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ABSTRACT

A disabled counselor discusses the psychological needs of developmentally disabled persons and suggests solutions for meeting those needs. Considered are the needs for family counseling, individual and group psychotherapy, and sexual counseling. Among approaches recommended are specialized training and practicum for counselors to work with disabled persons and accessibility (architectural and attitudinal) to existing community mental health facilities. (CL)

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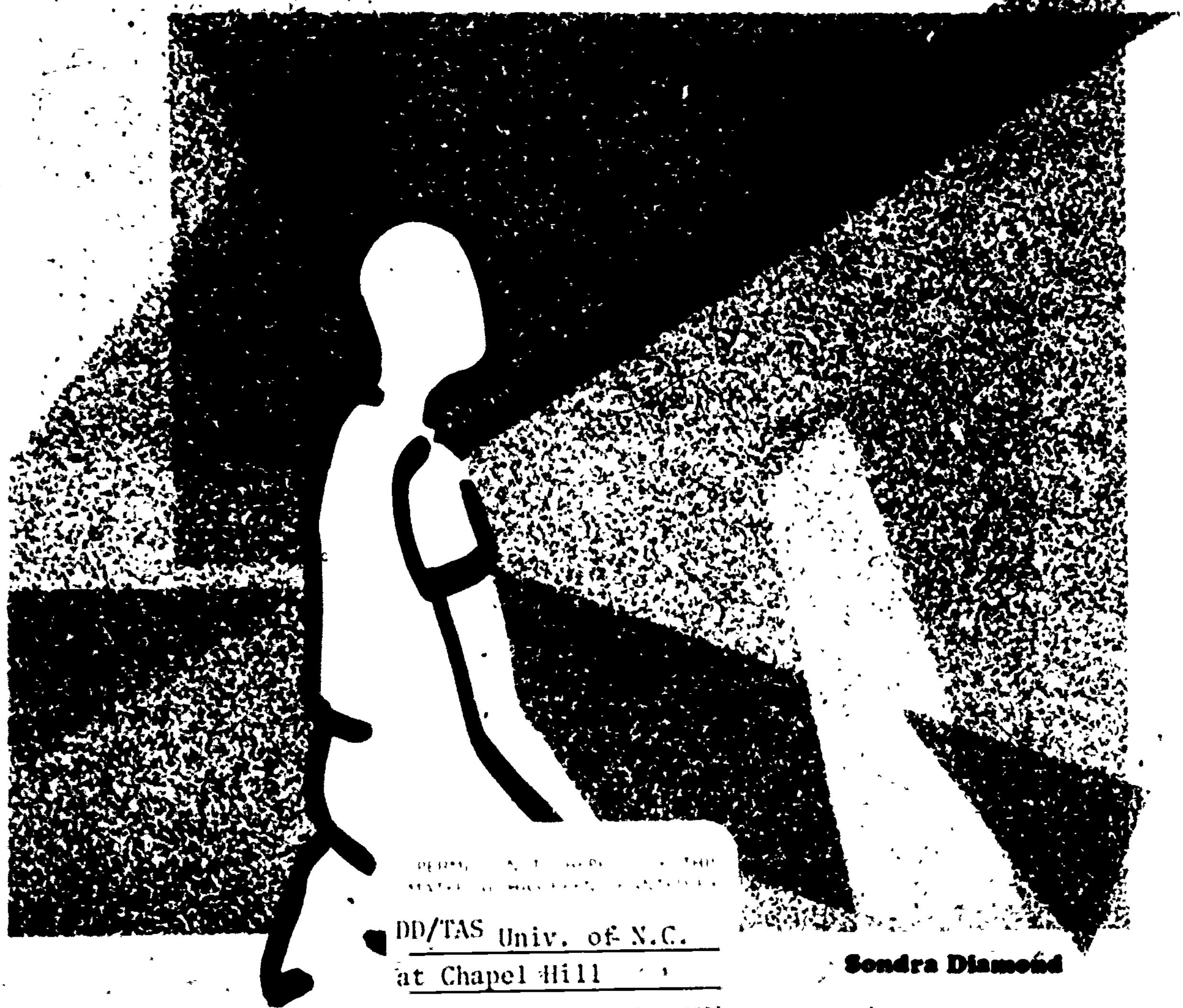
A Series of Topical Papers on Developmental Disabilities

The Unmet Psychological Needs of Persons with Developmental Disabilities



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Sondra Diamond has been in private practice as a Counselor since 1970 in Philadelphia, Pennsylvania. She has authored several articles, including a "Bill of Rights for the Disabled." Ms. Diamond has made frequent appearances on television talk shows, such as *AM America* and the Canadian Broadcasting Corporation's *Man Alive Program,* concerning the problems of disabled people. Most recently, Ms. Diamond was a member of the National Planning and Advisory Council to the White House Conference on Handicapped Individuals.

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The Unmet Psychological Needs of Persons with Developmental Disabilities

by Sondra Diamond

Introduction

It is my hope that this paper will result in an increased understanding of the psychological needs of people with developmental disabilities and recognition of the fact that these needs have been, as yet, unmet. These needs are here outlined and solutions which can be addressed are proposed

In discussing the psychological needs of disabled people, I bring to the subject two sets of expertise: one being the insights that have emerged as a result of having a disability, and the second being my professional status in the field of Counseling.

The first half of this paper is a statement and description of the psychological needs and emotional concerns that must be faced in order to help disabled people reach their full potential. The second half of the paper addresses itself to solutions and ways of implementing strategies.

That there is a dearth of psychological services for disabled people is a given. Our ignorance of this fact, and therefore our inaction, is unforgiveable! The irony is that aside from the common psychological problems that human beings must confront, disabled people are faced with unique psychological problems arising from dealing with and adjusting to a disability. The problems are myriad: the universal need for "private space" (the unseen boundary around our body which we do not want invaded by touch or look unless we give our tacit approval); the recurrent periods of self pity that are born out of the conflicts that we, disabled individuals, experience as a result of what we want to do, what we are capable of doing, and what we are permitted to do; and the distorted self-image which arises out of the conflict between the way a disabled person internally views himself, and the way others perceive him and relate to him.

With these basic concerns in mind, I will review the following needs: family counseling, individual psychotherapy, group counseling, vocational and educational counseling, and sexual counseling.

Family Counseling

Recently, my father spoke to me about the guilt feelings that a parent has as a result of having a disabled child. He said that, at the age of seventy-two, for the first time in his life, he understood his own guilt. He reflected that it is not guilt over having done something wrong by having a disabled child, but rather guilt in terms of not having done the best for his child. He used examples such as feeling that he could have gone to more doctors to get help for me; he could have explored other possible therapy treatments; and he could have smoothed more of the hurt to which I was exposed as a result of being disabled.

My father's reflections illustrate the first psychological need, family counseling. The fact that I have placed it first is not to be interpreted in any priority order. The order of importance of all the psychological needs described here depends on the need of the individual client.

The parent of a disabled person worries a great deal about his or her child. What will become of the child? And who will take care of the child in the event of the death of the parent? The parent asks himself: Am I being all that my child needs? Am I doing all that I can for my child? Am I helping my child to fully actualize his potential? Am I recognizing my child's emotional needs? Am I helping him to be as independent as possible? These are realistic, constant, gnawing questions.

Family counseling achieves many goals. It helps the family to adjust to the presence of the disabled member among them, affording emotional support and helping the family to understand that the needs of the rest of the family must not be neglected. Family counseling further affords an opportunity to learn management techniques of physically caring for the disabled person, and it can help the family to become aware of the services that are available, such as educational and rehabilitation programs. The benefits of family counseling are correlated with the creativity of the family counselor. The counselor may choose to work with an entire family, including extended members; or the counselor may combine separate family groups so that experiences and problems can be shared. A family that has a child with cerebral palsy has much to share with a family that has a child with epilepsy. Within family counseling it is the responsibility of the counselor to perceive whether or not there is a member of the family who requires individual counseling or psychotherapy outside of the family-counseling setting, and to act on that perception.

Family counseling will alleviate problems that may arise within the relationships of disabled and able-bodied siblings, guilt feelings over having a disabled child, and tension between parents heightening existing marital problems. Two conflicts have arisen between my parents as well as within them as a result of rearing a disabled child. These conflicts are born out of the fact that my father has been very protective of me, but my mother, on the other hand, has wanted me to be as independent as possible. To the onlooker, my mother has appeared cruel in her treatment of me. In view of these personality differences, conflict arose between my mother and father causing them to have disagreements more often in dealing with me than in dealing with their two able-bodied children. The second conflict that my parents have had to deal with lies within their relationship, in their attempt to balance out the two viewpoints for my best interest.

Family counseling encourages open communication between the parents and their disabled child. It further helps them to decide how and when to infuse a sense of independence in their disabled child. In the years when I was growing up, we were not fortunate enough to have access to family counseling. Although my parents floundered, they seemed to pull these concepts together as illustrated in the following anecdote concerning the first time I wanted to travel alone. Some friends had invited me to stay with them in Baltimore. I sat down and discussed this with my parents. I said that I wanted to go by train and that my friends would meet me in Baltimore at the train station. My parents were frightened and said so openly. They expressed their fears for my safety, of the fact that I couldn't help myself in case of an emergency, of possible physical attack by a stranger. We talked and argued and cried for hours. The decision was that I was to go. It was very difficult for my parents; I understood that. But I had a need to try my wings, and they understood that.

I'll never forget that day; it was shortly after my sixteenth birthday. Anxiety was our master. We arrived at the station two hours before the scheduled departure time. My father finally settled me in a train seat and stood on the platform waving good-bye. My mother's absence was deliberate, she had agreed to let me go, but was unwilling to watch the departure. I was trying not to cry and so was my father. Then, all of a sudden, I noticed that he still had my wheelchair, which he was clutching with the hand that was not waving. In the excitement, he had forgotten to put it on the train with me. The train began pulling out of the station. I had to forget how badly I was feeling about my first unescorted trip away from home. I shouted at a conductor passing my seat, "Stop this train!" By this time we were a few blocks out of the station. The conductor pulled the emergency cord and stopped the train. He had seen me being carried on to the train and apparently sensed the seriousness of my plea. I explained the need to back up the train to get my wheelchair. He had the train backed up to find my poor father still standing there, unaware that he was holding my wheelchair.

Individual and Group Psychotherapy

The second psychological need to be discussed is individual psychotherapy. Beginning in early infancy, the developmentally disabled child, as a result of impaired reflex actions, reacts differently to the mother than an able-bodied child. The difference in reaction triggers a differential response in the mother, although at an unconscious level, to her developmentally disabled child. Thus, in infancy, the abnormal psychological development begins. An impaired sucking response or impaired ability to put its arms around the mother produces feelings of rejection within the mother who responds in kind to the child, creating a damaging cycle. In other instances, a mother's unawareness of a disability in the child may precede the child's abnormal responses. She may reject the child because of its "imperfections," thus eliciting abnormal psychological responses from the child. Whether the cycle is begun by the child or the mother, although an important question to ponder, is not the issue. The more important issue is the ensuing abnormal psychological development.

A pattern having been set within the disabled child which no amount of psychotherapy can erase, the individual begins to move through and react to his or her environment. The value of psychotherapy lies in helping the individual to gain insight to cope with the need to accept and deal with one's limitations, and to understand and capitalize on one's abilities. The psychologist or psychiatrist must be ever mindful of the frustration tolerance level, which is different within each individual.

Throughout life, the disabled person will experience rejection from his peers as well as society in general. Everyone must experience rejection at one time or another, but disabled people must deal with rejection of a factor beyond their control, namely their physical being. Again, we must turn our attention to the individual differences within the problem of rejection. The individual who is mildly disabled or has an unseen disability, such as epilepsy, can get lost in a crowd, so to speak. His rejection experiences are different from the severely disabled individual's, whose rejection begins when he steps outside his door.

For the disabled person, societal rejection and expectation, in combination with his view of himself, create a distorted self-image. Individual psychotherapy can help to clarify and untangle this image. Individual counseling can help the disabled person deal with the deprivation which arises out of a constant violation of his "private space." Sociologists have taught us that we overlook this as a critical factor. It is not simply the implied rudeness in staring at a disabled person and perhaps making eye contact. Rather it is the invasion of his private space which, after repeated occurrences, creates an imbalance between the man and his environment.

An offshoot of individual psychotherapy is group therapy. For disabled people, as is true of the able-bodied, group therapy affords the opportunity to interact within the therapeutic setting and receive feedback from peers. In some instances, a group comprised of all disabled members may be beneficial and in other instances an integrated group of disabled and able-bodied people may prove more helpful.

Vocational and Educational Counseling

A fourth psychological need that requires our attention is vocational and educational counseling. I have grouped these two needs together, for they both require a similar problem-solving approach. Careful planning must take place, via testing, interviewing and counseling, in order for a disabled individual to be self-actualized through achieving meaningful vocational and educational goals. Although there is room for some trial and error, it cannot be the same haphazard process that it is for many able-bodied people. Vocational and educational opportunities are more limited for the disabled person, by society and by the limitations of the individual. But it is important to remember that disabled persons, when making vocational and/or educational choices, have the right to fail. We seem to think that disabled persons must make "fail-safe" life decisions, and yet we understand the margin for error among those who are able-bodied.

Sexual Counseling

A final, but certainly not least important, psychological need is sexual counseling and sexual education. People seem to feel, falsely, that the less a disabled person knows about sex, the less likely it is that he will be sexually irresponsible. And further, doesn't the disabled person have enough trouble learning how to read and feed himself; why should we worry him about sex? A disabled person has the same physical and emotional needs as everyone else. He experiences the same anxieties during adolescence as a result of the need for sexual role identification and control of sexual impulses. A disabled person has the same need for affection and the same hope for marriage and a family. Not only must we utilize already existing counselors, we must also develop specially trained personnel to educate and counsel disabled people concerning their sexual needs. And further, we must sensitize so-called "unqualified" people such as doctors, nurses, or teachers to help disabled people understand their sexual needs.

Sexual counseling must be non-directive in helping the individual explore his feelings, but it also must be directive where concrete information must be disseminated. Let us put aside our hang-ups and deal with what disabled people need to learn: 1) positioning that will circumvent problems within the disability, problems such as paralysis, contractions of the legs, and bladder and bowel control problems; 2) alternate techniques to sexual intercourse, helping to overcome limitations intrinsic in the disability; 3) birth control techniques; 4) child bearing. There are unique and different problems for each disabled individual in bearing and raising children. Depending on the type and/or severity of the disability, the solution to these problems depends heavily on the individual's capabilities. There may be a need for an assistive device for one new mother; another may need to learn a unique diapering technique, and a third case may require something altogether different.

Some Solutions and Strategies

Having delineated the psychological needs of disabled people; let us look at some solutions. In our age of specialization, I do not feel that we must have psychiatrists, psychologists and counselors specially trained to work only with those who are disabled. If this is done, we are compounding two of the major problems of disabled people, which are isolation and alienation from the mainstream of society. Rather, we must approach the problems of meeting the psychological needs of disabled people through different directions. These should include: 1) education in the universities; 2) specialized training during internships and residencies; 3) architectural and attitudinal accessibility of community-based mental health facilities; 4) psychological staffs within specialized agencies; and 5) research.

Within universities, just as courses are being given on the unique problems of women and minority groups, so should specialized courses in undergraduate and graduate programs be offered in fields related to disabled people. These courses must include the types of handicapping conditions and the physical problems that accompany them. We must also include courses on individual differences, such as religion, age socio-economic levels, and how these differences affect adjustment to a disability.

To particularize, let us look at how religion affects the adjustments and progress of a disabled individual. Religious attitudes toward individuals with physical disabilities are crucial. There are many, but the two most prominent are as follows: one attitude is that God, through the disability, is punishing someone. This is felt especially strongly by the parents of a disabled individual. However, the person who is disabled may also feel that his disability is a punishment from God. People feel that they have done something wrong or have sinned, hence they have been crippled. This point of view is an illustration of how people interpret a disability as something negative or bad. The effects of this attitude have many harmful ramifications for the disabled individual, both physical and psychological. Psychologically, he feels tremendous guilt, as does the family member who feels that he is being punished. The disabled person also feels as if he is a burden on both his family and his community. Physically, he feels that any rehabilitation program is useless, for if God has given this to him, God will take it away.

The second prevalent religion-based attitude concerning a disability is that it is a blessing from God. Many people feel that it is a stroke of good fortune to have someone who is disabled in the family. This has more positive psychological consequences than the former attitude that I described, but it hampers the physical, vocational, educational and social potential of the disabled individual, for there is very little pushing or motivating to fully actualize the disabled individual's potential. An overprotective attitude is exhibited by the people who care for the needs of the disabled person. Why should disabled people be provided with therapy, education, vocational rehabilitation, or social resources? In other words, why mess with a good thing?

A second solution lies in providing future therapists with real experiences in working with disabled people. During a psychologist's internship or a psychiatrist's residency, part of the training must be allocated to treating disabled individuals. My first contact with a blind patient was difficult for me as a counselor, due to the inability to make eye contact. In our newly found flexibility, therapists must learn, as I did, that our tools, such as eye contact, may have to be modified. My discomfort as a counselor got in the way during the initial stages of the therapeutic relationship with the blind patient. This could have been eliminated if I had had a range of experiences during my training.

The third solution is developing architectural and attitudinal accessibility to existing mental health facilities in the community. This should include architecturally accessible ramps for wheelchairs, accessible bathrooms, tactile cues for the blind, as well as visual cues for the hard of hearing.

Attitudinal accessibility will be achieved through the aforementioned education and training as well as the quality of referrals and follow-through by private specialized agencies, such as United Cerebral Palsy Association, National Association of Retarded Citizens, the Easter Seal Society, and others.

The next solution deals with psychological staffs within specialized agencies. Agencies that work with disabled people, such as the three I've just mentioned, must allocate funds for their own psychologists and counselors, as well as a consulting psychiatrist. Psychological services to disabled individuals are parallel in importance with rehabilitation services. An agency does not hesitate to advise disabled people and their families concerning the need for physical therapy, occupational therapy, or speech therapy. The agency must also advise on the importance of psychological services and provide these services. Aside from these agencies providing direct psychological services, they must also be aware of and disseminate information about community psychological resources. It is the responsibility of the specialized agency to make sure the psychological services to which they refer the client are architecturally and attitudinally barrier free.

The last solution to the psychological needs of disabled people is research. There is too little research in the area of psychological needs of disabled people. Time and money which add to our body of knowledge will be time and money well spent. There are many unanswered questions which leave a gap in our knowledge and therefore a gap in our efficacy in working with disabled people. Research can fill these gaps and answer such questions as: 1) Are our present tests and testing techniques valid for disabled people? 2) How do individual differences [illegible] disabled child? and 3) Are our existing developmental [illegible] disabled children?

The psychological needs of disabled people have been too long neglected. These needs [illegible] The solutions are clear. And the responsibilities of those who serve developmentally disabled people are clear as well.

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