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AUTHOR	Suelzle, Marijean; Keenan, Vincent
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ABSTRACT

Questionnaires on the experiences of families of developmentally disabled children were completed by 330 families. Data are reported on parent and child characteristics, utilization of services, attitudes toward special education, perceptions of social distance, and perceptions of unmet service needs. Among results discussed is that use of personal and professional support networks by parents varies over their disabled child's life and parents of older children use networks less often than parents of younger children. Parents of the oldest children appeared to be the least supported, most isolated, and most in need of expanded professional services. (CL)

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Personal and Professional Support Networks:
Parental Choice of Services for Children and Adolescents
in Lake County, Illinois*

Marijean Suelzle
Department of Sociology
Northwestern University
Evanston, Illinois 60201

and

Vincent Keenan
School of Public Health
University of Illinois at the Medical Center
Chicago, Illinois 60680

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Introduction

As the mediator between the individual and society, the family is the basic social institution. It interprets society's rules of conduct for its members. Yet the term, family, subsumes a wide range of diversity in structure, function, values, and lifestyles. The services that the family provides for its members, other than the affectional, have been transferred to outside agencies with the advent of industrialization and urbanization (Winch, 1971). Of particular importance, responsibility was transferred from home to school for increasing portions of the child's education. The family provides the child with a place in society, with an ascribed social position, to which a developmental set of expectations are attached. The educational system generalizes these expectations by age-grade levels to establish a standardized set of achievement norms which all children are expected to attain in order for their socialization and development to proceed as projected. The developmentally disabled child cannot attain all of the complex cognitive, physical, social, and emotional developmental achievement norms prescribed by the generalized educational system. For the developmentally disabled child, generalized norms must be replaced with ones which are more particularistic and individualistic. The extent of the child's disability, available alternatives, and the parents' emphasis on the importance of the generalized achievement norms will determine the nature of the particularistic and individualistic resolution sought.

Structurally the family is a unit which performs the functions of nurturance and control to enable the child to survive and avoid the hazards of the environment. Performance of the nurturance and control functions is facilitated or impeded by both the activity level of the child and the availability of assistance with the child's care. As these maintenance functions are fulfilled more easily then the emphasis on emotional bonds becomes more important. Healthy families provide their members with psychic, status, and interpersonal security. They provide emotional gratification and self-esteen based upon recognition of and affection for the unique individual strengths of each member, rather than the impersonal competitive criteria of the marketplace. The family is an interaction process in which individuals learn and practice roles appropriate for life cycle development. The degree to which families optimize emotional gratification and self-esteem depends upon the relative ease with which maintenance functions can be fulfilled. As maintenance functions are fulfilled, family members are enabled to participate in the usual activities of their relevant social networks.

Even the birth of a normal child can be experienced as a crisis to the extent that it involves readjustments of other role commitments (Rossi, 1974). Parents have developmental needs just as children do (McBride, 1973). The ease of the role transitions of the parents of a developmentally disabled child, just as for those of the parents of normal children, will be facilitated by anticipatory socialization. Anticipatory socialization can be defined as contact which allows identification with persons functioning in the role. It can be provided by contacts with professionals and by personal support networks.

But whereas parents of normal children can rely for some experience upon widely available handbooks such as Dr. Spock or upon primary emotionally [illegible] ct with friends and kin the parents of developmentally dis[illegible] children are not so fort[illegible] nt organization can provide an informative and intimate support group if one can be located (Auerbach, 1968: 180-208). More often the requisite information is provided by secondary unequal-status contact with professionals and specialists, often uncoordinated, uninformed about the complete range of resources available, and unable to supplement diagnoses with specific advice about parenting a developmentally disabled child (Gorham et al., 1975). The most bitter expression of feeling from parents often concerns their being advised to institutionalize their developmentally disabled children rather than assisting them to develop an adequate home adjustment (Zwerling, 1969; Washowitz, 1970). This lack of help can be contrasted with the positive assistance which parents get in coping with medical diseases such as diabetes or leukemia (Kugel, 1976). In addition to the ease or difficulty of obtaining information and assistance, community attitudes are an important factor. They may mediate, augment, or deemphasize the impact of the label - ranging from revulsion, condemnation, and avoidance to tolerance, altruism, love, and hope. Identifying community reactions is as important as ascertaining knowledge about available resources. Public information may be as important as the provision of services (Lippmann, 1976). Understanding the dynamics of family and community processes is essential to the formation of enlightened social policy for the developmentally disabled (Caldwell and Ricciuti, 1973).

Normalization relates to the belief that an individual should be allowed to live his/her daily existence in a style that is similar to those in the surrounding culture as is sex and age appropriate (Wolfensberger, 1972: 28). Deinstitutionalization of individuals who have been in a residential facility for a significant period of time is a measure which will redress past injustices by replacing or augmenting custodial goals with ones which are developmental in nature. The establishment of a responsive residential environment is crucial to optimize normalization. The crisis which any geographically mobile person experiences is accentuated for the older developmentally disabled person who has been socialized into a more structurally different institutional environment (Cherington and Dybwad, 1974). Considerable help may be required to teach life skills necessary for survival in the community (Hawkins and Folsum, 1975).

A more direct approach is one which is geared toward the prevention of admissions to full-time custodial residential institutions in the first place. This approach is analogous to the maintenance of health rather than the treatment of sickness and disease. It requires the integration of support systems at an appropriate pace for the developmentally disabled child just as the public school system is appropriately paced for the age-graded development of the normal child toward economic and social self-sufficiency. This implies the necessity for community-based institutions which interface with the family and maintain developmentally disabled individuals in a normalized family community environment throughout their entire life cycle. In the absence of a comprehensive social system designed to maintain the developmentally disabled as full participants in the community throughout their lives, an obvious place to begin to develop such models is with the actual experiences of families of developmentally disabled persons themselves.

RESEARCH METHODS

Sampling Procedures

The population was defined as Lake County, Illinois, parents of developmentally disabled children ages 0-21 who receive services in Lake County. For the purposes of this study, developmentally disabled is defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one of the foregoing, and whose handicap required more than 50 percent time in a special education program. Extensive correspondence and discussion with agencies at the State and local levels, as well as with individual facilities and parents contacted through the Illinois Governor's Advisory Council on Developmental Disabilities and local organizations, resulted in the identification of 751 families. Because of adherence to regulations governing rights of privacy, mailings requesting parents to consent to participate in the study went out through the educational facilities serving Lake County: Three special education school districts, a state residential facility, a federally funded early intervention program, and six private facilities. Due to the low percentage of consents received after the first mailing (37.7 percent) these educational facilities also conducted a follow-up mailing.

Data Collection Procedures

A computerized review of the literature and open-ended depth interviews with parents were used to construct a mail survey questionnaire. The questionnaire was pretested with 66 families of children attending three schools for the developmentally disabled in Evanston, Illinois. Following revisions based upon the pretest results, a 57-page mail survey questionnaire was developed for the Lake County population. Structured closed-ended questions were designed to provide data regarding:

--the manner in which parents first discovered that their child was developmentally disabled;

--the availability of extended family and community support networks for the parents and their children;

--the nature of the developmental disability, skill levels, and kinds of limits the children have;

--the manner in which parents successfully or unsuccessfully secure the community services needed by their developmentally disabled children;

--the current professional intervention encountered and its perceived value;

--parents' attitudes regarding the direct services currently used for their children;

--parental involvement in their children's educational programs and organizations concerned with developmental disabilities;

--parents' opinions about general policy directions for the provision of services for the developmentally disabled in their community; and

--long-term plans and objectives these parents have for their children.

Questionnaires were mailed out over the three-month period from mid-March to mid-June 1978 to the 458 families (61.0 percent) who finally consented to participate. Included with each questionnaire mailed was a return post card with the respondent's name and the statement, "I have mailed my completed questionnaire." Respondents were asked to mail the card, separately, at the same time they mailed the completed questionnaire. Since the questionnaires themselves were filled in anonymously, the post cards were our only check on which consenting parents had, in fact, returned questionnaires. A follow-up letter with a second return post card was sent approximately one month after the questionnaire was mailed if we had not received a post card notifying us of its return before that time. These procedures resulted in the return of 330 completed questionnaires (43.9 percent of the families identified and contacted; 72.1 percent of the families who consented to participate).

Returned questionnaires were coded and keypunched and a file defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. The data was cleaned by eliminating out-of-range errors and performing a series of contingency checks.

Characteristics of Parents and Their Children

The study was conducted in Lake County, Illinois. The county is in close proximity to Northwestern University, which minimized travel time and expense. Lake County offers a wide range of services to developmentally disabled persons. There is a major state-operated residential center for severely and profoundly retarded persons. There are other smaller residential programs operated by private non-profit groups. The county is known for its comprehensive programs of special education offered through the public school districts. There are several sheltered workshop facilities for developmentally disabled persons. Within the area alternative residential programs for developmentally disabled persons are beginning to be developed (e.g. community living facilities, foster home networks, group homes).

The area of Lake County was selected for the research population because: (1) it is geographically compact yet includes urban, suburban and rural populations; (2) it offers a wide variety of services for the developmentally disabled; (3) providers and consumers of developmentally disabled services have a history of cooperation with past efforts to secure related information; and (4) the county contains people of wide range of socioeconomic, ethnic and racial backgrounds.

Although the questionnaires were mailed to both parents in two-parent families, almost all were completed by the children's mothers. Of these mothers, 20 percent had not completed high school, 33 percent were high school graduates, 31 percent had some college or special career training, and 16 percent were college graduates. In 1978 dollars, 33 percent had yearly family incomes before taxes of less than $15,000, 39 percent between $15 - 25,000, and 28 percent over $25,000. The vast majority (86 percent) were currently married; that is, most children in the study were from two-parent homes. About half of the mothers (48 percent) were employed outside the home, a group about equally divided between those holding full-time and part-time jobs. In terms of racial composition, 83 percent of the sample were white, 11 percent black, 3 percent Latino, and 3 percent Asian or American Indian.

Of the children reported on in the questionnaires, 21 percent were identified by their parents as mildly retarded, 34 percent as moderately mentally retarded, 20 percent as severely and profoundly mentally retarded, 12 percent as having cerebral palsy, 4 percent as autistic, and 9 percent as having epilepsy. Of the children, 57 percent were male and 43 percent female. Four stages in the life cycle of the developmentally disabled children in the study are defined for the present analysis: preschool (birth to 5 years old), elementary (6 to 12 years old), teenage (13 to 18 years old), and young adult (19-21 years old).

RESULTS

Utilization of Services

Because the general public's experience interacting with developmentally disabled persons is very limited, parents are often not able to avail themselves of the usual networks of information (i.e., family, friends, neighbors) regarding children's services, networks that are available to parents of "normal" children. As a result of this information vacuum, the advice of health care and educational professionals takes on an added weight (see Table 1, Panel A).

Table 1 about here

Parents were provided a list of 13 health care professionals and asked to indicate which they had gone to see about their developmentally disabled children. Parents of younger children reported the most contact with pediatricians only. This reflects a trend in specialization occurring within the life cycle of children in the study. For the most part one would expect contact to increase as children grow older. Contact did increase over the life cycle for five types of health care professionals (family doctors, dentists, oral surgeons, neurologists and psychiatrists). No differences in service utilization over the life cycle were found for the remaining seven types of health care professionals (ear, nose, and throat specialists; opthalmologists; cardiologists; orthopedists; orthodontists; and plastic surgeons).

In their search for appropriate schools and programs, parents of younger children cast a wider net than did parents of older children (see Table 1, Panel B). Parents of younger children relied heavily upon recommendations of doctors, while also utilizing personal support networks of other parents of developmentally disabled children, family members and friends. Recommendations from school personnel, however, were those most frequently sought. In contrast to the recommendations of doctors, other parents, family members and friends, the recommendations of school personnel were increasingly sought over the life cycle. By young adulthood, school personnel emerge as the most authoritative group for parents.

Utilization of personal support networks declines over the life cycle (see Table 1, Panel C), in contrast to utilization of health care professionals and school personnel. Undoubtedly, the decline is related to the development of competence on the part of both children and parents. Nonetheless, over one-half of the young adults in the study still had other family members or friends as babysitters and over one-quarter still had paid babysitters.

Attitudes Towards Special Education

Theoretically, mainstreaming can be conceptualized as a continuum providing developmentally disabled children with an increasing amount of contact with other children. Attitudes towards mainstreaming are based upon judgments about both the educational and social needs of developmentally disabled children (see Table 2). Discrepancies with average rates of development become much greater over the life cycle. At the same time, parents become more appreciative of the efforts of special educators and have had a longer period of exposure to the rationale for special education. Whatever the attitudinal sources, parents are less supportive of mainstreaming and report a greater need for special education.

Table 2 about here

Perceptions of Social Distance

Labeling a developmentally disabled child as deviant may result in both the child and the family being isolated from regular social contacts. Increased social distance and isolation can occur as a result of the family's withdrawal from social interactions as well as because others exclude the family and child from their social activities (see Table 3). If parents are willing to initiate social invitations, most perceive their neighbors as willing to visit when their developmentally disabled children are at home. Perceived willingness of neighbors to visit remains high and stable over the life cycle. In contrast, actions which require initiative on the part of neighbors are perceived to become less likely over the life cycle. From the family's point of view, social isolation of the child in the community appears to result more from exclusion than from avoidance.

Table 3 about here

Perceptions of Unmet Service Needs

Some parents are more satisfied than others with the services that are available to developmentally disabled children in their community. Given a list of 19 items covering family support, educational and diagnostic services, living alternatives, and general community services, few respondents categorized any of the 19 services as adequate. The vast majority felt all should be expanded regardless of the age of their children. Seven of the services were perceived as less adequate, i.e., more in need of expansion, by parents of young adults than by parents of younger children (see Table 4). Conversely, none of the remaining 12 services were perceived as less adequate by parents of younger children.

Table 4 about here

There is undoubtedly a learning effect for parents as optimism becomes tempered by variability encountered in the availability and quality of services. Hoped-for outcomes are not always achieved and their children's developmental progress is bound to be uneven. Even so, compared to the federally mandated availability of early intervention and special education programs, provisions for the adult developmentally disabled are sparse indeed. While the majority of parents of younger children do perceive unmet service needs for diagnostic services and living alternatives, this awareness is much more widespread among parents of young adults.

The diagnosis of a developmental disability presents a crisis to the psrents as fantasies about the perfect child are shattered or fears about developmental lags are substantiated. With the children's entrance into the preplanned and orderly school system, anxiety declines, but then as the children enter adulthood, a new crisis emerges, engendered by the relative paucity of services. In terms of need for family support, unmet service needs for crisis lines, respite care, and counseling services all exhibit a u-shaped function. Perceived unmet needs are high among parents of preschoolers, drop off for parents of elementary-aged children and teenagers, and rise again among parents of young adults substantially beyond the original levels.

Perceptions of Needs for Developmentally Disabled Adults

The concepts of mainstreaming, normalization, and deinstitutionalization will be implemented only to the extent that parents and health care, social service, and educational professionals engage in life-course planning for which viable employment and residential options are available. This did not appear to be the case for the parents in the study. Optimism among the parents of younger children gave way to planning for more protected employment and residential care among the parents of young adults (see Table 5). The sharpest increase in the perception of a need for a sheltered environment occurred between the parents of teenagers and those of young adults. For the most part then, it does not appear to be a gradual acceptance of the severity of a disability that could account for the findings so much as a realistic appraisal of the limited options available once the period of formal schooling draws to a close.

Table 5 about here

Discussion

Utilization of personal and professional support networks by parents varies over the life cycle of their developmentally disabled children. Perceived needs change accordingly. Parents of older children actually use personal support networks less often than do parents of younger children (Table 1, Panel C). They also perceive their neighbors to be less accepting of their children (Table 3). It is this group, parents of the oldest children in our study, who would seem to be the least supported, the most isolated, and the most in need of expanded professional services. Their increased reliance on school personnel and commitment to special services (Table 1, Panel B and Table 2) would support a policy decision to target families with older developmentally disabled children for the provision of additional services. In the absence of such a change in public policy, the majority of developmentally disabled children who remain at home with their families still seem destined for sheltered employment and residential care (Table 5).

TABLE 1. Percent of Respondents Utilizing Services by Age of their Developmentally Disabled Children.

A. Health care professionals seen more often by:	Preschool	Elementary	Teenage	Young Adult
Parents of younger children--				
Pediatrician	91.5	91.8	72.8	77.5
Parents of older children--				
Family doctor	49.3	44.4	86.4	90.5
Dentist	82.1	95.7	89.7	100.0
Oral surgeon	11.3	15.7	34.3	36.7
Neurologist	67.6	58.5	59.7	82.1
Psychiatrist	25.0	29.9	45.5	50.0
B. Recommendations sought in selecting schools and programs more often by:				
Parents of younger children--				
Doctors	47.9	47.8	27.6	18.4
Other parents of developmentally disabled children	33.3	19.5	23.6	20.0
Family members and friends	32.4	29.3	23.5	17.5
Parents of older children--				
School personnel	56.3	76.3	73.4	75.6
C. Personal support networks used more often by:				
Parents of younger children--				
Babysitting by family and/or friends	88.0	75.3	44.0	55.3
Paid babysitters	68.9	63.9	21.6	27.7
"Rap sessions" with other parents	41.9	32.3	29.5	23.3
Parent counseling and guidance	26.0	19.8	12.5	14.0
100% =	(76)	(101)	(99)	(47)*
				(323)
				MD = (7)

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*Actual N's fluctuate somewhat due to missing data on the service utilization questions.

TABLE 2. Percent of Respondents Perceiving Benefits of Special Education

	Preschool	Elementary	Teenage	Young Adult
Perceive special school as most appropriate	27.9	43.4	56.4	63.8
Child learns more in special education	52.3	74.7	68.5	71.7
Child does better in special recreation	45.3	57.3	57.1	68.2
Child would not benefit from meeting more normal children	51.7	63.3	73.4	86.7
Child would have difficulty socially if all other children normal	16.9	36.8	45.1	52.3
Mainstreaming an excuse for cutting funds	18.5	26.0	26.1	34.9

TABLE 3. Percent of Respondents Perceiving Neighbors as Accepting Child Under Various Circumstances.

	Preschool	Elementary	Teenage	Young Adult
Visit us when developmentally disabled child home	89.3	86.5	90.5	87.2
Accept child as friend for own children of same age	79.0	57.1	54.3	48.9
Invite to visit in their homes	77.0	64.6	67.8	68.1
Accept as neighbor in community living facility upon reaching adulthood	71.6	54.1	61.6	61.7
Accept child as friend for own children of opposite sex	68.9	38.8	40.2	38.3
Accept as classmate at same school as own children	66.7	47.4	47.9	44.4
Accept as coworker upon reaching adulthood	66.2	47.9	45.7	51.1
Accept as adult with full legal rights	60.3	35.8	36.5	37.8

TABLE 4. Percent of Respondents Perceiving Unmet Service Needs in their Communities.

	Preschool	Elementary	Teenage	Young Adult
Diagnostic services and clinics	46.2	61.7	72.9	85.8
Living alternatives--				
Community living facilities	72.6	78.2	72.6	82.9
Residential facilities	71.9	76.4	69.6	90.4
Nursing homes	57.1	73.9	57.3	74.4
Family support--				
Crisis lines for parents in times of stress	89.2	87.8	84.6	97.7
Respite care	83.0	78.7	80.0	94.5
Parent or family counseling services	61.8	56.6	77.8	72.1

TABLE 5. Percent of Respondents Perceiving Occupational and Residential Service Needs for Child at Age 21.

	Preschool	Elementary	Teenage	Young Adult
Sheltered workshop or supervised job will be appropriate	44.8	70.1	66.7	95.2
Future plans include residential care	53.9	57.4	55.5	74.5
Residential placement already planned	2.9	8.4	11.8	26.2

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