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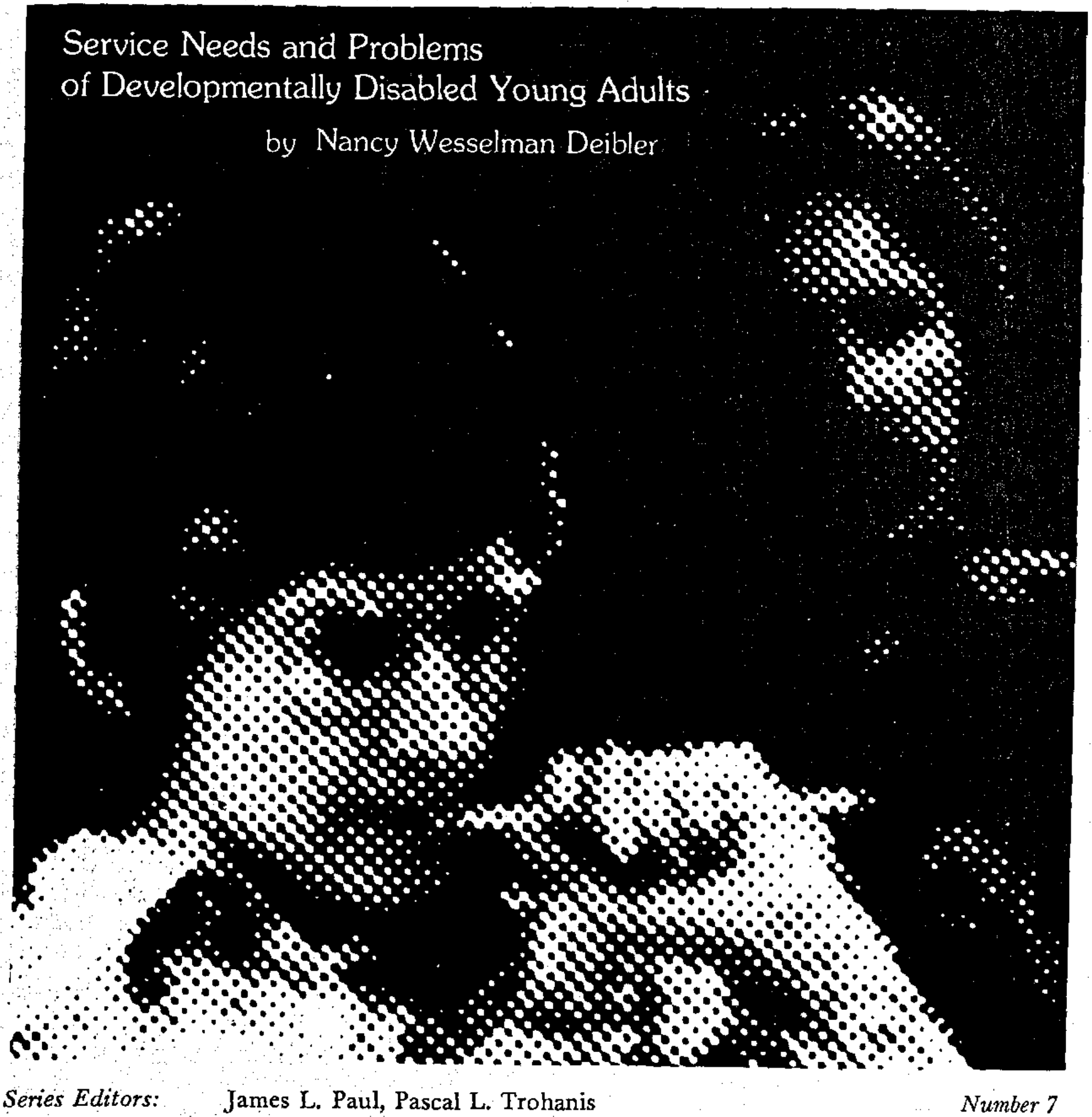

Service Needs and Problems of Developmentally Disabled Young Adults

by Nancy Wesselman Deibler

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ABOUT THE AUTHOR

Nancy Wesselman Deibler is currently serving as coordinator of youth activities for United Cerebral Palsy Association, Inc. Ms. Deibler's experiences in developing and maintaining a department of youth activities have enabled her to serve as a strong consumer advocate for developmentally young people. Additionally, she has planned and implemented national conferences aimed at increasing public sensitivity to and awareness of the problems faced by developmentally disabled people.

CONTRIBUTING STAFF

Copy Editor	Zena Harvley-Felder
Editorial Assistant	Ann Ramsbotham
Typist	Lynn Harmon

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Introduction

The following discussion of the problems and service needs of developmentally disabled young adults is not the result of scientific inquiry. Rather, the contents of this paper are derived from conversations I have had and experiences I have shared with disabled young people.

As a preface to the paper it is important to point out that most of the disabled young people with whom I have developed a personal relationship have been very capable intellectually. The problems I intend to identify here will be those perceived by young adults whose disability is primarily of a physical nature.

Secondly, most of the young people with whom I have contact were enrolled in segregated school programs or classrooms at least during the early years of their education. It is my impression that some of the difficulties these young people are now facing can be traced to their segregated childhood experiences. If this is the case, it can be expected that future 17 to 25 year olds who have an opportunity for integrated educational experiences may have different or fewer problems than today's 17 to 25 year olds.

Thirdly, it seems to me that disabled young people have basically the same problems as nondisabled young people, only worse. In most cases the "usual" problems associated with the maturation process are amplified for the disabled young adult.

Finally, it is difficult to generalize about the needs of disabled young people. Degree of disability, socioeconomic environment, family situation and geographical location are variables affecting the difficulties the disabled young person encounters.

After taking the above points into consideration, however, there is still much that can be said about the problems and service needs of developmentally disabled young adults. It also seems to me that the identification of the problem areas described below has useful implications for the planning and delivery of services to meet the needs of the developmentally disabled young adult population.

Significant Problem Areas

Identity. One of the most often mentioned areas of concern to disabled young adults is identity. Sorting out "who I am" from "who I am expected to be" is especially difficult for a disabled young adult.

Not only must the disabled young person sort through the usual baggage of family expectations and learned behavior in attempting to establish an individual identity, but, he/she must find him/herself while under the influence of societal myths and stereotypes concerning "the handicapped."

The effort to find out "who I am" is a natural step in the maturation process of human beings. There are some factors, however, that make this phase a particularly difficult and crucial period in a disabled young person's life.

Having learned since childhood that they have special problems and needs, disabled young people tend to feel that any problem thay have is related to their disability. A young moderately disabled woman told me that until she went away to college, she did not have opinions independently of what she had been taught by her family. It was a surprise to this person to learn that many of her nondisabled peers could relate similar experiences.

A large proportion of disabled young adults do not have nondisabled friends. They may know a lot of nondisabled people but most disabled young adults do not develop the gut level relationships with nondisabled peers that permit an exchange of inner feelings. Thus, disabled young people have no way of knowing which of their problems are the result of the maturation process and which are particular to them because of their disability. More significant, it does not even occur to many young people that some of the problems they are experiencing are common to their nondisabled peers. I sincerely believe, for example, that some disabled young adults feel that "fear of not being accepted" is a problem never experienced by nondisabled people.

Increased interaction among disabled and nondisabled young adults is needed in order to provide a forum for the exchange of ideas and feelings. Superficial encounters, however, are not enough. Perhaps the trend toward increased integration of disabled and nondisabled children in school settings will result in the development of peer relationships at an early age. For today's young adult, however, it may be necessary to organize rap groups consisting of both disabled and nondisabled young people. Discussions could help sensitize the nondisabled participant to the "humanness" of the disabled participants and vice versa.

A related factor contributing to identity problems is that self-images are the result of interactions between an individual and his environment. The powerful social stereotypes that govern the actions of many individuals with whom the disabled person comes in contact have great influence on the disabled person's self-image.

Having grown up in a society that has been conditioned to seeing disabled individuals presented as objects to be pitied, pampered and protected, the disabled young adult may have come to think of him/herself in the same way. It surprised me to hear one disabled 24 year old woman, whom I consider to be very aware, express self-doubts about her own humanness. As she put it, "My physical differences from my peers have been stressed since I can remember. It's hard to overcome questioning whether I'm different on the inside too."

An 18 year old disabled male with no speech and with considerable physical involvement told me he had trouble seeing himself in a leadership role when I discussed such a position with him. From his past performance, it was obvious to me that he is leadership material. However, because of his lack of speech, it was assumed by teachers and community members that he should not be groomed for leadership roles. The young man's self-image reflected this attitude.

Disabled individuals, themselves, are not immune from internalizing the societal stereotypes. A major problem for many of the most severely disabled young people is that there is a hierarchy in the disabled community. That is, individuals with spinal cord injuries are more highly regarded than persons who have been disabled by polio. Persons whose disability resulted from polio are more highly regarded than persons with cerebral palsy and speech problems. While some disabled young people have found membership in disabled activist groups an important source of emotional support, the most severely disabled population has often felt rejected by the activist leadership.

Agencies and organizations representing disabled individuals must be extremely sensitive to the type of client image they present to the public. While the "pity them" technique works well in terms of the money it solicits, it may cause irreparable damage to the self-image of disabled individuals. Steps must be taken to see that the image put forth by public relations and fund raising materials is a positive and dignified one.

Lack of adult role models is another reason for the identity crises during the young adult years. Therapists, teachers, parents and parent's friends are usually able-bodied individuals. When the disabled child reaches the young adult years he/she may have difficulty in seeing him or herself in any of the usual adult roles.

Just as stereotyped roles for men and women make it difficult for some women to see themselves as the family breadwinner or for some men to see themselves as a nurse, lack of role models makes it difficult for disabled young adults to see themselves as professionals, parents and leaders. This problem comes to the foreground during the young adult years when most people make career choices, establish long-term relationships and develop leadership potential.

In the daily course of events, disabled young adults need to encounter disabled high school teachers, college instructors, cafeteria managers, dorm counselors, book store managers, car dealers, married individuals, fathers, mothers, and political party chairpersons. Career days might be organized so as to involve disabled professionals and community leaders.

Over protective families may narrow the space a disabled young adult has to experiment with his own identity. Most nondisabled young people spend hours with peers, out of parents' control, experimenting with new kinds of relationships, taking physical risks and trying out new patterns of behavior. Many disabled young people are fed, dressed and toileted by parents and end up doing only those things that have the parents' approval.

The disabled young adult who is physically dependent on his/her parents for transportation or mobility, who is delivered to school or a party and picked up as soon as class is over or at a preset time, lacks the opportunity for experimentation by which one defines oneself. Opportunities must be made available to young adults for getting out of the house, away from parents for evenings and weekends. They must have the freedom to experiment, to try out new behaviors and to find out what they like and dislike.

Every young person is at one time or another a victim of the Madison Avenue syndrome, i.e. bodily imperfections are socially unacceptable. A pimple is devastating for a nondisabled 18 year old. It is not hard to imagine how difficult it is to accept one's twisted limbs or misshappen hands or feet. Our society is not very accepting of differences. Working toward greater tolerance of people who are unlike oneself in any number of ways would seem to be a worthy societal goal.

The young adult years for most disabled people are a time for much self-evaluation and asking the question, "Who am I?" Getting to the point of asking this question is in itself an important step, but the answer the individual finally provides "makes all the difference."

Socialization. It has been discovered that most sexual problems facing disabled adults (except those with spinal cord injury) are not caused by physical disfunction but are the result of the inability to establish social relationships which will lead to sexual activity.[1] Previous lack of opportunity to develop social skills has a great impact during the young adult years.

Many disabled young people have not been part of 4-H Clubs, Girl Scouts, Junior Achievement, Thespians or other organizations in which most young people develop social and organizational skills. These skills are prerequisite for functioning in an employment setting, serving on a board, or choosing a mate - all "expected" activities for most 17 to 25 year olds.

Organizations serving youth need to develop programs aimed at involving disabled young people. Places catering to youthful clientele and audiences should make special attempts to accomodate disabled individuals. Provisions for wheelchairs need to be made in auditoriums, theaters and discotheques. Entrances to centers of social life need to be made architecturally barrier free.

Opportunities for sex education and family planning services need to be made available to disabled young adults. This includes access to treatment for venereal disease. Most young people are able to get to a doctor by themselves if they suspect a physical problem or need information. For physically dependent young adults this may be impossible, and rather than risk telling a parent what is wrong, they will not seek help.

When a disabled young woman complained of lower abdomen pains and was rushed to the emergency room of a hospital, the diagnosis was appendicitis. Once on the operating table, however, it was discovered that the problem was gonorrhea. I was told that it would have been standard procedure to check for venereal diseases if such symptoms had been reported by a nondisabled young woman. No one even stopped to consider the possibility in this case. After all, the woman was cerebral palsied. Furthermore, the woman, a college graduate, was unaware of the symptoms of venereal disease. No one had ever discussed such things with her.

Therapists, volunteers, administrators must also be sensitized to the need to discourage unacceptable social behavior among clients. It is common to see extreme amounts of teasing going on between disabled young people and persons involved with them in rehabilitative settings. Social behavior that would not be tolerated in nondisabled teenagers is often accepted or even unknowingly encouraged by persons with whom disabled young people come into contact. This kind of interaction is counter productive for the disabled young person when he/she tries to relate in the "real world."

Mobility. Although mentioned earlier in connection with identity, lack of transportation deserves separate emphasis. Living in a mobile society, where most people over 16 have access to some form of transportation, puts disabled young adults at an immediate disadvantage.

Transportation provides access to social, educational, and employment opportunities. Even if special transportation is provided, for example, to and from college classes, the disabled young person is at a disadvantage. Usually the service is restricted to a direct home - school route which limits the amount of spontaneity in the disabled student's plans. Use of private transportation services which would permit the disabled young person some degree of freedom and independence from parents is usually impossible due to the high costs of such services.

Many disabled young adults are learning to drive. Access to their own transportation opens up a whole new world for those disabled individuals who are fortunate enough to be able to afford an automobile and whose parents or counselors have been supportive of drivers training.

Insurance remains a problem in some states. Experiences vary greatly, but efforts must be taken to educate insurance companies about the excellent driving records of disabled individuals.

While architectural barriers have been receiving much publicity in recent years, they still remain serious obstacles in the lives of disabled young adults. Nondisabled peers who otherwise might ask the disabled individual to join them for a movie, dinner, or weekend in a summer home may not extend the invitation because it is a lot of work to lift a wheelchair in and out of a car and up and down stairs.

Big cities present different problems architecturally than rural towns. It is extremely difficult and dangerous to take most forms of public transportation if someone in a group uses a wheelchair or has a severe mobility problem. Thus, either everyone in the group must take a taxi or else the disabled individual must take a taxi while everyone else uses the public transportation system. In both cases the cost of a taxi can be expensive for the individuals involved.

Employment. Too many disabled young people receive poor vocational training. Exchanges of horror stories are often heard about experiences with vocational rehabilitation counselors. Most stories center around the attitude of the counselor toward the client.

There are many disabled young adults who at 24 have fine academic backgrounds but who are unable to find work. Inadequate vocational counseling is one of the factors resulting in this situation. One common complaint about vocational guidance is that the counselor decides for the client what field the client should pursue regardless of what the client says he/she would like to do. The result is that the young person may end up in a field for which he/she has little or no personal interest.

One disabled young woman was asked by a counselor what her strong points were. The young woman responded that she wrote well. The counselor then said, "OK, you'll be a technical writer." Counselors often make their determinations on what they "think" the disabled young person is capable of doing physically and not on the basis of what the young persons think they can do. It is the assumptions that are made about their abilities that frustrate disabled clients. Furthermore, clients do not feel they have the option to choose a field more to their liking if they are not satisfied with the decision of the counselor. The dissatisfied person is often told that vocational rehabilitation services will not fund the alternative choice.

A second problem is that counselors sometimes fail to inform a client fully about the career the client desires to pursue. A young woman interested in social work went into the field having no idea that being a case worker would require a lot of mobility.

Disabled young people feel it is unfair that they have to make career decisions between the ages of 16 and 18. Many young people graduate from college without having answered the question of "what I will be when I grow up." Disabled young people are forced by the vocational rehabilitation system to determine career paths in their middle teen years.

Decisions regarding a career must often be made without the benefits of prior work experience. Unlike most nondisabled young people, disabled young adults have no work experience, no summer jobs and no internships. Aside from offering practical experience that looks good on a resume, such work opportunities provide young people with information useful in making career decisions and with personal contacts that can be helpful in locating permanent work later on.

Another aspect to the problem of employment is the fear of being cut off from the existing support system. Disabled young adults, accustomed to receiving SSI, Vocational Rehabilitation and Medicaid benefits are leery of putting themselves into a situation in which they may no longer be eligible for benefits from these programs.

Fear of taking risks is the result of two factors. Most disabled children have their lives programmed for them by teachers, parents, therapists and doctors. Making independent decisions and dealing with the consequences may be new experiences for the disabled young adult. It was pointed out to me by one disabled young woman that she felt that people were always trying to protect her and that she was never given a chance to "fail." She felt that if she had been given the freedom to fail and recover early in life that she would have been better prepared to take the risks necessary for a full adult life.

The second factor responsible for making it difficult for disabled young people to be self-supporting and independent from the government support system is that the consequences of taking the step and failing are considerable. Should a disabled person fail on the job or be fired, there may be a long waiting period before he/she can start receiving benefits from the public system again.

In order to pay for the special transportation services often needed to move the disabled young adult to and from work and to "buy" the benefits formerly provided under the public support system, the person's salary must exceed the amount one can normally expect to make on a first job. These barriers to entering the job market often result in the disabled young person passively deciding to remain in the "safe" territory of the public support system.

Finally, if a person needs assistance in toileting or feeding, places of employment are not prepared to offer these kinds of services. Either the disabled person needs to be able to provide his/her own aide or forfeit the job. Experiments need to be conducted to find ways of helping employers accomodate severely disabled employees. For example, the responsibility to assist a disabled employee could be written into another employee's job description. The person would be hired knowing that his work responsibilities included the aide function. The disabled employee should not have to depend on the good will of fellow employees to help him or her on a regular basis.

There is no one remedy to the employment problems of disabled young people. Efforts to improve the situation must focus on several aspects of the problem. Vocational counselors must develop more positive attitudes toward their clients. Disabled young people must be informed of their rights within the system. They do have the right to appeal decisions of vocational counselors and to request a new counselor. Many young people are unaware of these options.

Internships and summer jobs must be made available to disabled young people. Volunteer opportunities also should be opened up. Disabled people are always on the "recipient end" of the volunteer relationship. If volunteering and doing for others is a rewarding experience, it should not be available only to the abled bodied.

Support systems, not necessarily financial, should be made available to disabled people during the transition periods from dependence on the system to becoming self-supporting. Psychological and emotional support could make the difference between making a successful transition and falling back to the government support system.

A tax break for transportation to and from work is essential until or unless accessible public transportation is made available to all citizens. Without the tax break or a federal subsidy for transportation services, it will never "pay" some disabled young people to get a first job.

Fear Of The Future. For most young adults the future is something to be anticipated with great expectations. Seventeen to twenty-five year olds are beginning to think about setting up homes and starting families. They are looking forward to being financially independent from their families. The same period for the disabled young adult may not yield such rosy expectations. During these years, perhaps, the young person may give the first serious thought to his/her future. For those disabled young adults who have been heavily dependent on their parents, the threatening question becomes, "What will happen to me when my parents die?" Fearful of making the attempt or unable to get a job, the issue of employment presents no cause for optimism. Socially retarded in comparison to their nondisabled peers, integration into the community for some disabled young adults becomes a difficult if not impossible task.

The years from 17 to 25 constitute the transition period from youth to adulthood. If the disabled young adult does not take his or her place in society during these years, a self-perpetuating cycle develops in which the barriers to participation in usual adult activities multiply as a result of nonparticipation, and the greater the barriers, the less the likelihood of participation.

Alternative living arrangements need to be made available for every disabled young adult who cannot or who chooses not to live with his/her family. The living situation should include supportive services for physical care, shopping, cleaning and other personal maintenance activities. It must also provide access to social, employment and educational opportunities. Isolation from the community should be avoided.

Conclusion

Perhaps the most important step that could be taken to insure that the needs of disabled young people will be known and met is to train them to be their own advocates. Disabled young people must be encouraged to speak out, to understand their rights within the system, to learn how to go about seeking change within the system.

I am not suggesting that the advocacy function be left solely up to disabled young people. However, I do think that the chances of accurately diagnosing the problems and of identifying possible solutions are increased if disabled young people are actively involved in the advocacy role.

Footnote

Robert C. Geiger, M.D., Susan E. Knight, Herbert Vandervoort, M.D. "Sexuality and Cerebral Palsy Project Final Report" (Unpublished study conducted by the Human Sexuality Program of the University of California Medical School) 1973-74, p.4.

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