



The Users of Institution Libraries

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MEDICAL AND TECHNOLOGICAL ADVANCES are lengthening the lifespan of people, thus increasing the number of individuals who will survive with disabilities. Under the social security program, the disabled population in 1960 numbered 450,000; in 1970, under the same program, this population numbered about 1.5 million.¹ Current social security statistics indicate a steady growth in this segment of the beneficiary population.²

It is difficult to ascertain the number of institution libraries throughout the United States,³ but because of legislation⁴ and increased political activity⁵ among the disabled, librarians will be serving this special group of people perhaps more so than ever before. Whether or not they will be served in institution libraries remains to be seen, since current trends are toward deinstitutionalization.⁶

For purposes of this chapter, institutions will be defined as those places of "residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life. . . [where the] enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution."⁷ Consequently, each resident lives, receives care and may work in a closely structured environment that reinforces conformity rather than individuality.

While the institution library will reflect administrative policy, and at times legislative posture, under the librarian's skillful and creative leadership it can become an accepting and pleasant place where institution

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residents may find sanctuary from the imposed lifestyle and thus a semblance of freedom to be themselves.

WHO ARE THE USERS OF INSTITUTION LIBRARIES?

The people who use institution libraries will be as diverse as their disabilities and as individualistic as their background and personality. Above all, they will be human beings who are developmentally, physically or psychiatrically disabled. To be disabled means simply to be less able. Yet, this word is often used synonymously with handicap and sometimes with impairment. In 1969 the World Health Organization's Expert Committee on Medical Rehabilitation distinguished between disability and impairment and used a British definition to distinguish handicap. These definitions are:

Disability: The reduction of functional ability to lead a fruitful daily life. It is the result not only of mental and/or physical impairment but also of the individual's adjustment to this.

Impairment: A permanent or transitory pathological condition resulting in diminution of functions.

Handicap: The disadvantage or restriction of activity caused by disability.⁸

Since disability refers not only to mental and/or physical impairment but also to one's adjustment toward the impairment, disability is a more workable word. It is also more workable when seen in the context of Hamilton's time-tested definition: "A disability is a condition of impairment, physical or mental, having an objective aspect that can usually be described by a physician. . . . A handicap is the cumulative result of the obstacles which disability interposes between the individual and his maximum functioning level."⁹

While this general understanding of disability is useful, some additional definitions will help to individualize the user of an institution library. Some of these users may be aging people or blind children. Some may be hearing-impaired adolescents, while others may be paraplegic adults. Some users may be mentally ill or mentally retarded. Thus, the institution librarian will be serving people who may be disabled developmentally, physically or psychiatrically.

To be developmentally disabled means to have a disability which originates before the age of eighteen, which may be expected to continue indefinitely, and which constitutes a substantial handicap to an individual.

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The disability is attributable to mental retardation, cerebral palsy, epilepsy or other neurologic conditions, and includes autism when it is found to be closely related to mental retardation and to require treatment similar to that required for mentally retarded individuals.¹⁰ A physical disability may be seen as an illness or as a bodily deprivation which "produces incapacity, and therefore limits or inhibits the performance of accustomed tasks."¹¹ The psychiatrically disabled are people who have deprivation of intellectual or emotional capacity or fitness. As defined by the federal government, it is "inability to engage in substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last or has lasted for a continuous period of not less than 12 full months."¹²

Not only will users of institution libraries bring their respective disabilities to the library, they will also bring their respective personalities and their respective social, economic and cultural backgrounds. Consequently, the librarian will meet the total person; responding to this total person can be a compelling experience. Some visibly disabled individuals may present such a startling physical appearance that the nondisabled person may experience an immediate visceral response; in addition, an attitudinal response may also occur. Furthermore, the response of an attitude as a value cannot be overlooked.

Uneasiness and uncertainty may arise as the user's limited physical and/or intellectual functions are recognized; the librarian may be embarrassed to find himself/herself staring at the disability; discomfort may be forthcoming as one worries about hurting the disabled person's feelings. Such responses may also be accompanied by attitudes about disability and about people who are disabled and hence different. How one views differences may depend on one's value system. To be different may be seen by some as deviating from the norm; Erikson notes that deviance is not a property inherent in particular forms of behavior, but is rather a property conferred upon that behavior by the people who have direct contact with it.¹³ The nondisabled person must be aware not only of the disabled individual as a total person, but also of his/her own attitudes and how these are communicated. Such self-awareness requires the librarian's self-evaluation and constant discipline in the professional use of self. This expectation can become less difficult when it is consciously remembered that disabled individuals are first and foremost human beings who share a common humanity with librarians.

SOME PSYCHOLOGICAL NEEDS OF INSTITUTIONALIZED DISABLED PEOPLE

While the spectrum and intricacies of human need cannot be studied here, a general awareness of some psychological needs besetting institutionalized disabled people can be noted in a manner which, it is hoped, will have utility for librarians working with these individuals.

Whenever anyone is removed from a familiar environment, he/she may experience fright and bewilderment.¹⁴ Older people may become disoriented; in fact, Otten and Shelley speak of a higher mortality rate among older people who are removed from familiar surroundings.¹⁵ According to one social worker in a state hospital, the newly committed patient's primary concern centers on the known environment, which usually means home and family.¹⁶

Just as it is important for human beings to feel needed, it is also important for them to feel secure; throughout time the family has provided security, and this has been buttressed by positive social relationships leading one to know that he/she shares in the life of others. When a person is institutionalized, these relationships become limited at best and often terminate. Various defense mechanisms may be utilized to cope with these and other traumatizing events associated with separation from one's known world.¹⁷

The child's reaction to institutionalization may have long-lasting effects on personality and behavior. The trauma of hospitalization and separation from parents is vividly illustrated in the film *A Two-Year-Old Goes to the Hospital*¹⁸ and Freud notes the regression which children undergo when they are separated from parents.¹⁹ Separation anxiety confronts institutionalized children of any age — nor is this anxiety a privilege possessed only by the young. Institutionalized children as well as adults may have to give up some hard-won independence. Such mastery is not easily relinquished by children,²⁰ and adults — who must surrender their usual sense of freedom to become "passive partners" with those upon whom they must rely for protection and care — may respond with various reactions.²¹

Motor restrictions may increase children's aggressiveness; it is not uncommon for a person who is a paraplegic or encased in a body cast to become verbally abusive.²² As Buxbaum says:

Aggression must have an outlet, and it finds this outlet in the motor apparatus. Hyperactivity in children can often be traced back to severe early restrictions. The reactions, in these cases, have contin-

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ued long after the original cause was removed. I remember a four-year-old girl who constantly ran through the schoolhouse and up and down the stairs; when we tried to stop her, she had a temper tantrum. We learned that the child had spent more than a year before starting the school term in a body cast.²³

The onset of puberty and adolescence can be a time of turbulence for a healthy teenager. If this adolescent is disabled and institutionalized, the conflict can be heightened. Wright comments that adolescence requires attention in any discussion of disability: (1) because the adolescent's self-concept is changing; (2) the physique plays a prominent part in this new look at self; and (3) the psychological situation of the adolescent can be dynamically overlapping both childhood and adulthood.²⁴ This observation is especially telling when Sorenson's findings point out that teenagers resent being defined as adolescents and dislike labels imposed by adults.²⁵ Consequently, the inner commotion of a teenager who carries the label of disability and who is also institutionalized can be viewed with understanding. Such understanding can be deepened when it is remembered that hormonal changes are also occurring during this developmental phase; the primary and secondary sex characteristics are developing, and all of these are accompanied by changes in weight, height, muscular development and body proportions.²⁶ Consequently, as Wright adds, the adolescent with a disability must cope with two persistent and overlapping situations, one owing to his/her disability and the other owing to his/her status as a child-adult.²⁷

Regardless of age and sex, disabled individuals are often perceived as different from society's mainstream. Even though they may not feel handicapped, society may handicap them.²⁸ Goffman notes that disability may separate the individual from society and thus spoil his/her identity.²⁹ When institutionalization occurs, physical and geographical separation from society is complete. Such separation may be difficult to accept. Being institutionalized is a new experience. Even if the individual has been institutionalized before, each situation is different and some uncertainties and frustration are bound to arise. Anyone who comes in contact with the institutionalized person should remember the following statement:

Situations that are psychologically new in the sense that they are perceptually unclear, unstructured, or ambiguous arise in regard to a person's disability when: (1) the person is unsure as to whether he will be able to manage physically. (For example, he may not know whether the building has steps that he must negotiate but

that he may be unable to manage.) (2) the person is unsure of his reception by others. (For example, he may not know whether he will be accepted or rejected, shown sympathy or devaluating pity, reacted to with fear or trust, helped or ignored, etc.) (3) the person is unsure of what kind of person he himself is. (For example, he may have difficulty in reconciling his physically imperfect body with personality characteristics that are acceptable and even complimentary.)³⁰

The impact of institutionalization may be eased or intensified by the resident's acceptance of his/her disability. If the disability is recent his/her reconciliation with reality may not have happened. Even with a long-standing disability reconciliation may never be complete.³¹

Wright has described acceptance of disability as a series of value changes including: "(1) enlarging the scope of values, (2) containing disability effects, (3) subordinating physique, and (4) transforming comparative values into asset values."³² She asserts that acceptance "frees the person of devaluation because of a disability and also frees him to seek satisfactions in activities that befit his own characteristics as a person rather than those of an idolized normal standard."³³

The findings of Linkowski and Dunn demonstrate a positive correlation between acceptance of disability and self-esteem and satisfaction with social relationships.³⁴ Therefore, persons who accept their disability would appear to be better adjusted than those who do not.

In spite of this evidence, the institution librarian will be serving users who, whether or not they have accepted their disabilities, will also be coping constantly with the process of institutionalization, the meaning it holds for them and the impact it has on them. In such situations the librarian will be well served by the basic concept: "Emotional needs take priority over reasoning."³⁵ So while it might be easier to work with the disabled person who has accepted his/her disability and adapted well to institutionalization, he/she still carries a heavy burden. Therefore, relating positively to the disabled user lies primarily with the librarian, because this is a facet of professional responsibility. As a professional the librarian must be prepared to give and to communicate.

RELATING TO USERS OF INSTITUTION LIBRARIES

To associate with someone in a meaningful way so that understanding and awareness exists is the essence of relating to people. An understanding of disability and of some general psychological needs of disabled

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people provides a solid foundation for relating to them. There are, however, additional actions which can bring a rich and remarkable dimension to the relationship between a librarian and a disabled user.

First, the librarian must be able to communicate with this special user. Interacting on a verbal and nonverbal level requires an ability to accept and individualize the user and to recognize his/her need for self-determination.

Acceptance is recognizing the person as he/she really is, with assets, with limitations and with dignity and worth as a human being.³⁶ This principle provides an effective working base with disabled people, because if the librarian can truly accept the person, then the disability is also accepted. When this occurs, the disabled person can be individualized and seen and treated as this human being³⁷ who has a name, a sex, a background and a personality, as well as a disability. All these factors make him/her unique not only among the institution residents, but also among the library users. Applying these two principles will help the user feel important to the librarian even if he/she feels the loss of self-identity noted by Goffman.³⁸ If the user of an institution library is accepted, individualized and seen as an important person, the librarian will also recognize the significance of self-determination.³⁹

Of all the places within an institution, the library is probably one of the few where the individual can still make some free choices. If, for example, reading or listening to music is an important leisure-time activity for a retarded person, and since leisure time rather than work endeavors may be a more meaningful way for the developmentally disabled to grow and express themselves,⁴⁰ the librarian will endorse self-determination in this direction.

If, on the other hand, the librarian has accepted and individualized a long-term user who becomes terminally ill and is passing through the stages of dealing with death,⁴¹ a firm relationship can be mutually rewarding during such a time of sharing.

Not only does application of the above principles demonstrate objectivity, but it also demonstrates sensitivity. To be lacking in objectivity implies a lack of professional discipline, and thus a lack of direction toward the person and his/her special needs. This is being insensitive. No incompatibility exists between objectivity and a sensitivity to the feelings of others.⁴² Newman notes the significance of sensitivity toward deaf people:

Let us go even further and mention emotions. Without the checks and balances of sound, what is a deaf person thinking when some-

one's laughter seems to be directed at him? What is a deaf person's feelings when there is a sea of communication around him and he is not a part of it? Perhaps the following [anecdote] will bring home to you the direction pent-up emotions can take:

. . . A [deaf] student returned to school highly agitated. She was like a cornered animal, coiled and ready to strike. "My father, my father," was all she could say. A few minutes later her father drove up. He was in tears. Again and again he said, "I can't make my daughter understand."

What is done to a deaf person's self-image when there is the constant and subtle pressure not to accept the fact one is deaf but to strive to be like those who can hear?⁴³

While some studies have been conducted regarding societal attitudes toward disabled people, "little has been done," states Kutner, "to help understand how change may be brought about."⁴⁴ Within this context and within Linkowski's and Dunn's findings, the "practical considerations" of Evans's study bear quoting:

One is that persons with disabilities themselves can affect the attitudes of those nondisabled persons with whom they socially interact. Disabled persons can place their nondisabled counterparts at ease during such social encounters, and the result of this reduction in any existing strain within the social interaction can lead to the formation of positive attitudes. . . .

Thus, a second applied, practical consideration is the possibility that specific skills can be made available to disabled persons through socialization courses. Such skills should focus on showing disabled persons how to accept the incapacity of the nondisabled and how to deal with it. However, disabled persons should not accept a passive, submissive role, but rather they should assume control of the social environment around them by creating a positive image and displaying behaviors that lead to positive, accepting attitudes on the part of the nondisabled population, both toward themselves and other persons.⁴⁵

Therefore it can be said that the responsibility for attitudinal change is a mutual one to be undertaken by both the disabled and the nondisabled. The sensitive librarian may encourage self-determination in this direction when it pertains to library matters and when he/she is knowledgeable about and comfortable with encouraging assertiveness. However, as stated

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before, insofar as the users of institution libraries are concerned, the greater responsibility for attitudinal change rests with the professional, because he/she bears not only role authority, but also the lighter burden.

Until such time as formal studies are undertaken by the library profession to determine how attitudes can be changed, the immediate source for attitudinal change must be the librarians themselves. Motivation to provide a thoroughly effective professional service to users of institution libraries will strike a responsive chord about the efficacy of services and the usefulness of sound relationships. Consistent motivation to examine (and, when necessary, to modify) attitudes can be fostered through self-awareness, role simulation and keeping records of one's own progress. This is not new in librarianship; throughout the country libraries have taken new directions to meet some of the needs manifested during this age of anxiety.

This section has viewed the users of institution libraries as developmentally, physically and psychiatrically disabled human beings who must cope with institutionalization, with their disability and with their humanity. These are the people whom the institution library serves. The challenge of serving these people calls upon librarians' professional skill and creativity and upon their human ability to be an aware and informed professional who cares about the men, women and children who use institution libraries.

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31. This writer is reminded of a conversation with an independent, middle-aged woman confined to a wheelchair since birth. We were discussing her disability and I said, quite thoughtlessly, "I suppose you are used to this by now." She gave me a long look, then finally sighed, "I will never get used to this."
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