DOCUMENT RESUME

ED 249 687 EC 170 486

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TITLE Preventing the Institutionalization of Developmentally Disabled Persons.
PUB DATE [84]
NOTE [illegible]p.
PUB TYPE Reports - Research/Technical (143)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Age Differences; *Community Services; Decision Making; *Deinstitutionalization (of Disabled); *Developmental Disabilities; *Family Environment; Family Problems; Institutional Environment; Institutionalized Persons; *Placement

ABSTRACT

In order to determine what support services may prevent or delay institutionalization of developmentally disabled (DD) children, 128 families with DD children under age 5 and living at home were interviewed concerning currently received and recommended support services. In addition, 52 families with institutionalized DD children (of all ages) completed a questionnaire focusing on major reasons for placement and services that, had they been available, may have prevented institutionalization. The majority of parents with DD children living at home reported satisfaction with support services received and 95% had no immediate plans to place their child outside the home. Essential support services cited by parents included infant screening and diagnosis, early intervention (for children below age 3), day programming, and a parent support system. Sixty percent of parents who placed their DD children outside the home indicated that no additional support services would have prevented or delayed such placement. The three major reasons for placement (in order of frequency) were physical size of child, behavior problems, and adverse effect on family or other siblings. The need for support services directed toward family members and toward older DD children was cited. (JW)

Preventing the Institutionalization of Developmentally Disabled Persons

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Running Head: PREVENTING INSTITUTIONALIZATION

ABSTRACT

Deinstitutionalization involves three processes: reducing the number of residents in public institutions, improving the living conditions of these settings and reducing initial admissions to MR centers. While the first two processes above have received a great deal of attention, the latter has not. One possible method of reducing initial admissions to MR centers is by providing support services for natural and foster parents of developmentally disabled children. The general purpose of this study is to determine what support services may prevent or delay the placement of DD children in institutions or other out-of-home settings. One hundred-twenty eight families who have developmentally disabled children living at home were interviewed in order to obtain their reactions concerning support services they receive, and the type of new services that should be offered. In addition, 52 families who had previously institutionalized their child completed a questionnaire focusing on the major reasons for placement, and services which might have preventea this. Recommendations for services that may prevent or delay institutionalization are made.

Preventing the Institutionalization of Developmentally Disabled Persons

Until recently, most parents of the developmentally disabled (DD) were encouraged to place their children in state or private institutions. However, beginning in the late 1960's, a nationwide trend toward deinstitutionalization and community placement emerged. This movement was spurred for the most part by ethical concerns over institutional treatment (e.g. Gage, Baldwin, Grove & Moore, 1977), and by government support of returning institutionalized residents to community settings (e.g. Bruininks, Kudla, Hauber, Hill, Wieck, 1981).

The deinstitutionalization movement is largely based on two major concepts. These are the normalization principle and the least restrictive alternative. Wolfensberger (1972) has discussed the concept of normalization in depth. Basically it can be described as making available to developmentally disabled persons the opportunity to experience a wide variety of culturally normative conditions and environments, (e.g. Nirje, 1976).

The least restrictive alternative (LRA) is a wide encompassing concept which has been defined by various court decisions for both education (e.g. PARC vs. Commonwealth of Pennsylvania, 1972) and treatment (e.g. Wyatt vs. Stickney, 1972; Welsh vs. Likens, 1974; Halderman vs. Pennhurst, 1977). Interestingly, this concept had its origin in the 19th. century, but was mostly ignored until the middle of this century. More recently (prior to PARC vs. Commonwealth of Pennsylvania) it was first addressed by courts regarding commitment of mentally ill persons to institutions (Burgdorf, 1981). The LRA can be defined as providing interventions that are the least intrusive and restrictive, (the least departure from culturally normal living) that meet the developmentally disabled persons' needs.

The principles of normalization and LRA, together with the widely publicized deplorable living conditions of some institutions, plus government intervention characterized the 1970's as the decade of deinstitutionalization. Since 1967 the number of mentally retarded persons in public institutions has decreased from 194,000 to 117,000 (Rotegard, Bruininks, and Krantz, 1984). At the same time, the number of small (15 beds or less) community programs has increased from about 600 to over 5,700 since the early 1970s, and the number of clients living in these programs now number about 43,000 (Janicki, Mayeda, and Epple, 1983).

Unfortunately, there has been some concern that deinstitutionalization in and by itself does not necessarily insure that treatment is less restrictive or more normalizing in community settings (e.g. Leland, 1981; Butler and Bjaanes, 1977; Turnbull, 1981). In some cases, residents may be "dumped" into poorly run nursing homes or other settings where living conditions are as unsatisfactory or more so than the institution (e.g. Menolascino & McGee, 1981). The apparent shortcoming of community placement has led to an increased emphasis toward other aspects of deinstitutionalization which have not received a great deal of attention in the past. One of these is returning institutionalized mentally retarded persons to their natural families (e.g. Willer, Intagliata, and Wicks, 1981). Another is preventing institutionalization, which is the topic of this report.

One method of reducing the number of admissions to institutions is to provide support services for natural parents in order to increase the likelihood that they will keep their DD children at home. The use of family support systems to care for and train these children helps avoid both the abuses of the institution and inadequate community care. Furthermore, reliance on the family system carries with it some potential economic advantages as the cost of residential maintenance may be offset (Scheenerenberger, 1981).

In order to determine what types of services would best help parents to care for their DD children, two groups of families were interviewed. The first group (group 1) was made up of 128 families of developmentally disabled children, under age five, who were currently receiving some type of support service. The second group (Group 2) was made us of 52 families whose children (of all age groups) were currently living at some type of public residential setting. The interviews consisted of questions designed to elicit information concerning the major reasons why parents had or had not institutionalized their children, and what types of support services would prevent or delay institutionalization. Most interviews (about 70%) were face-to-face, and involved both the mother and father of the disabled child. When this was not possible, one or both parents completed the questionnaire at home and returned it to the authors. The interviews were part of a larger study funded by the Michigan Department of Mental Health and was carried out during 1981-1982. The results summarized below represent the section of the questionnaire related to the topic of this report.

Interviews

Group 1: Parents with DD children living at home (N=128).

Parents reported that the type of support services most frequently received were counseling, parent support, skill training, or a combination of all three. Most services were provided by the local school district free of charge. The great majority of the parents were very satisfied with the support services they received, and more than half said that these had influenced them in deciding to keep their child at home. About 95% of the families had no plans of placing their child outside the home in the immediate future.

This group stated that essential support services included infant screening and diagnosis; early intervention (for pre-age three children); day programming and some type of parent support system.

Group 2: Parents who placed their DD children outside the home (N=52).

Approximately 70% of the children were currently living at a state institution, 20% were in a nursing home, and the rest were in some other type of community placement. The mean age of placement was 12, and ranged from birth to 45. Only one family had any plans of eventually bringing their child back home.

The major reasons for placement (in order of frequency) were as follows: Child became physically too large to handle; behavior problems; adverse effect on family or other siblings; inability of both parents to work; child's physical condition; recommendation from physician; and support services were inadequate at time of placement.

When asked what services might have prevented or delayed placement of their child, about 60% responded that no additional support services would have done so. Approximately one-third of the parents suggested a full time nurse and/or housekeeper. Other responses included financial aid, full-day programming and greater access to medical/dental services.

Discussion

The major reasons associated with the institutionalization of mentally retarded persons presented above are similar to those reported in earlier studies (e.g. Graliker, Koch, and Henderson, 1965; Shellhaas and Nihira, 1969; Allen, 1972; and Carver and Carver, 1972). Since that time, there is evidence suggesting that family support services have had an impact on preventing or at least delaying institutionalization. The responses of parents (group 1) presented above clearly indicate that support services are a critical factor in keeping DD children at home. In addition, the mean age of placement for group 2 children was 11, which is well below the current mean age of first admission. A critical factor here is that these children were placed a mean of 15 years ago, which is before the current emphasis on support services.

At a national level, a similar way of gauging the impact of these services is by again looking at the age of first admissions to MR facilities. The mean age for first admissions was relatively stable between the early 1950s through 1970s. However, recently this age has greatly increased. For example, Lakin, Hill, Hauber and Bruininks (1982), report that the average age at first admission to institutions has increased from a mean of 13 to one of 18 between 1968 and 1978. In addition, the percentage of first admissions who were in the 0-19 year old group has decreased from 88% in 1967 to 65% in 1977 (Lakin, et al, 1982), indicating that the median age is also increasing. It is probably no coincidence that the time of these changes corresponds with major reforms in support services with legislation such as P.L. 94-142, and the DD Assistance and Bill of Rights Act of 1975.

Despite this promising trend, an estimated 5,500 mentally retarded persons were newly admitted to public residential facilities during 1981-82. Of special interest here is the fact that approximately 40% of these were mildly or moderately retarded (22% of school age), and 40% of all new admissions come from their natural home (Scheerenberger, 1982). Furthermore, decreases in new admissions have slowed substantially in the previous few years as compared to a decade ago, and at the same time the number of readmissions has been steadily growing (Lakin, et al, 1982). All of this suggests that the need for greater and more varied family support services is still warranted.

Despite P.L. 92-142 (which serves children to at least age 21) many family support services have largely focused on and emphasized intervention to infants and young children. The reason for this is that many studies have shown that this period may be critical in terms of mother-child bonding, preventing further disabilities and shaping life-time behavior repertoires. While there is certainly a need for intervention in this age group, there is evidence suggesting that services for other age spans may be as important (if not more so) for preventing or delaying placement. For example, data from the State of Michigan (fiscal year 1981-1982) concerning number of first admissions to public institutions from natural families indicate that the three greatest "high-risk" periods (in order of frequency) are: 1) the years around puberty (ages 11-16); 2) early adulthood (18-26); and 3) adulthood (30-40). These time periods accounted for approximately 70% of all first admissions. In addition, essentially the same trends are noted in a nationwide sample (Lakin, et al, 1983).

Information gathered from the parents (group 2) interviewed in this study provide some possible factors for placement during these time periods. For example, during puberty (1), the child often becomes physically too large to handle, or develops problems associated with increasing sexual maturity. Early adulthood (2) is associated with the time when normal children typically leave the home, either to marry, attend school, or join the military. Secondly, this is also when public education terminates, and a transition has to be made to other types of day programs. Adulthood (3) is when parents begin to get older, and physical problems on their part may make it difficult to provide necessary care. This is often when they begin making plans for the continued care of their disabled child in preparation for their own old age or death. Responses of these parents made it clear that family support services will have to focus on these other periods in order for new admissions to continue decreasing.

In addition, responses by parents whose young DD children are living at home suggest that current services for infants and young children are adequate, indicating that further intervention may not be needed for this age span.

However, one major problem here (and for support services in general) seems to be the lack of coordination between various agencies providing services. Most parents felt that there should be an individual coordinator, or agency (with school systems being the most likely choice) to oversee and organize services. Other studies have also discussed this lack of coordination (e.g., Elder, 1979), indicating that this is an area requiring further attention.

Another consistent concern of parents of both groups who were interviewed has to do with the normalization of the families who keep their handicapped child at home. That is, the child often makes it impossible for these families to engage in activities regarded as routine in normal households. These include various social activities, both parents pursuing a career, vacations and the like. Of special concern is the fact that unlike normal children, theirs would never leave the home (upon reaching adulthood) unless they were placed. Thus, keeping their child is often looked upon as a life-long commitment. This was less emphasized by parents whose child was very young and living at home, but was often cited by parents who had placed their offspring after caring for them for a number of years. The major point here seems to be that most support services are designed to focus on the disabled child, rather than family members, and stressers related to raising DD children. Most parents made it clear that more services focusing on family members are needed (see Intagliata and Doyle, 1984 for a further discussion of this issue).

No matter how successful family support services are in preventing institutionalization, there will come a time when, due to old age, family illness or death, placement may be necessary. Programs suggested by parents that may have an impact here include home services geared toward treating both the sick or elderly parent and the retarded child at the same time. Such services might include housekeeping or visiting nurse programs, or allowing handicapped children to reside in some of the senior citizen housing projects. Other services might focus on extended family care, placement of the individual with other members of the family, foster family care, or community programs located near the natural family.

It should be mentioned that in certain situations, staying with the natural family may not be the least restrictive or most suitable situation for all mentally retarded persons. However, when appropriate, families should have available a wide variety of services to help keep their children at home. In addition, providing family support services does not mean that other community programs should be eliminated or less emphasized. As noted above, most mentally retarded persons will eventually have to be placed somewhere, and when this time comes, there should be an ample number of community living arrangements available to avoid institutionalization.

CONCLUSION

The prevention or delay of institutionalization by providing family support services has a number of potential advantages:

1. It is likely to be cost effective;
2. It is consistent with the principles of normalization and the least restrictive alternative.
3. It may allow more time for community programs to be developed, and facilitate deinstitutionalization; and
4. It is likely to be in the best interest of the mentally retarded person.

While the previous decade focused on reducing the number of persons in institutions, it is hoped that the upcoming years will concentrate on reducing the number that are admitted.

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