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PERSPECTIVES ON DEAFNESS AND MENTAL HEALTH

McCay Vernon, Ph.D.

HISTORICAL PERSPECTIVE

Until 1955 there was not a single mental hospital or clinic anywhere in the U.S. or the world to serve mentally ill deaf people (Rainer and Altshuler, 1971). A few schools for the deaf had been doing some basic psychological testing, but even in the schools there was no treatment for mental illness (Levine, 1963). Instead, deaf patients who were psychologically disturbed or thought to be disturbed were dumped into regular mental hospitals where neither the staff nor other patients could communicate with them. Such placement was and is essentially anti-therapeutic custodial isolation more for the convenience of society than for the humane care of the deaf patient.

Finally, in the 1950's Edna Levine, Boyce Williams, and some other leaders in deafness interested the famous psychiatrist, Franz Kallmann, in the condition of deafness. Actually Dr. Kallmann's primary interest was not deafness, but a genetic biological theory of schizophrenia he thought could be tested by studying deaf twins and deaf schizophrenics.

Dr. Kallmann's reputation and the support of the Rehabilitation Services Administration enabled the first mental health clinic for deaf patients in history to open in 1955. By then, Dr. Kallmann had recruited two bright resident psychiatrists, John Rainer and Ken Altshuler into his work in deafness. Hans Furth, now a professor of psychology at Catholic University, was another of the brilliant young researchers with Dr. Kallmann during these early

years at the New York Psychiatric Institute.

Even before Kallmann entered the field of deafness, a young psychiatrist at St. Elizabeths Hospital, Luther Robinson, started taking an interest in deaf patients. This was in 1947. Finally in 1963 Dr. Robinson established an in-patient program for St. Elizabeths' deaf patients. His efforts were totally independent of the work being done by the New York Psychiatric Institute. Today the Mental Health Project for the Deaf at St. Elizabeths which grew out of Dr. Robinson's work is world renown as is that of the New York State Psychiatric Institute.

In 1966 another famous psychiatrist, Roy R. Grinker, Sr.; McCay Vernon, a psychologist in deafness; and Eugene Mindel, a young child psychiatrist who had had some experience at Gallaudet College, undertook a three year study of psychosis and deafness at Michael Reese Hospital in Chicago (Grinker, 1969.) They knew of the New York clinic and were building on the experience of Kallmann's group.

At about this same time, i.e., around the late 1960's, the first treatment services for deaf children were begun at Langley Porter under Hilde Schlesinger and Kay Meadow (Schlesinger and Meadow, 1972). The former had been a dormitory counselor at the Arizona School for the Deaf and Blind where she had begun to learn sign language. Dr. Meadow was a sociologist who brought her research and administrative skills to Langley Porter to work with deaf children.

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Once these four pioneering projects began to publish their findings and to present at professional meetings, many others became interested. Thirteen state hospitals in the U.S. established at least some basic units to serve deaf patients (Goulder, 1976). In these units they taught staff to use sign language. The work in the U.S. soon spread to other countries such as England, Sweden, Norway, and Denmark all of which began to group deaf patients together and provide them mental health services (Montgomery, 1978; Robinson, 1978).

Despite these encouraging beginnings, today in the United States only two percent of the 43,000 deaf persons needing mental health services are receiving them (Robinson, 1978). Many of the programs offering services are pitifully understaffed. Most of the mental health personnel in deafness are unqualified by the professional standards held necessary to treat hearing patients (Cantor and Spagins, 1977; Curtis, 1976; Levin, 1971). Remember, only 13 of 50 states have any hospital program at all.

MAJOR TRENDS IN MENTAL HEALTH

Before getting deeper into the current issues of mental health and deafness, let's look at some relevant trends in the general field of mental health and relate them to deafness. This is important because what happens to deaf patients is inevitably determined by the policies governing mental health services for the general population, even when such policies are inappropriate for deaf people.

Deinstitutionalization of Mental Health Services

In the last twenty years there has been a major push to get patients out of mental hospitals into the community (Sharfstein, 1978). As a result the population of these hospitals has dropped to two-thirds of what it had been (Bassuk and Gerson, 1978). This apparent progress has been offset by the huge numbers of these patients who have to be readmitted in a sort of revolving door policy. For example, in 1972 sixty-four percent of hospital admissions

were, in fact, readmissions (Bassuk and Gerson, 1978). Often, pumped full of drugs, these patients leave the hospitals as "walking zombies" (Berger, 1978). They are often relegated to bleak lives in nursing homes, to run-down single-room occupancy hotels, and to skid row rooming houses.

It is these new "less restrictive" facilities which are taking the place of hospitals. Even when the facilities are satisfactory, follow up in the community is often inadequate, funding insufficient, and there is a confusing overlap of programs, many of which undercut each other (Bassuk and Gerson, 1978; Lamb, 1979).

In this rush to deinstitutionalization, many basic realities have been ignored. For example, some forms of severe emotional disturbance are incurable and require hospitalization (Bassuk and Gerson, 1978). Another reality is that care in the community is far more expensive than had originally been expected. Most importantly of all, the fact that neither the hospital nor the community is inherently more humane has been ignored. In fact, the entire movement to deinstitutionalization has made the assumption, as yet unproved, that the community is inherently the more humane setting for the mentally ill. One other factor of relevance: Hospital programs, where all services are under one roof, are a hundredfold easier to administer than community services where many separate programs have to be coordinated (Bassuk and Gerson, 1978).

The issue that must be raised is how all of this affects deaf people. First, because the population of hospitals has dropped to the point that they are now two-thirds empty, administrators have become far more open to new programs that will fill the empty beds. Thus, when a unit for deaf patients is proposed to a hospital administrator there is often a willingness to provide space and some staff. We in deafness have failed to be as aggressive as we should in going after this space in each of the 50 states. This is evidenced by the fact that only 13 states have units for deaf patients in their state hospitals despite the fact that these hospitals are two-thirds empty.

Along with this positive consequence of potential available space are two negative ones.

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The deaf patient is even more vulnerable than the hearing patient to the inadequate community programs to which he is sent. Once he arrives in the community there is almost never anyone in the program there who can communicate with him. He also faces the task of negotiating with a complex bureaucracy of programs in order to get what he needs to survive. For the deaf patient this is a nightmare.

Another problem in the deinstitutionalization picture is the catchment area concept. It says, in essence, that every patient who is from a given geographic area must be hospitalized and treated with others from the same place. The idea is to keep patients from the same home communities together. This may have value for hearing patients, but it ignores the fact that deaf people represent a community. Thus, they should be housed together. However, the catchment area concept precludes them from being grouped together in a hospital. It denies them the companionship of other deaf people and the treatment staff who can communicate with them in sign language.

Community Mental Health Centers

While at one end of the continuum hospitals have been emptied, at the opposite end there has been the spawning of federally funded community mental health centers (Sharfstein, 1978). In the optimism, social idealism, and large budgets of the sixties these centers were started. In the seventies they are still surviving, but precariously (Bassuk and Gerson, 1978; Sharfstein, 1978). For example, when after 51 months of existence the promised non-federal dollars were not forthcoming (an old story), Uncle Sam had to come in with an eight year extension of the original proposal establishing the centers. These community mental health centers are now like a prehistoric dinosaur in that they are a huge organism unable to obtain the fiscal nutrients that are required for their survival.

Deaf patients have, with few exceptions, been totally ignored by community mental health centers. The system itself is anti-deaf, not out of maliciousness or ill will, but because it is intrinsically impossible to have the

specialized therapists and staff deaf patients require in the small clinics that characterize this movement. The only exception to this generalization would be in the large cities where certain of the centers could have the specialists needed to serve deaf patients appropriately.

Current Status of Primary Prevention

Primary prevention of mental illness means stopping it before it happens in much the same sense that the small pox vaccination assures that small pox never occurs. Naturally, the primary prevention of such a dreaded condition as mental illness has a powerful, almost irresistible, attraction (Lamb and Zusman, 1979). It generates slogans such as "Curing is costly . . . prevention is priceless." However, we are now finding that most major mental illnesses, e.g., schizophrenia and manic depressive psychosis, are in large part genetic and biochemical (Ketty, Rosenthal, and Wender, 1976). Therefore, mental health practices cannot do as much to prevent them as we once had thought and hoped. In fact, not only are such practices unable to prevent major mental illnesses effectively, they may also be limited in their capacity to modify these illnesses (Lamb and Zusman, 1979).

When we leave the area of major mental illnesses and get into the primary prevention of neuroses, character disorders, unhappiness, feelings of distress, etc., we are dealing with behaviors fundamentally different from psychotic disorders. These behaviors are highly correlated with low socio-economic status, going to war, and extremes of poverty (Lamb and Zusman, 1979). To prevent these conditions requires a sweeping social and economic revolution beyond the scope of mental health workers. For example, the social worker treating an inner city drug addict, uneducated, living on welfare in a tenement, is treating a problem that could be described as at least 60 percent socio-economic and 40 percent mental. Curing the mental part of the difficulty may do little to cure the problem.

In view of these facts about primary mental health prevention, its potential to greatly reduce major mental illness in deaf people is

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limited. The breakthroughs we hope for will probably come more from the fields of biochemistry and genetics than from psychology, psychiatry, or social work.

Mental Health and Deafness Today

As indicated earlier, currently two percent of deaf people needing mental health care are getting it. Where are some of the biggest service gaps in an area that is almost nothing but one big gap?

Child Treatment Facilities

There are absolutely no in-patient services for deaf children in the United States. This is perhaps the most glaring gap of all. Almost every professional who works in the field of mental health with deaf people gets frequent calls from families and schools asking where a psychotic deaf child can get hospital care. The answer has always been, "There is no mental hospital serving deaf children." Appeals to establish such a hospital made to state and federal governments by leading scientists working in deafness have always been rejected. In the current political climate, unfortunately, no change in the rejection is foreseen.

School Psychology

A 1977 study (Cantor and Spragins) indicated that there were no programs in the U.S. preparing school psychologists to work with deaf children. In fact of the 178 persons who were working as school psychologists with deaf children only 9% had appropriate basic school psychologist qualifications. In addition they had no special training to work as school psychologists with deaf children. This year Gallaudet College has started a school psychology program.

Nebulously defined school counseling services are more prevalent, but are often provided by untrained staff (Curtis, 1977). Once again it is Gallaudet which has established a school counseling program to meet this need.

Services to Parents

The heart of any preventive program in deafness and mental health has to start with parents. What are their needs, if they are to

provide appropriate psychological support for their deaf children?

First, parents need strong counseling programs which are available to them at the time of their child's diagnosis. These programs should involve the self help model of Alcoholics Anonymous, i.e., they should involve parents who have successfully raised deaf children, deaf adults, and a therapist.

Second, parents need full awareness of the options and services available to their deaf child. Rarely is this information made known to parents early in the life of their child. For example, frequently, oral educational programs will get a deaf child early and never tell the parents of total communication or of programs using it. Another example relates to hearing aids. Often parents are led to believe these aids are a panacea to deafness when, in fact, they are useless to many profoundly deaf people.

Other needs of parents are professionals who understand deafness. For example, physicians are notoriously naive about what is appropriate for a deaf child yet parents depend on them heavily for advice (Vernon, 1976). Teachers who are totally unable to use sign language are given masters degrees to teach deaf children. Most rehabilitation counselors also lack such skills (Tully, 1970). In addition there are needs for psychologists, social workers, and psychiatrists able to work with deaf children and adults.

Programs for Mentally Retarded and Other Multiply Handicapped Deaf People

Only 14 percent of schools for the deaf and 30 percent of facilities for the mentally retarded have specific programs for those who are both deaf and retarded (Hall and Tarkington, 1972). There is also a gross lack of trained personnel to work with this dual handicap (Hall and Tarkington, 1972). Obviously many deaf retarded persons are either without services or are receiving treatment and education not geared to their needs.

Data on deaf people with other handicaps, but who are not retarded, is less complete. However, it has been clearly documented that there are no programs for huge numbers of

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these people (Vernon, 1975).

Lack of Psychological Tests

Many of the misdiagnoses that occur with deaf patients are due to the lack of available psychodiagnostic instruments. Cases abound of deaf people incorrectly hospitalized for years as mentally ill due to the use of inappropriate tests such as the MMPI (Rose, 1969). The MMPI and other verbal tests yield inaccurate pictures of most deaf person's mental status because the language level is too high. What these kinds of tests reflect is the language disability associated with deafness, not psychopathology. This problem needs to be corrected by the development of performance tests for use with deaf subjects.

Legal Resources

One could go on and on about the needs and the gaps in mental health services for deaf people. It is possible that appropriate enforcement of section 504 of the Vocational Rehabilitation Act of 1973 and other current legislation will correct these problems. Surely, if the law can require an interpreter be provided by any college a deaf student wishes to attend, the same law should demand that mental hospitals provide at least interpreting services to patients. Most hospitals do not.

FIRST STEP IN A SOLUTION TO THE PROBLEM

It is one thing to talk in idealistic terms about programs and needs. It is an entirely different matter to come up with a realistic attainable program that can be relatively easily implemented at the state level. The rationale for such a program and an operational statement of how it would be structured is given below.

Rationale

There are critical unmet mental health needs present in the deaf population today that are going to become greater in the future (Rainer and Altshuler, 1973).

1. There are hundreds of deaf youth and adults in state hospitals in the United States who are receiving custodial care which is actually antitherapeutic treatment

and isolation. Many of those people are misdiagnosed and do not belong in a hospital. Others are individuals capable of returning to society as productive members. This has been demonstrated in New York (Rainer and Altshuler, 1973).

2. Roughly 15 to 25 percent of deaf youth are dropped from school for broadly defined behavioral disorders. These youth need psychiatric and psychological help which they are presently not receiving. As a consequence, they are winding up in penal institutions, state mental hospitals, etc. (Vernon, 1972).

3. The few existing mental health programs are very primarily dependent upon "soft money" grant fund support. Solid longitudinal programs are needed and they require stable dependable support that can attract people with career interests.

4. Deaf non-hospitalized disturbed persons in the community who need mental health services get none.

5. Few preventive mental health programs exist for pre-school deaf children's families.

6. Many multiply handicapped deaf youth will not be able to function competitively in today's job market. Sheltered facilities are needed for these persons.

Recommendation

Federal government funding that will make it feasible and attractive for states to provide specialized centralized services for deaf youth and adults on an inpatient and outpatient basis should be provided.

Suggested means of implementing the recommendation

1. The money states now spend on custodial essentially non-therapeutic care could be used as funds which the government would match, provided the states agreed to centralize inpatient and outpatient treatment and assign professional specialists to these treatment centers. This funding should be on a permanent basis, not on short term grants. Alcoholics, narcotic addicts, sex deviants, etc., are now

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provided this kind of specialized care. The emotionally disturbed deaf deserve at least equal consideration. In the few states where populations are small, regional centers should be considered.

2. Programs should be established for orienting the specialists in state hospitals who are to work with the deaf.

3. Fellowships similar to those now available to people wanting to become teachers of the deaf should be available for professionals training in mental health-specialties—psychology, psychiatry, social work, etc.

4. In addition to the above-mentioned outpatient and inpatient centers which will serve the majority of emotionally disturbed deaf adults and youth within existing state mental health systems, one or two regional residential facilities should be established for handicapped (not mentally retarded) deaf youth; these should be research-service facilities with a primary responsibility to devise diagnostic and therapeutic approaches. More permanent sheltered workshop programs should be considered in these facilities.

5. Preventive mental health services should be provided involving home visits and parent counseling and training.

6. The same funding procedures used to provide for emotionally disturbed deaf hospital patients should be established for deaf retardates in state hospitals for the

retarded.

7. Public Law 89-313 and 88-164 should be considered for funding these recommendations.

Effects of De-Centralization

In conclusion, it is important to present a basic principle of crucial importance which applies not only to mental health services for deaf people, but to all services for those who are deaf. The principle generalizes beyond deafness to any small minority group. It must form the basis for any plan for delivery of services.

The principle is that the less centralized the service the more likely small minority groups, such as deaf people, are going to be excluded. This generalization has to underly our efforts to get mental health services (and other services) in the field of deafness. For example, when we have mainstreaming of deaf children in the educational system, they get lost. It becomes impossible, and financially exorbitant in most communities, to provide the supportive programs a deaf child needs. It is equally impossible to develop the mental health and vocational rehabilitation services unless they are centralized.

While trends to de-institutionalize mental hospitals and to mainstream in the educational system may be good for certain groups, they are devastating to deaf people.

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