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THE DEVELOPMENT OF A STATE-WIDE MENTAL HEALTH SYSTEM FOR DEAF AND HARD OF HEARING PERSONS

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Abstract

In many states coordinated mental health services for hearing-impaired persons is non existent. South Carolina had developed a model system for providing accessible mental health services to hearing-impaired persons on a state wide basis. This paper describes the evolution of that system and the components which make it a model for other states seeking to provide similar services.

Julia was born in 1947, to alcoholic parents, in a mid-sized Southern city. At the age of 3 years, she was diagnosed by a pediatrician as being profoundly deaf. Apart from language and listening delays, her developmental milestones were attained normally, and she entered a large residential school for the deaf, at the age of five. The school was located some 150 miles from her parents' home, and necessitated her living in the dormitory on weekdays, returning home on weekends. At the age of five years, Julia's parents divorced, and when she was seven years old, her mother remarried another man who was also an alcoholic.

At approximately eleven years of age, Julia's stepfather began sexually molesting her, during those periods she resided at home. In his eyes, she represented the "perfect victim" since because of her deafness, he believed her unable to "betray the secrets" of the abusive activity which was going on. In later years, Julia reported that her mother was aware of the activity that occurred between her stepfather and herself, and on several occasions, her mother forced her to perform sexual favors for her stepfather.

At the age of 17, Julia was expelled from the residential school for promiscuous behavior, and for what is described in her school records as "bizarre thinking and conduct." After leaving school, she obtained work in the field of housekeeping, although she was unable to keep a job for any longer than approximately one year. She worked in several hotels, motels, and medical facilities. Throughout this period of time, she continued to reside with her mother and stepfather, and the sexual abuse continued unabated. She also attended a church which had services for the deaf, and a minister who was fluent in sign language. The minister reported a number of concerns related to Julia's beliefs that she was married to God, and that she had numerous children by this relationship. Julia additionally reported that God often spoke with her, sometimes at night, but also through the television and other electrical appliances such as light fixtures and the toaster. At one point, the minister was so concerned about Julia's mental health, that he accompanied her to a psychiatrist who prescribed a sedative to help her sleep, but provided no further treatment.

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When Julia was 25 years old, she attacked her stepfather with a broken beer bottle, inflicting lacerations. She was also superficially cut in several places as a result of this altercation. The police intervened, and Julia was arrested, but placed in a state psychiatric hospital, rather than in jail.

Julia remained in the hospital for approximately eighteen months, where she was treated with neuraleptics, but, according to medical records, her apparent hallucinations did not diminish. She was eventually discharged from the hospital and returned to her mother and stepfather's residence, where the sexual liaison between herself and stepfather began once again. She attempted to gain employment, but was unable to maintain a job for any appreciable length of time, and was hospitalized on several different occasions over the next twelve years.

During inpatient and outpatient treatment, a number of medications were prescribed, with little benefit to Julia's thought disorder. From time to time, interpreters were also used to assist in the treatment process and discharge planning, but Julia never revealed the fact or the extent of the sexual abuse that was occurring in her home.

In 1988, Julia was hospitalized again, after a particularly violent attack on her stepfather. As a result of this incident, her hallucinations and delusions became extremely florid and frightening, and she had to be placed in seclusion on several occasions as a result of fear of everyone in her environment, particularly males. After being in the hospital for ten days, a probate judge discharged her, once again back to her parents' home, but with little improvement in her symptoms. A day after she returned home, her stepfather again made sexual advances towards her but she was able to escape to a room where a handgun was kept. When her stepfather entered the room with the apparent intent of gratifying his sexual needs, she took the gun and shot him three times, killing him.

Julia was immediately arrested, charged with murder, but judged not guilty by reason of insanity. Although an interpreter was utilized during the legal process, there is considerable questions as to the interpreter's competence to convey the gravity of the proceedings in a manner which Julia understood, and also serious questions as to Julia's ability to participate in her own defense. Although the interpreter was aware of the history of sexual abuse, none of this information was ever shared with the court.

For the next two years, Julia was placed in a forensic psychiatric inpatient unit, and later transferred to a high management unit at a state psychiatric hospital. Although interpreters were occasionally provided for specific purposes such as treatment team meetings, she had very little opportunity to communicate with nursing or treatment staff, and was extremely isolated, being the only deaf person in the general psychiatric population.

Introduction

People who are hearing-impaired, like everyone else, from time to time find themselves in need of mental health services. Deaf people experience the same kinds and degrees of mental illness as the rest of the population, but what distinguishes deaf people from others is the inability of the mental health system to adequately serve their needs, due primarily to the communication barrier imposed by the hearing impairment. While mental health services are usually available to the entire population, most mental health services and programs are inaccessible due to language and communication barriers.

In 1973, section 504 of the Rehabilitation Act was enacted by the Federal Government, which stated,

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> "No...handicapped individual in the United States...shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal assistance."

In 1990, the Americans with Disabilities Act expanded and more clearly defined the scope of the rights of people with disabilities to receive equal treatment.

Since its establishment in the early Nineteenth Century, the South Carolina Department of Mental Health has likely provided some services to persons who have hearing impairment. However, because communication is often difficult, the needs of these individuals have been largely unmet; historically, services usually amounted to little more than long-term hospitalization for the most disruptive individuals. Little or no treatment was available to the majority of deaf persons with a psychiatric disability.

In 1984, the Department conducted an assessment of mental health services available for deaf persons nationally and in South Carolina (Brant, 1984). The report concluded that appropriate services were woefully lacking nationally, and virtually non-existent in South Carolina. The report recommended: (1) that a statewide continuum of services be established; (2) that outpatient services be established on a regional basis; (3) that an inpatient unit be established for deaf persons who use sign language; and (4) that deaf individuals in need of housing be placed in appropriate supported living situations where American Sign Language is used fluently.

Mental Needs of Deaf and Hard of Hearing People

After studying the results of an exhaustive literature search, discussions with a statewide task force, and a comprehensive needs assessment, a number of significant program improvements were identified, which, if implemented, would make mental health services more accessible to deaf and hard of hearing people. The first of these was for an appropriately staffed and supported inpatient treatment unit.

While inpatient services may seem, at first glance, to be somewhat inappropriate as a top priority when the concepts of deinstitutionalization and community responsibility for mental health care are being widely promoted, there was, and will likely continue to be, a small number of seriously mentally ill individuals in need of the support and protection of an acute care inpatient facility. Criteria for the establishment of this program included:

1. Enthusiastic support of the facility administration.
2. Available services for psychiatric as well as substance abuse patients of all ages. The reason for including all of these populations in a single treatment unit is the economy of sharing the highly specialized staff members needed for these treatment programs. In accordance with accreditation guidelines, each age and treatment group needs to be housed in appropriate units.
3. To have access to appropriate community mental health services to ensure after-care support.
4. To be located in an area in which the support of the deaf community may be elicited.

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Regionalized Community Mental Health Services

It was proposed that qualified mental health professionals with fluency in American Sign Language be located in strategic locations throughout the state, covering multiple mental health center catchment areas. These professionals would provide direct client service, case consultation services, staff training and a host of other services in support of deaf and hard of hearing people who are unable to directly access the traditional mental health system.

It is acknowledged that interpreter services need to be available throughout the state, in all mental health programs and facilities. While there are a number of limitations and drawbacks to utilizing interpreters, the need for these services is unavoidable, and while, by definition, they provide less than equal treatment, interpreters are certainly an improvement over communicating through writing notes or attempting to lip read for deaf persons with mental illness.

Appropriate housing was found to be a significant need among members of this population. The numbers of "homeless" deaf and hard of hearing people with mental illness is on the increase, and the options available to such persons are extremely limited in South Carolina, as well as most other states. Most deaf people with mental illness live in family situations, but in many cases, it is this aberrant family environment which exacerbates the problems imposed by mental illness. It has been observed that minimal communication tends to exist in such homes, and deaf family members are unable to appropriately express needs, concerns or feelings. A broad range of housing options needs to be available, in which communication is not a barrier, but a facilitator to appropriate daily living experiences and recovery from the symptoms of mental illness. This range of options may need to include group homes, supported apartments, independent apartments, nursing homes and shared living situations. All housing needs to be affordable, decent, and available throughout the state.

Existing emergency intervention services also need to respond to the needs of deaf and hard of hearing people. Crisis telephone lines need to be accessible by TDD, and face-to-face interventions in emergency situations must be structured so as to be able to accommodate the communication barriers imposed by a significant hearing impairment.

Psycho-social rehabilitation programs need to be developed and/or made accessible to deaf individuals. In some circumstances, deaf people may be accommodated in existing programs, while in communities where the size of the population is sufficient, specialized programs serving only deaf individuals need to be developed.

Special services for deaf and hard of hearing children are another area of need. Research indicates that among hearing-impaired children, the rate of emotional disturbance may be as high as 27% (Klopping, McTigue & Critchfield, 1985), but in most educational systems, especially mainstream programs, virtually no appropriate intervention services are available, and emotionally/behavioraldisorderedhearing-impaired children go largely unserved. It is likely that such children will develop into adults with significant mental health needs.

Inpatient and outpatient services to persons with addictions to alcohol and other drugs need to be developed and supported at the community level. Integration with non-hearing-impaired persons might be feasible for some services, but most intervention services need to be provided by professionals highly skilled in addiction treatment and deafness. Detoxification and treatment programs also need to be accessible to deaf and hard of hearing individuals.

Another area of significant need within the deaf community is for mental health information and prevention programs. The deaf community is severely handicapped by a lack of information about mental health issues in general. Services need to be provided to all age levels, and appropriate education and prevention activities must be supported to reduce the information gaps which exist.

Program Implementation

In 1988, a statewide plan for mental health services for deaf and hard of hearing people was completed and attached to the overall South Carolina Department of Mental Health State Plan. Also in 1988, a program director was hired to coordinate services to deaf and hard of hearing people. The director was tasked with the implementation of the plan, and the development of resources to cover the cost of these services.

In 1989, a complaint was filed with the U.S. Office for Civil Rights, by South Carolina Protection and Advocacy for the Mentally Ill, alleging inappropriate inpatient treatment services for deaf and hard of hearing individuals. As a result of this complaint, the Department of Mental Health committed itself to provide not only appropriate inpatient services, but also to develop a continuum of community options as well, to ensure that deaf and hard of hearing patients have access to a broad range of mental health options and are not limited to a restrictive inpatient program.

In January, 1990, deaf patients were transferred from various inpatient facilities throughout the mental health system to a single lodge at Patrick B. Harris Psychiatric Hospital, and staff members fluent in American Sign Language were recruited to provide care and treatment for these people. A social worker, psychologist, activity therapist, program nurse specialist, several mental health specialists and a driver were all employed to meet the unique needs of these patients. Fluency in American Sign Language was required at the outset prior to these individuals being offered a position. Three of the staff members are hearing-impaired themselves.

Interpreter services were developed through a contract with the South Carolina School for the Deaf and the Blind, which operates a statewide interpreter referral service. Through this contract, all mental health services and programs throughout the state have become accessible to many deaf persons, and any mental health professional who needs these services is able to access them with minimal advance notice. Since several of the staff members are also deaf, these interpreter services are used as a communication bridge for staff members as they interact with other professionals. An additional feature of the interpreter contract is that it also incorporates instruction in sign language. Any mental health program wishing to establish sign language classes is encouraged to do so, with sign language instruction being provided by certified interpreter/teachers. A training program for interpreters functioning in the mental health setting is offered by South Carolina Department of Mental Health. This training orients interpreters to the unique needs and demands of interpreting in the mental health setting and provides some assurance to the mental health system that confidentiality and cooperation are protected and enhanced.

Staff training is an area of intense need by all members of the mental health community. The length of time necessary to develop an appropriately trained mental health professional in deafness is variously estimated between three and five years. Training in deafness includes not only the learning of sign language, but also of deaf culture, sociology, and numerous other critical aspects related to deafness. While basic signs can

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be learned relatively quickly, neophyte signers often falsely assume that they can communicate with deaf persons, even though they are unable to understand the language used by deaf people. Training of inpatient staff and community mental health center personnel has been an ongoing challenge and responsibility. Regular training is offered in the following areas: orientation to deafness, psychology of deafness, cultural aspects of deafness, counseling and psychological services as well as the use of interpreters. Other deafness related training options have been developed and offered as needs arise.

Community mental health counselors for the deaf are available in two mental health centers, and the remainder of the state is covered by four regionally based mental health professionals. These professionals typically cover three or four mental health center catchment areas, and provide both direct and indirect community-based services. Since reliable data concerning the size of the deaf population in South Carolina is not presently available, an arbitrary figure of one regional counselor for every 800,000 individuals in the general population was initially proposed. After approximately two years of experience, it is recognized that this ratio is inadequate to meet the need, and additional positions are being considered.

As mentioned earlier, the need for appropriate housing is critical if mental health services are to be successful with this population. An eight unit apartment project with support staff available around the clock is currently under development, with more facilities being added to the currently inadequate pool of housing alternatives.

Resource Allocation

Costs for appropriately serving deaf and hard of hearing people within the mental health system need not be significantly greater than those of the general population. During the initial discussion phase regarding an inpatient program, there was considerable debate regarding the advisability of establishing a separate, free standing unit for the deaf versus integrating deaf patients into the general psychiatric population. Pros and cons were weighed on both sides, and while everyone was not in total agreement, economic factors dictated the integration of the deaf program into an existing psychiatric unit. Advantages of this approach are significant in terms of economic feasibility. Nursing care, attendant support, psychiatric services and general hospital support services are all shared with other hospital programs. A social worker, psychologist, program nurse specialist and activity therapist were added to the staff to work exclusively with deaf patients, but it was not necessary to staff and maintain a free standing unit. It is acknowledged by the hospital administration that deaf admissions have priority for service on the particular lodge housing the program, and if bed space becomes a problem, non-hearing-impaired patients are moved to other psychiatric units in the same hospital. Building modifications were required, including a visual alarm and signalling system, captioned decoders for televisions, text telephones (TTs), and audio amplification equipment. Nevertheless, when all appropriate costs are factored in, the cost for serving deaf patients have been determined to be only $28.00 per day more than serving the general psychiatric population.

Funding for the community mental health positions has been an area of continuing interest. Although these individuals are hired as general mental health counselors, their duties tend to deviate somewhat from the norm, since they are required to travel a great deal, and spend their time working at various mental health center sites throughout the state. Automobiles, travel expenses, telecommunication devices, amplification

equipment, and visual signaling devices are some of the additional costs associated with this type of service delivery. Annually, a supplement of $40,000 is provided to support each of these professionals, to cover salaries, fringe benefits, and other expenses. While this amount does not cover the entire cost for the services they provide, their services are revenue generating, and in the first two years of program operation, this amount appears to be adequate to cover the additional costs incurred.

Professional communication and collegial support among deafness professionals is an area of significant need. South Carolina is a largely rural state and because professionals are working significant distances from one another, several unique approaches have been developed to assist the staff in accomplishing the task of delivering mental health services to deaf and hard of hearing people. All staff members, both inpatient and outpatient, as well as administrative meet together at least bi-monthly, to discuss common concerns, to receive training, and to provide support and encouragement to one another. In addition, a statewide computer electronic mail system has been established in which all of the professionals serving deaf and hard of hearing people are linked together using an international deafness-related messaging service. This approach has allowed South Carolina's deafness professionals to have rapid, personal contact with professionals throughout the United States, to receive consultation and information, and especially to share concerns with one another. Additionally, this electronic mail system has permitted higher quality patient services, since when a hospital admission is considered, the inpatient staff can be involved in planning, and when patients are ready for discharge, the hospital staff may be in direct contact with local counselors to make recommendations for follow-up services and also can periodically check on the progress of patients who have been discharged. Funding for the hardware for this system was obtained through a special project grant, and the entire system was implemented for less than $30,000.

While funding for any new program is usually a significant obstacle, it has been found that appropriate services to deaf and hard of hearing people can be provided for a cost which is not significantly greater than that for providing mental health services in general.

Conclusion

In a time of declining revenues and economic hardships, the South Carolina Department of Mental Health has demonstrated a commitment to development of services to a previously underserved and virtually unknown population of persons with mental illness. Obstacles in the development of these services have been significant, but the need for these services dictated innovative approaches be taken and significant obstacles challenged. While far from being a perfect system of services, the steps taken thus far have demonstrated the feasibility of providing these services and the intrinsic worth of doing so.

Conclusion to Case History

In 1990, Julia was transferred from the high management unit at the state psychiatric hospital, where she was the only deaf patient, and placed with the other deaf patients at another hospital. She continued to exhibit bizarre speech and emotional behaviors, but for the first time in her many years of psychiatric treatment, she was able to express some of the internal conflicts she had been experiencing. In particular, she was able to share, in group therapy, the trauma she had experienced at the hands of her abusive stepfather.

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Other patients and staff members were able to empathize and provide support for her. In an environment where she could receive information about her illness and about medication, her medication was changed to Clozaril, and within a period of two months, nearly all of her bizarre thoughts and behaviors came under control. She assumed a leadership role among other patients, and began to assist staff members in providing care for more severely disturbed individuals. After an appeal to the court, she was discharged to a community placement where she is receiving follow-up mental health services, including case management, by a counselor fluent in American Sign Language. She also receives home health care services to help her with medication management and control of her diabetes. She is adapting well to community living, and is currently pursuing employment in the housekeeping department of a large hotel, for which she received vocational training during her lengthy hospitalization in the deaf program. Without the availability of appropriate and accessible services in the mental health system, the likelihood of her ever living outside an institutional environment would have been extremely bleak.

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