would reemphasize that, if our task is to advocate nationally and in individual states for a high quality life for all adults who are deaf-blind, and I would stress the word "all," then we must do the following:

1. Identify the diverse service needs of this population.
2. Identify the totality of services which rightly should be accessible.
3. Plan to offer those services in a coordinated delivery system addressing individual communication needs and supports.

I would further add that advocacy will only be successful if it is undertaken by a coalition of

consumers, families, and professionals in education and rehabilitation. We cannot afford to be fractured or divisive if we are to undertake the task of improving adult service delivery for all individuals who are deaf-blind.

Recommendations of the National Coalition on Deaf-Blindness

Finally, I would note as important the position paper of the National Coalition on Deaf-Blindness on reauthorization of the Rehabilitation Act. This paper includes specific recommendations to RSA regarding improvement of rehabilitation services on a national level for individuals who are deaf-blind. Several recommendations have been stressed in my paper, specifically, vital needs in personnel preparation. Others include the following:

1. Monitor and mandate the inclusion in state plans of procedures for the delivery of rehabilitation services for individuals who are deaf-blind. Planning will include the following:

- assignment of lead agency
- prioritization in order of selection
- determination of appropriate evaluation and eligibility procedures
- casefinding, referral, and intake procedures
- coordination of support services for communication, vision, and hearing

- utilization of supported employment along with appropriate supports and observation of progress
- requirement that transitional planning begin at age 14
- specific development and coordination of independent living services

2. Issue a minimum of four 5-year grants targeting model service development and capacity building.

3. Adopt a uniform definition along with a specified coding and tracking system to provide data on the experiences of individuals who are deaf-blind who are receiving rehabilitation services.

4. Develop three multi-state demonstration projects in supported employment to examine a longitudinal data base of costs, benefits, supports, and sensory aids in accessing employment for individuals who are deaf-blind.

5. Target funding to advance research and training to further develop personnel training, program models and components, and use of technology.

6. Identify a minimum of one RSA staff specialist with people who are deaf-blind to monitor the development and content of individual state plans, provide technical assistance to state agencies, and provide oversight in target grant development.

I also urge RSA to work in collaboration with representatives of the National Coalition on Deaf-Blindness on the implementation of the above recommendations and to create dialogue on future initiatives.

The Missing Link

In closing, I wish to add that, over the last few years, a body of literature has been developed urging us to examine issues of quality of life for individuals with disabilities and to develop quality assurance planning in program development (Bradley & Bersani, 1990). In discussing this issue with Mary O'Donnell several weeks ago, I was reminded of something that happened when I was involved in the development of community residential programs.

At the time I was involved in a struggle with the administration of one program in trying to develop specific staff training and program components to address the communication needs of four persons who were deaf-blind. At the beginning of one of our meetings, when I was determined these issues would be resolved, the administrator handed me a copy of a quality assurance review of the program conducted by a newly commissioned family/citizen advisory board, which incidentally, did not include either family members or individuals who were deaf-blind. The report lauded the program as exemplary. It cited capacity measures of community participation, access to neighborhood

resources, and variety in recreation activities. Indeed, these and other wonderful things were happening, but they were happening without any interaction with the individuals who were deaf-blind and living in the program. There were no modified calendars or systems to help people understand when activities would take place or to express opinions or choices about those activities. Several staff in the program were new, yet there had been no effort in training in the communication methods of the individuals. As a result, interactions around basic life needs were missed and ignored.

I believe this illustrates the link I referred to earlier in this paper. That is the link between what we know about "best practices" in service delivery and "best practices" in providing services to individuals who are deaf-blind. We have a tremendous task ahead of us to forge that link, in order to translate "best practices" into daily practices, in promotion of a higher quality of life for all individuals who are deaf-blind.

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