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AUTHOR	Suelzle, Marijean; Keenan, Vincent
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ABSTRACT

Findings are presented from a 1978 survey of 330 parents of developmentally disabled children in Lake County, Illinois regarding their current satisfactions and projected needs. The first section portrays the sample demographics (age, sex, type of disability, yearly family income, area of residence). A section on family support analyzes responses in the following service areas: health care delivery, social service delivery, recreation and leisure, and emotional and informational sources of support. Among results described are that approximately two-thirds of the parents were satisfied with the initial diagnosis and assessment; the relationships of family income to health care services and social services was complex; the younger the disabled child, the more likely parents were to be satisfied with social service professionals; and the greatest informational needs reported were for a parent manual and a referral service. Life course planning is the focus of the final three chapters which analyze findings on schools and developmental programs, residential options, and community acceptance and consumer action. (CL)

PARENTS' CURRENT SATISFACTIONS AND PROJECTED NEEDS: COMMUNITY-BASED SERVICES FOR DEVELOPMENTALLY DISABLED CHILDREN

Marijean Suelzle and Vincent Keenan

Northwestern University
Center for Urban Affairs
2040 Sheridan Road
Evanston, Illinois 60201

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Paper presented at Family Support Unit's Conference for Service Providers, Countryside Center for the Handicapped, Barrington, Illinois and American Academy on Mental Retardation Annual Meeting, Miami Beach, Florida. The research was supported in part by the Extramural Research and Development Grants Program of the Illinois Department of Mental Health and Developmental Disabilities.

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Background of the Project

The Developmental Disabilities Project at Northwestern University's Center for Urban Affairs was undertaken for the two-year period beginning July 1977 with funding from the Extramural Research and Development Grants Program of the Illinois Department of Mental Health and Developmental Disabilities. The study is being carried out in Lake County, Illinois. The research focus of the project is parental decision making in the choice of services for children with developmental disabilities. The long-range objectives of this project are: (1) to investigate factors influencing parental decision making in the choice of services, and (2) to assess the consequences of the decisions made at both the institutional and individual levels within particular family, neighborhood, and community networks. Three specific tasks are contained within the project.

(1) The collection of quantitative survey research data and the analysis of that data to develop a report investigating the relationship between families, community resources, and policy orientations toward normalization in the parental decision making process;

(2) To develop a handbook for parents and professionals listing resources and strategies for optimizing the development of disabled children;

(3) To develop a model for similar research in areas with more complex populations and delivery systems such as Cook County.

The first year of the project was devoted to carrying out the survey. Preparatory work included a review of the literature, depth interviews of parents in Lake County, meeting with administrators of programs for the developmentally disabled in Lake County, and a pretest of the questionnaire with families of children attending three schools for the developmentally disabled in Evanston, Illinois. The final 57-page survey questionnaire was completed by 330 Lake County parents of developmentally disabled children ages 0-21 years. (See Table 1 for response rate by facility.) Interview and survey data are being analyzed in order to produce the report on parental choice of services, focuseing on the family as the mediator between the disabled individual and society. This is a report on the findings concerning current satisfactions and projected needs.

During this second year of the project a handbook for parents and professionals has been written. A premise underlying the original proposal was that a handbook for parents and professionals would be an important contribution towards reducing the information vacuum which delays parents in obtaining available and appropriate services for their children. An item was included on the survey questionnaire to determine whether or not parents themselves perceived the need for such a manual; 60 percent reported such a need.

Open-ended questions included on the survey questionnaire obtained specific information on the networds of services actually utilized by Lake County parents. Background materials and samples of handbooks from across the country were also gathered. On-site visits were made to facilities serving developmentally disabled children from Lake County and over 70 interviews were conducted with professionals, administrators, and members of parents' organizations. Information was organized for the handbook in terms of five sections -- life course planning, family support, consumer action, the developmental disabilities, and history and philosophy. The handbook also includes an index directory of facilities and services. (See page 4 for extended outline of handbook and order form.)

Table 1

Lake County, Illinois families with developmentally disabled children 21 years of age and under--identified, consenting to participate in survey, and returning survey questionnaire

Educational Facility	Families contacted (N)	Families who consented to participate (N)	% of those contacted	Families who returned surveys (N)	% of those contacted	% of those consenting
Special Education School Districts						
Waukegan	(274)	(141)	51.5%	(73)	26.6%	51.8%
NSSED*	(77)	(45)	58.4	(35)	45.5	77.8
SEDOL**	(214)	(154)	72.0	(118)	55.1	76.6
State Residential Facility						
Waukegan Developmental Center	(29)	(21)	72.4	(18)	62.1	85.7
Federally Funded Early Intervention						
Lake-McHenry Regional Program	(70)	(39)	55.7	(33)	47.1	84.6
Private Facilities						
Countryside	(10)	(5)	50.0	(5)	50.0	100.0
Glenkirk	(7)	(6)	85.7	(6)	85.7	100.0
Grove	(22)	(22)	100.0	(19)	86.4	86.4
Klingberg	(2)	(2)	100.0	(1)	50.0	50.0
Lambs	(1)	(1)	100.0	(1)	100.0	100.0
Moraine	(3)	(3)	100.0	(2)	66.7	66.7
Out-of-County Facilities Identified through Special Education School Districts						
Waukegan	(2)	(2)	100.0	(1)	50.0	50.0
NSSED*	(15)	(10)	66.7	(7)	46.7	70.0
SEDOL**	(25)	(7)	28.0	(5)	20.0	71.4
Missing Data				(6)		
TOTALS	(751)	(458)	61.0%	(330)	43.9%	72.1%

* Northern Suburban Special Education District
**Special Education District of Lake County

HANDBOOK FOR PARENTS OF DEVELOPMENTALLY DISABLED CHILDREN IN LAKE COUNTY, ILLINOIS

Marijean Suelzle, Ph.D. and Vincent Keenan

The Developmental Disabilities Project at Northwestern University's Center for Urban Affairs was funded by the Extramural Research and Development Grants Program of the Illinois Department of Mental Health and Developmental Disabilities to develop a handbook for parents and professionals in Lake County, listing resources and strategies for optimizing the development of disabled children.

The handbook, which will be available this summer, is organized into five sections--

Life Course Planning

gives parents a guideline to choose successfully a proper clinic, hospital or program for diagnosing and assessing their child's disability

describes medical and educational professionals who may have contact with a developmentally disabled child

provides information on educational options and suggests ways that parents can participate to create continuity between home and school

discusses the importance of vocational training for the developmentally disabled and their options for employment upon leaving formal schooling

explores questions about where and how developmentally disabled adolescents will live after formal schooling ends

Family Support

describes how to locate health care (such as medical, dental, and counseling) services and professionals as well as how to complement professional care with practices in the home that promote physical well-being

includes ideas for family recreational activities and public and private recreational programs for the handicapped

informs parents of financial planning alternatives to provide for their disabled child now and in the future

relates information on the prevention of more developmental disabilities

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Consumer Action

provides educational activities and practical ideas that parents can use at home with their handicapped child

identifies areas of school programs in which parents can work to ensure the best education for their child

describes how national and local parents' organizations help parents and their disabled child

tells parents about the administration of organizations for the handicapped and how to start new programs

explains the legal rights of the handicapped and how parents can ensure due process for their child

Developmental Disabilities

defines mental retardation, epilepsy, autism, and cerebral palsy and discusses non-categorical levels of functioning for the disabled

History and Philosophy

traces briefly the history and philosophy of care for the handicapped in Illinois and Lake County

This handbook also includes an indexed directory of facilities and services available to the developmentally disabled who live in Lake County.

The handbook is provided free of charge to parents and professionals through funding from the Illinois Department of Mental Health and Developmental Disabilities. If you are interested in receiving a copy of the handbook, please fill out the blank below and return it by mail to:

The Developmental Disabilities Project
Center for Urban Affairs
Northwestern University
2040 Sheridan Road
Evanston, IL 60201

Please send me a copy of the Handbook for Parents of Developmentally Disabled Children.

Name ______________________________

Address ______________________________

City ______________ State ______________ Zip ______________

Parents' Current Satisfactions and Projected Needs: Findings from 1978 Survey in Lake County, Illinois

Page

I. SAMPLE DEMOGRAPHICS

Table 2

Age of Developmentally Disabled Child*	
Preschool (birth to 5 years old)	23.5%
Primary (6 to 12 years old)	31.3
Secondary (13 to 18 years old)	30.7
Transitional (19 to 21 years old)	14.6
	N=323

Table 3

Sex of Developmentally Disabled Child	
Male	57.3%
Female	42.7
	N=323

Table 4

Type of Disability**	
Mental retardation - mild	21.5%
Mental retardation - moderate	33.9
Mental retardation - severe and profound	20.1
Cerebral palsy	11.7
Autism	3.7
Epilepsy	9.1
	N=298

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*If there was more than one developmentally disabled child in the family, the parent was requested to answer the survey questionnaire for the <u>oldest</u> developmentally <u>disabled</u> child. N's are less than 330 due to missing data on certain questions.

**When children were reported as multiply handicapped they were categorized by type as follows: (1) mental retardation and epilepsy--categorized under epilepsy, (2) mental retardation and cerebral palsy or mental retardation, cerebral palsy and epilepsy--categorized under cerebral palsy.

Table 5

Yearly Family Income	
Less than $15,000	33.1%
$15-25,000	39.0
Over $25,000	27.9
	N=308

Table 6

Area of Residence	
NSSED	16.4%
SEDOL South of Highway 120	27.6
SEDOL North of Highway 120	25.7
Waukegan	30.3
	N=323

Table 7

Yearly Family Income by Area of Residence

	Yearly Family Income		
Area of Residence	Less than $15,000	$15,000-25,000	Over $25,000
NSSED	6.9%	10.1%	39.3%
SEDOL, South	25.5	25.5	36.9
SEDOL, North	26.5	36.1	7.1
Waukegan	41.2	28.6	16.7
	100.0%	100.0%	100.0%
	N=(102)	(119)	(84)

$x^2=63.01$, df=6
$p < .00001$

II.

FAMILY SUPPORT

A. HEALTH CARE DELIVERY: SATISFACTIONS

1. Initial diagnosis and assessment

- Approximately 2/3 of the parents were satisfied: their doctor provided a clear explanation, in a supportive manner, and took enough time to explain. (see Tables 8-10).

- Few differences were reported by age of child or type of disability:
  more parents of older children reported doctor's manner as sympathetic;
  more parents of younger children reported doctor's manner as matter-of-fact and harsh;
  more parents of autistic children reported doctor's manner as unsure and that not enough time was taken.

2. Global satisfaction

- Majority (86.5%) of parents satisfied with all current medical professionals. Similar level of satisfaction regardless of child's age or type of disability, although families with higher incomes tended to be more satisfied. 1/3 of the parents changed doctors because of dissatisfaction with the care provided. Parents were more likely to change doctors if the child's disability was severe or if their family income was higher. (See Table 11.)

- Most common source of referral to another doctor or clinic was the doctor initially seen (47.4%) with self-referral closely following (36.2%). (See Table 12.)

- Less than half of the first doctors seen provided information concerning referrals or family support. (See Table 13.)

Table 8

When the doctor told you what she/he thought the developmental disability was and used medical words that you did not understand, what did you do?	
I asked questions and got them better explained.	45.9%
I let it pass, since the doctor seemed too busy to take time to explain them.	5.6
I was reluctant or too shocked to ask further questions at the time.	11.9
It did not happen: the explanation was clear to me.	36.6
	N=303

Table 9

Doctor's manner when child's diagnosis first explained to parent.	% agree
Supportive manner	
Patient	77.4%
Matter-of-fact	72.2%
Sympathetic	64.9%
Broke the news gently	60.9%
Negative manner	
Pessimistic	33.5%
Unsure	30.2%
Evasive; nervous	20.6%
Harsh	11.7%

Table 10

About how long would you say this first doctor spent with you, after telling you about the developmental disability?	
No time at all.	12.9%
Not enough time to answer all my questions.	15.9
Not enough time then to answer all my questions but made another appointment.	9.7
Enough time to explain it adequately.	61.5
	N=309

Table 11

Satisfaction with medical professionals.	% yes
Are you satisfied with all the medical professionals your child is going to now?	86.5%
Have you ever changed any of your developmentally child's doctors because you were dissatisfied with the care provided?	35.4%

Table 12

Whose idea was it to take your child to another doctor or clinic?	
I and/or my husband	36.2%
A friend or relative	3.0
My first doctor	47.4
Another professional (for example, social worker, teacher, public health nurse).	13.4
	N=268

Table 13

Did the first doctor you talked to about the developmental disability do any of the following? (rank ordered by frequency with which help provided).	% yes
1. Give a specific label for your child's developmental disability.	46.8%
2. Refer you to a specialist.	45.5%
3. Suggest what the future would look like for your child.	37.9%
4. Ask to talk with you and your husband (the child's father) together.	31.8%
5. Tell you about services available in the community.	25.8%
6. Refer you to organizations concerned with your child's disability.	21.7%
7. Suggest institutionalizing your child, either immediately or in the future.	18.8%
8. Suggest you meet other parents of children with developmental disabilities.	11.1%
9. Suggest a particular program for your child (for example, early intervention, Montessori, Dolman-Delacato, orthogenic).	11.1%
10. Tell you how to explain the disability to family, friends, and others.	8.3%

Parents' Evaluations of Medical Professionals

They respect the pers[illegible] and treat him with understanding without putting him [illegible]n. (#288)

My husband and I were totally satisfied with our pediatrician and ophthalmologist. Their understanding, explanations and concern about our child's problem were very helpful. (#95)

Dissatisfied with cold, impersonal, impatient, unkind attitude -- disrespect for feelings or right to kindness and concern due to every-person, handicapped or normal. Told doctors so, firmly and plainly, and found another. He was equally qualified and possessed of the proper rapport. (#356)

I was dissatisfied with the pediatrician as I had to really insist to get him to test to see if the child had a problem and what the nature of the problem was. I do believe that in earlier stages he (Dr.) felt I was being the typical "Hysterical Mother". When he finally agreed to test, at about age 4, which I think might have been just to pacify me, and found a problem, I feel he could have given more specific direction. The testing took over a year to complete--their goal being causes and type of disability, but no on-going service as to what to do now that we've ascertained there is a problem. In the following years, I think he used the information we had gained to increase his own knowledge. All is not in vain if he (Dr.) can apply his knowledge to other cases. (#91)

Had child evaluated and was told he would never speak, his IQ was zero and that institutionalization was best. Believe this was an honest opinion, but child now speaks reasonably well, understands virtually everything said to him, is almost totally able to care for self and after special schooling from age 6 to 12 has an IQ of 34, or more (have had different evaluations). Perhaps today- this was thirteen years ago--doctors are more aware of what can be done with children with Down's Syndrome. (#310)

Most had very little real knowledge of the problem of Autism [illegible] those that did were obviously trading on knowledge that was at least 20 years old. Had we received more informed medical help earlier we would be farther along now in helping our child. We feel we have been subjected to a great deal of medical quackery and literally wasted thousands of dollars just to get straight answers. (#358)

It took almost 2 years to prove to pediatricians and family that there was something wrong. J. was always the last percentile of normal development. (#5)

B. HEALTH CARE AND SOCIAL SERVICE DELIVERY NEEDS

1. Health care delivery. Developmentally disabled children have the same health care needs as do all children. In this respect it perhaps should be of concern that 10% of the parents do not anticipate ever having any contacts with either a pediatrician or a dentist. Developmentally disabled children often have additional health care needs. Neurologists, ophthalmologists, audiologists, and ear, nose and throat specialists are contacted by approximately 3/5 of the parents; psychiatrists, orthopedists by approximately 1/3; obstetricians, orthodontists, oral surgeons, cardiologists and plastic surgeons by ¼ or less. (See Table 14).

Frequency of contact is influenced by demographic factors.

Age of child.

- One would expect contact to increase as children grow older. This is the case for contact with: family doctors, obstetricians, ear, nose and throat specialists, opthalmologists, dentists, oral surgeons, neurologists, and psychiatrists.
- On the other hand, parents of preschool children report the most contact with pediatricians, orthopedists, and audiologists. This may reflect the availability of early intervention programs and resultant increase in parent awareness.
- Supporting the argument that both availability and awareness influence use of health care services is the finding that parents of primary and secondary-age children are more likely to contact orthodontists than are parents of either preschoolers or 19 to 21-year-olds. Preschoolers would be less likely to need the service; parents of the oldest group the least likely to have been aware of the service and its benefits.

Type of Disability.

- In general, the more severe the retardation, the more likely parents were to have contacted medical professionals. The two exceptions are that parents of the mildly retarded were more likely to have contact with family doctors and psychiatrists.
- Parents of children with autism were most likely to have contact with audiologists, ear, nose and throat specialists, and psychiatrists. The difference for the latter was quite pronounced with 90% having contact with psychiatrists. The next most frequent contact with psychiatrists by type of disability occurred for parents of mildly retarded and epilepsy (44% in each case). On the other hand, no parent of an autistic child had or expected to have contact with a plastic surgeon.

·Parents of children with cerebral palsy were the most likely to have contact with ophthalmologists, orthopedists, and neurologists (87%, 84% and 94% respectively). There are no systematic patterns for parents of children with epilepsy.

·Higher income enables families to purchase more services. On the other hand, sliding fee scales make services available to lower income families; and risk factors associated with low income (such as lower birthweight, poor nutrition) may increase the need for medical services.

·The higher the income, the more likely families were to contact: pediatricians, dentists, neurologists, ophthalmologists, ear, nose and throat specialists, orthopedists, orthodontists, and plastic surgeons.

·Conversely, lower income families were more likely to contact: family doctors (G.P.'s), psychiatrists, and cardiologists.

·Income did not exert a systematic effect on the frequency with which families consulted: audiologists, obstetricians, or oral surgeons.

2. Social Service Delivery. A developmental disability may create social service needs for both children and their families. A majority of families have had contact with speech therapists, social workers, and physical therapists. Between ¼ and ½ of the families have had contact with clinical psychologists, public health nurses, occupational therapists, and recreational therapists. Less than ¼ of the families have had contact with family groups or individual therapists, genetic counselors, vocational counselors, nutritionists, house or foster parents, and professional homemakers. (See Table 15.)

Age of Child.

·Needs for social services at this time seem to be much more stable over the life cycle than was the case for health care services. Age of child was not related to families' contact with: clinical psychologists, public health nurses, occupational therapists, recreational therapists, nutritionists, and professional homemakers. Stability of contact could be due to relatively unchanging needs over the life cycle of a developmentally disabled child, lack of awareness of how these professionals may provide assistance, and/or lack of availability.

·Planning for vocational and residential options does increase the frequency of contact with some professionals over the child's life cycle. There are more needs and services to be coordinated in adolescence and early adulthood. Parents of older children have had more contact with: social workers, vocational counselors, and house or foster parents. As can be seen from Table 15, the increased utilization of these professionals is projected for vocational counselors only.

- Conversely, parents of younger children have had greater contact with speech therapists, physical therapists, family, group or individual therapists, and genetic counselors. These seem to reflect areas where early intervention programs and increased awareness have had an impact.

Type of Disability.

- Severity of mental retardation is related to utilization of social service professionals. The more severe the retardation the more likely families are to have had contact with: speech therapists, social workers, physical therapists, occupational therapists, genetic counselors, house or foster parents, and professional homemakers. Parents of mildly retarded children are more likely to have had contact with: clinical psychologists, public health nurses, and family, group or individual therapists. (This is consistent with the finding that, among health service professionals, parents of the mildly retarded are more likely to have had contact with psychiatrists.) Parents of the moderately retarded are the most likely to have had contact with recreational therapists and vocational counselors.

- Parents of children with autism are more likely to have had a higher frequency of contact with social service professionals than parents of children with any other type of disability. The only exceptions are contacts with public health nurses, and physical and occupational therapists. Frequency of contact is especially higher for: social workers (91%), clinical psychologists (82%), family, group or individual therapists (60%), recreational therapists and vocational counselors (56% each), genetic counselors (40%), and nutritionists (30%).

- Parents of children with cerebral palsy are the most likely to have had contact with: speech therapists (94%), physical therapists (94%), and occupational therapists (75%).

- There are no systematic patterns for parents of children with epilepsy.

Family Income

- As was true for health care services, the relationships of family income to utilization of social services is complex.

- The higher the income, the more likely families were to have had contact with: occupational therapists, recreation therapists, genetic counselors, and vocational counselors.

- Conversely, the lower the income, the more likely families were to have had contact with: physical therapists, public health nurses, house or foster parents, and professional homemakers.

- Middle income families ($15,000 to $25,000 annual family income) were least likely to have had contact with: clinical psychologists, family, group or individual therapists, and nutritionists.

- Income was not associated with likelihood of contact with speech therapists or social workers.

Table 14

Health Care Delivery

Parents of children with developmental disabilities often need to see different kinds of doctors. Which have you gone to see about your developmentally disabled child? (rank ordered by frequency of contact).

	Have Seen	Expect to See	Do not expect to see	
1. Pediatrician	88.0%	1.0	10.9	N=293
2. Dentist	78.5%	12.6	8.9	N=293
3. Family doctor (G.P.)	65.5%	1.7	32.8	N=293
4. Neurologist	63.2%	1.8	35.1	N=282
5. Ophthalmologist (eye doctor)	61.2%	10.6	28.2	N=273
6. Audiologist (hearing specialist)	59.3%	4.7	36.0	N=275
7. Ear, nose and throat specialist	57.8%	6.7	35.6	N=270
8. Orthopedist	37.2%	4.0	58.7	N=247
9. Psychiatrist	36.6%	1.9	61.5	N=265
10. Obstetrician	26.7%	2.8	70.6	N=248
11. Orthodontist	21.1%	11.3	67.6	N=256
12. Oral Surgeon	17.9%	4.5	77.6	N=246
13. Cardiologist (heart specialist)	16.7%	2.0	81.2	N=245
14. Plastic surgeon	6.2%	2.1	91.7	N=242

Table 15

Social Service Delivery

Below is a list of other professionals that parents sometimes contact. Which have you seen about your developmentally disabled child? (rank ordered by frequency of contact).

	Have Seen	Expect to See	Do not expect to see	
1. Speech therapist	78.5%	5.2	16.3	N=289
2. Social worker	56.8%	4.3	38.8	N=278
3. Physical therapist	52.0%	3.6	44.4	N=275
4. Clinical psychologist	42.7%	6.7	50.6	N=267
5. Public health nurse	37.9%	1.5	60.6	N=269
6. Occupational therapist	33.1%	14.4	52.5	N=257
7. Recreational therapist	27.5%	10.4	62.2	N=251
8. Family, group or individual therapist	19.5%	6.1	74.4	N=246
9. Genetic counselor	15.4%	5.7	78.9	N=246
10. Vocational counselor	13.4%	30.0	56.5	N=253
11. Nutritionist	10.1%	2.8	87.0	N=247
12. House parent or foster parent	7.2%	2.4	90.4	N=250
13. Professional homemaker	2.8%	1.6	95.6	N=248

C. SOCIAL SERVICE DELIVERY: SATISFACTIONS

Table 16

Are you satisfied with the social service professionals you are dealing with now?*	
Yes	54.9%
No	6.3
Not seeing any now	38.8
	N=317

*This question appeared beneath the question asking parents about their contact with 13 types of social service professionals (see Table 15 for listing).

Of the families who were currently dealing with one or more of the 13 types of social service professionals listed (N=194), [illegible]0% were satisfied.

Age of Child. The younger the developmentally disabled child, the more likely parents were to be satisfied with social service professionals (preschool 100%, primary 89%, secondary 83%, transitional 82% satisfied).

Type of Disability. The less severe the mental retardation, the more likely parents were to be satisfied (mild retardation 100%, moderate retardation 91%, severe or profound retardation 85% satisfied). Parents of children with other types of disabilities reported: cerebral palsy 95%, epilepsy 78%, and autism 71% satisfied.

Family Income. There is no relationship between income and satisfaction with social service professionals.

Parents' Evaluations of Social Service Professionals

Our child and we have had the services of a speech therapist, social worker, psychologist, and group therapy as provided by the program our child is in. I myself did not seek these people out. They were provided by the Special Education District and have proved to be extremely helpful. (#540)

Have been helpful in giving materials to read, suggestions for helping development, tests, evaluations, referrals. (#607)

I feel in the short time my son has been in school I have seen a tremendous improvement in concentration, speech, behavior. They were able to give him the one-to-one attention. (#001)

They always seem to refer to someone else and the buck continues to be passed. (#134)

Most of what I have found out to help my daughter was on my own digging and asking questions. There is not enough help given to parents--mostly parents help each other. (#771)

Most of the social service professionals we are associated with are from the school that our child is attending. They are helpful, encouraging and set goals for us and the child to work together with them and to attain the goals. (#372)

Some are fantastic and seem to care very much. Others only look in their books and if child fits in no category they do nothing for you. At one time had 7 social workers trying to find school child would fit into. (#255)

At the Junior High Level there is not enough Speech therapy, there are not enough options. The system seems to serve the very young adequately but when it gets to the Junior High level the options are either for the very low functioning child or the very bright L.D. child. The child in the middle is over-looked. (#541)

They are human and we ask for, want and need superhuman things when we have problems. (#397)

D. RECREATION AND LEISURE

1. Family-centered Activities

- The great majority of children are included in everyday family activities. Children are more likely to be excluded, or the family as a unit is less likely to participate, when activities would require group participation of a scheduled duration (i.e., going to movies, sports events, or religious services). (See Table 17.)

Age of child influenced only one of the 7 family activities about which parents reported. Families of younger children were more likely to take walks, go to the beach or park, or similar activities (see item #3) than were families of older children (99% with preschool or primary age children compared to 88% with adolescent children).

Type of Disability. Severely and profoundly retarded children were less likely to be included in family activities.

Family Income. The only family activity influenced by income was religious participation. Lower income families who participated in church or temple were more likely to include their developmentally disabled children.

- During the time developmentally disabled children are at home on regular week days, they are most likely to be involved in passive activities such as watching TV, followed by socializing with other family members, helping around the home, and developmental activities. Very few have no real activity. (See Table 18.)

- Pattern of involvement is not affected by age of child or family income.

Type of Disability. As might be expected, severely and profoundly retarded children and children with cerebral palsy are less likely to be involved in developmental activities or doing household chores.

2. Community-centered Activities.

- Although parents feel special recreation programs, social events and clubs are important for the community and that their children would do better in a special recreation program than in a regular program, 2/5 report that they do not use or need special recreation programs for their own children (see Table 19).

Perceived need for special recreation for one's own children is influenced by type of disability and family income. Parents of mildly retarded children and those with higher family incomes are less likely to report a personal need.

Few groups have more leisure time than the developmentally disabled. Often free time is forced upon them due to lack of planned opportunities. In this respect, it may be of concern that less than 1/3 are involved with organized youth groups and only slightly more than 1/3 have ever gone to a summer camp program. (See Table 20.)

Table 17

Below are some activities families might do together. Does your developmentally disabled child do the following with you? (rank ordered by frequency of family involvement)

	Child does with family	Child does not do with family	Family does not do	
1. Go for rides in the family car	96.6%	1.8	1.6	N=319
2. Visit friends or relatives	95.6%	4.4	0.0	N=318
3. Take walks, go to beach, or park, or similar activities	91.4%	5.4	3.2	N=315
4. Eat away from home (for example, ice cream parlors, hamburger stands, or restaurants)	90.2%	6.9	2.9	N=317
5. Watch TV	87.1%	11.3	1.6	N=318
6. Go to movies, concerts, plays, sports events, or similar activities	65.2%	24.5	10.3	N=319
7. Go to church or temple (including Sunday School)	56.3%	17.3	26.4	N=318

Table 18

During the time your developmentally disabled child is at home on a regular week day, what is she/he usually doing before going to bed? (rank ordered by involvement in activity; 38 families excluded where child does not live at home)

	Often	Sometimes	Hardly Ever	
1. Watching TV or listening to radio or record player.	72.5%	18.6	8.9	N=280
2. Playing with brothers and sisters or other children.	51.3%	28.4	20.3	N=275
3. Activities with parents (for example, games, reading, talking).	50.9%	37.7	11.4	N=273
4. Helping around home (for example taking out trash, setting table, sweeping, feeding pets).	28.8%	30.3	40.8	N=274
5. Working on developmental skills, doing homework, or reading.	18.1%	37.4	44.5	N=265
6. Wandering aimlessly; no real activity.	5.9%	19.8	74.5	N=258

Table 19

Special Recreation

	Adequate	Expand or Offer	Not Necessary	
Rate according to how important it is to expand or offer . . .				
Special recreational programs	26.5%	70.9	2.6	N=306
Social events and clubs (including dances and parties)	22.1%	67.5	10.4	N=289
	Agree	Uncertain	Disagree	
My child would do better in a special recreation program than in a regular program.	73.4%	14.0	12.6	N=300
	Yes	No, but would like to	No, do not need	
Do you use . . .				
Special recreational programs?	25.7%	31.3	43.0	N=307

Table 20

Youth Groups and Camps

	% Yes	
Is your developmentally disabled child involved with an organized youth group (for example, Scouts, YMCA, church group)?	28.2%	N=316
Is the group especially for developmentally disabled children?	70.2%	N= 84
Has your child ever gone to a summer camp program?	38.2%	N=325
Were the camps especially for developmentally disabled children?	79.7%	N=118

E. EMOTIONAL AND INFORMATIONAL SOURCES OF SUPPORT

1. Confidants and Consultants.

·Significant others are utilized as sources of emotional support, as confidants (see Table 21) and as sources of information, as consultants (see Table 22).

As might be expected, members of primary groups are frequently confided in when there are worries about the developmentally disabled child (husbands 88.8%, and friends and relatives 41.9% being confided in often). What is perhaps more interesting is that social service professionals also seem to be operating in this capacity traditionally associated with members of the primary group of extended family (48.5% often confide in social service professionals). Conversely respondents are least likely to confide in a rabbi, minister or priest, or to keep their worries to themselves.

When advice is sought, as might be expected, health service and educational professionals are those most likely to be talked to as "expert" sources of information (4/5 would talk to their child's doctor, or teacher or principal). Again, what is perhaps more interesting is that parents are next most likely to talk to other family members or friends, choosing these primary group members as consultants ahead of organizations specifically concerned with their child's disability or other professionals such as social workers or psychologists. Least likely to be consulted for advice are librarians or staff members of a State governmental office. Underutilization of these information sources could result from either a lack of awareness of their expertise or availability, or from negative evaluations of the value to be gained from contacting these sources.

2. Personal Sources of Support and Needs.

·Significant others, both primary group members and professionals, are utilized to meet the day-to-day management needs of caring for developmentally disabled children. (See Table 23.)

Child (day) Care. Personal resources--family, friends and paid sitters -- are more likely to be used and perceived as necessary than are community resources -- after school day care or respite care. Although needs are highest for younger children, over ½ of the families still use family and friends as babysitters for their adolescent children; approximately 1/3 still use paid sitters. All 4 types of child/day care arrangements are used most frequently by families whose children are the most severly disabled (those with severe and profound retardation, cerebral palsy, and autism). The higher the family income, the more all 4 types of care are used.

Household Maintenance. Household assistance is relatively unavailable for the 10% of families who report that they need the service.

Self-Help/Therapeutic. Approximately ½ of families desiring self-help or professional counseling are currently using these services. The younger the developmentally disabled child, the more likely parents are to report that they use or would like to use both services, the informal and the professional. This could reflect either a learning effect, so that less support is necessary over time, or changing patterns of awareness and service availability. Parents of children with cerebral palsy and autism are most likely to use or want to use informal rap sessions; the reported need for professional counseling is not affected by the type of child's disability. Family income is not associated with the reported need for either service.

Information. There is a paucity of information sources utilized by families reporting such a need. The greatest need reported is for a parent manual (which will be one of the products from this research project), closely followed by the need for a referral service (undertaken by the Family Support Unit at Countryside Center for the Handicapped the year following distribution of the survey questionnaire). Relatively high unmet needs are also reported for an ombudsman, and for professional and informal crisis lines. Age of child was associated only with need for an ombudsman and for a referral service. Reported need for an ombudsman increased with age of child, whereas need for a referral service was reported highest by parents of the youngest and oldest children. The more severe the mental retardation, the more likely parents were to report needs for all 5 types of information sources. Needs for information sources reported by parents of children with cerebral palsy and autism were similar to those reported by parents of the severely and profoundly retarded.

Table 21

Confidants (sources of emotional support).
When you are worried about something concerning your developmentally disabled child, how often do you confide in each of the following? (rank ordered by frequency as source of emotional support)

	Often	Sometimes	Hardly Ever	
1. My husband	88.8%	9.8	1.4	N=276
2. Social Service professionals (school personnel, social worker, etc.)	48.5%	32.6	18.9	N=307
3. A friend or relative	41.9%	32.1	26.0	N=308
4. A doctor or other medical professional	39.0%	34.7	26.3	N=308
5. Other parents with developmentally disabled children	19.5%	30.3	50.2	N=297
6. No one; I keep it to myself	7.5%	12.2	80.3	N=295
7. A rabbi, minister or priest	4.7%	12.0	83.3	N=300

Table 22

Consultants (sources of information).
Parents often react differently to advice depending upon who gives it. If you had a serious decision to make about your developmentally disabled child, would you talk to any of the following? (rank ordered by frequency as source of information)

	Would	Depends	Would not	
1. Child's doctor	81.8%	12.0	6.1	N=308
2. Child's teacher or principal	79.3%	12.9	7.8	N=309
3. Other family members or friends	67.7%	15.7	16.6	N=300
4. An organization specifically concerned with your child's disability	63.8%	25.2	11.0	N=309
5. Other professional (such as a social worker or psychologist)	59.4%	27.1	13.5	N=303
6. Other parents with developmentally disabled children	40.4%	33.7	25.9	N=297
7. A priest, minister, or rabbi	24.5%	24.2	51.4	N=298
8. Someone in a State governmental office	14.8%	26.6	58.6	N=297
9. A librarian	5.1%	8.5	86.4	N=294

Table 23

Personal Sources of Support and Needs.

Do you use any of the following to help you take care of your developmentally disabled child?

	Yes	No, but would like to	No, do not need	
Child (day) Care				
Babysitting provided by family and/or friends?	65.7%	5.7	28.6	N=315
Paid babysitters?	47.1%	6.1	46.8	N=310
After school day care?	3.7%	11.3	85.0	N=301
Respite care provided by a residential facility?	7.0%	13.6	79.5	N=302
Household Maintenance				
Regular paid domestic help?	1.3%	11.8	86.8	N=304
Visits by a homemaker/home-health aide?	2.7%	7.0	90.4	N=301
Self-Help/Therapeutic				
"Rap" sessions with other parents of developmentally disabled children?	32.5%	25.6	42.0	N=305
Parent counseling and guidance?	17.7%	22.6	59.7	N=305
Information				
An informal "crisis line" with other parents of developmentally disabled children to provide support in an emergency?	5.9%	30.7	63.4	N=306
A "crisis line" supported by the State for contacting the necessary professionals in an emergency?	3.6%	40.4	56.4	N=305
A referral service funded by the State to provide help in finding services and programs when needed?	9.8%	55.2	35.0	N=306
An ombudsman to investigate complaints about services for the developmentally disabled?	4.3%	40.5	55.3	N=304
A parent manual that would identify local, state, and national services available and suggest ways to utilize them?	11.7%	61.8	26.5	N=309

Parents' Comments on Relationships with Family and Friends As a Result of Having a Developmentally Disabled Child

We have been most fortunate in having kind-hearted, sympathetic and understanding friends and relatives. They were educated along with us and have not been made to feel uneasy or uncomfortable in any situation or surroundings. We have also received a great deal of encouragement from them. (#091)

Friends are concerned and sympathetic but do not know quite how to respond to child. Some even a little embarrassed about asking about the child. Family has been a great help and all seem genuinely to love and care about this child. (#318).

Very few friends and most of family were unable to accept my child's severe retardation. (#773)

Our friends and family have accepted our son very well. I think we have all become considerate and thoughtful to any handicapped person. Most of us had no contact with handicapped people before. We have, also, become very active in my son's school and our community. Out of this, we have many new friends with handicapped children. (#321)

I find most relatives overreact to the disability and are afraid to be left alone with the child. Also they either expect too much from them or treat them like babies and hand out advice without having any idea of what living with or raising a disabled child is like. Friends, on the other hand, respect the way I treat my child and treat her the same always asking me to bring her along to play with their child or children although children of the same age seldom have the patience to play with her and would rather be with their own friends. (#382)

Many friendships ceased to exist. Some people were afraid their children would "catch it", too. Some of our "normal" child's friends couldn't visit at our home because of our d.d. child. (#258)

The attitude changes of all those involved by knowing a retarded child are remarkable. Most people I have met and become good friends with and do not have retarded children seem to grow in their awareness of the value of life. They tend to stop and think of the importance of time and slow down in their rat race of living to appreciate what they have. (#774)

We are more or less by ourselves. We can't go with him too many places. Not too many people are willing or able to babysit with him. And we couldn't afford it too much anyhow. His brother and sister don't want much anything to do with him. They may babysit with him when it's really necessary. We don't have too many friends or relatives come to visit us.

III.

LIFE COURSE PLANNING

A. SCHOOLS AND DEVELOPMENTAL PROGRAMS

1. Selection of Schools and Programs

· School personnel were relied on most heavily by far when parents selected their children's current school or program, with 62.5% having done so and being staisfied with the recommendation. About 1/3 were satisfied with recommendations from social service professionals or doctors, having visited other schools or programs first, and having contacted organizations. Next in order of utilization for information, about 1/5 of the parents were satisfied with available literature, recommendations from other parents of developmentally disabled children, and recommendations from family members and friends. Relatively few received recommendations from State officials or religious leaders. In general, parents were overwhelmingly satisfied with whatever source of information they utilized. (See Table 24.)

· The way in which parents go about seeking information when selecting a school or program is influenced by demographic factors.

Age of Child. Parents of younger children, especially preschoolers, are less likely to rely on the recommendations of school personnel (56% of parents with preschoolers contrasted to over 70% of parents of older children). Parents of preschoolers are more likely to spread their search for information over a variety of sources, with doctors, social service professionals, organizations, other parents of developmentally disabled children, literature, and family members and friends about as likely to be contacted as are school personnel. At the opposite end of the age range, parents of the oldest transitional (19-21-year-old) children increased their reliance on organizations, being as likely to contact organizations as school personnel (over 70% in each case).

Type of Disability. The more severe the mental retardation, the more likely parents were to seek information from a variety of sources. Parents of children with cerebral palsy or autism were similar to parents of severely and profoundly retarded children in seeking information widely.

Family Income. Lower income families were more likely to have obtained information from doctors, social service professionals, religious leaders, and government officials.

2. Satisfaction with Schools and Programs

· In general, approximately 90% of the parents were satisfied with their children's current school or program, felt the staff were interested in their children as individuals, and reported that teachers welcomed them as visitors. (See Tables 25, 26, and 27.)

- Interpersonal communication between home and school appears to be an area where relationships could be improved. About ½ of the parents (45.5%) reported that they did not really know what questions to ask at the initial placement interview. Whereas approximately 3/4 of the teachers offered suggestions to parents, only ½ asked parents for suggestions about how to handle their children. Efforts to both provide parents with more information and to elicit more information from them would help involve parents more fully as members of the team.

- The only other barrier to participation in school meetings seems to be one of logistics, with 40.1% of the parents reporting difficulty in arranging meetings due to such factors as work schedules, transportation, and babysitters. This is an area where professionals and parents could work together to provide cooperative exchanges to facilitate meeting attendance.

- Demographic factors did not seem to exert systematic influences on satisfaction.

3. Attitudes Towards Mainstreaming

- Theoretically mainstreaming can be conceptualized as a continuum providing developmentally disabled children with an increasing amount of contact with other children. However, parent's attitudes do not seem to be organized in this fashion of increasing or decreasing favorability towards amount of contact provided. Rather their attitudes are bimodal, favoring either separate buildings or a combination of special and regular classes within a regular attendance center. Conversely, there is little support for either total integration or for self-contained classrooms within a regular attendance center. (See Table 28.)

- Slightly over 2/3 of the parents reported that their children were in the type of environment they perceived as most appropriate, although not necessarily in their own community (see Table 29). Of the parents who reported that their children were not in the most appropriate environment, virtually all had children who were attending separate schools for the developmentally disabled. Not surprisingly parents of mildly and moderately retarded children were more likely to favor a combination of special and regular classes within a regular attendance center.

- Attitudes towards mainstreaming are based upon judgments about both the educational and social needs of developmentally disabled children (See Table 30.) A majority of parents feel their children learn more in special education classes (82.7%) and would have difficulty getting along socially if all the other children in the program were normal (59.5%). On the other hand, they also feel their children would greatly benefit from meeting more normal children (60.0%). This complex assessment of different needs may account for their ambivalence about the motivation for mainstreaming (see item #5, Table 30).

Age of Child. Parents of younger children are more likely to express attitudes favorable towards mainstreaming. This may reflect a more hopeful outlook among younger cohorts and/or that developmental delays are not as accentuated for younger children.

Type of Disability. As was true for feelings about appropriate environments, not surprisingly parents of mildly and moderately retarded children were more likely to favor mainstreaming than were parents of children with severe or profound retardation, cerebral palsy or autism.

Family Income did not seem to be systematically associated with attitudes toward mainstreaming.

4. Parents' Priorities for Programs

Program priorities are clearly child-centered (see items ranked #1-5, Table 31), with parents needs second (see items ranked #6 and 7), and mode of service delivery least important (see items ranked # 8 and 9).

Table 24

Before you enrolled your developmentally disabled child in his/her current school or program, did you do any of the following? (rank ordered by frequency of effort to exercise choice)

	Yes, glad	Yes, not helpful	No, wish I had	Not necessary	
1. Rely on the recommendation of school personnel.	62.5%	8.6	0.3	28.6	N=304
2. Rely on the recommendation of another professional (for example, social worker).	33.2%	6.2	2.4	58.2	N=292
3. Rely on the recommendation of a doctor.	31.3%	6.5	2.0	60.2	N=294
4. Visit at least one other school or program first.	30.5%	7.5	5.5	56.5	N=308
5. Contact an organization specifically concerned with your child's disability.	28.8%	7.1	11.5	52.5	N=295
6. Read any materials about options which might be available.	20.8%	12.3	12.6	54.3	N=293
7. Ask for or receive any recommendations from other parents of developmentally disabled children.	18.4%	5.4	6.1	70.1	N=294
8. Ask for or receive any recommendations from other family members or friends.	17.6%	8.4	1.4	72.6	N=296
9. Ask for or receive any advice from a person working in a government office.	5.7%	3.7	3.4	87.2	N=296
10. Ask for or receive any recommendations from a rabbi, priest or minister.	3.4%	2.7	1.7	92.2	N=295

Table 25

All in all, how satisfied are you with your child's current school or program?

Satisfied	88.0%
Mixed feelings	6.3
Dissatisfied	5.7
	N=317

Table 26

Feelings about the interview or staffing among the parents who went for such a meeting before their children were placed in their current school or educational program.

	Agree	Uncertain	Disagree	
I felt the staff was interested in our child as an individual.	92.9%	4.2	2.9	N=283
I felt my child and I were being evaluated.	56.4%	15.4	28.2	N=266
I did not really know what questions to ask about the program.	45.5%	12.5	42.1	N=264
I could not really understand what was being said.	12.6%	5.7	81.6	N=261

Table 27

Below are some things parents say about meeting with their developmentally disabled child's teacher(s). Do you agree or disagree?

	Agree	Uncertain	Disagree	
The teacher(s) welcome(s) you to visit your child's classroom or program.	92.6%	3.9	3.5	N=310
The teacher(s) offer(s) suggestions to you on how to handle your child.	72.3%	5.3	22.3	N=300
The teacher(s) ask(s) you for suggestions on how to handle your child.	51.3%	5.6	43.1	N=302
It is difficult for me to arrange meetings (for example, because of work schedule, transportation, babysitters).	40.1%	2.3	57.7	N=307
The teacher(s) has/have little to offer me as a parent.	10.0%	8.3	81.7	N=301
Such meetings are usually unpleasant.	5.6%	5.6	88.9	N=304

Table 28

There is a lot of talk these days about "mainstreaming" children with developmental disabilities into programs and classrooms with normal children. Mainstreaming means different things to different parents. If your child were to be mainstreamed into the environment which you felt to be most appropriate for his/her developmental disability, which of the following alternatives would you choose?	
Having child attend a special education program or school for the developmentally disabled located in your community.	47.3%
Having child attend special education classes in the same building as other children attending regular classes.	12.5
Having child involved in some special education classes but also in some classes or activities with normal children.	38.7
Having child involved only in regular classes and activities with normal children.	1.6
	N=313

Table 29

Is your child actually in the type of environment which you checked above as most appropriate?	
Yes, in our own community	40.8%
Yes, but not in our own community	27.3
No	31.8
	N=311

Table 30

Some parents have made the following statements about mainstreaming. Do you agree or disagree?

	Agree	Uncertain	Disagree	
My child learns more in special education classes than would be possible in regular classes.	82.7%	12.7	4.6	N=307
My child would do better in a special recreation program than in a regular program.	73.3%	14.0	12.7	N=300
My developmentally disabled child would greatly benefit from meeting more normal children.	60.0%	18.7	21.3	N=310
My child would have difficulty getting along socially if all the other children in the program were normal.	59.5%	14.4	26.1	N=299
Mainstreaming is an excuse for cutting back funds for special education.	38.9%	29.6	31.6	N=301

Table 31

If you had a choice in selecting your developmentally disabled child's program, how important would the following be in making your decision? (rank ordered by importance of factors)

	Important	Uncertain	Not Important	
1. That my child likes the program.	96.8%	3.2	0.0	N=311
2. That there are support staff available (psychologists, social worker, doctor or nurse, therapists).	96.2%	2.9	0.9	N=313
3. That the program is developmentally sound (small staff/student ratio, regular written progress reports, skills instruction provided).	95.2%	3.2	1.6	N=313
4. That the facility is attractive (clean, well kept-up, have recreational and social areas, provide meal services).	94.9%	3.5	1.6	N=312
5. That the program is easily accessible (within walking distance or with transportation provided).	85.8%	1.9	12.3	N=317
6. That there is an opportunity for parent involvement.	83.9%	10.3	5.8	N=310
7. That I like the staff.	82.9%	6.8	10.3	N=310
8. That other students in the program have developmental disabilities which are about the same as my child's.	78.5%	9.0	12.5	N=311
9. That my child remain in the public school system.	54.4%	20.1	25.5	N=309

Very difficult in New Jersey. When we moved to Illinois it seemed like a dream. (#358)

While in Grade school my son was put in regular classes with normal children. I fought in vain with schools for special classes and was told it wasn't needed. When he entered high school I again contacted a counselor and explained the situation. She had him tested and then and only then was he finally put in special classes where he has been extremely happy and has made slow but STEADY progress for the last 8 years. (#710)

It was relatively simple. She was tested by a psychologist (which was suggested by our pediatrician), and upon her recommendation to place our child in the Special Education program, we did and have been very pleased with her progress ever since. (#095)

It took me many months work and much wasted time and money to have my child placed in an institution. So much red tape of forms, questions, waiting, state not having facilities available were involved. Caused much mental strain on entire family and probably hastened my husband's death. (#257)

J. was enrolled at a special education program and after 6 years they told me they "had no program for J" for September. This was in August so they did not give me much time to find a place for J. I did put "heat" on the school district for no programs directly for J., so they "threw him out". We had to settle for a school that we felt did not meet J's needs and still doesn't! (#641)

I haven't found what I hoped for and don't guess I will. There don't seem to be anything for a child like mine. It isn't even fair but that is just the way it is. I don't even want to talk about it. I tried to find help, but haven't got what I want yet. I want therapy and lots of it, but can't get it. (#650)

Started a class (parents own expense) for 3 to 7 year olds. As a volunteer, got retarded children's society to take over cost and provide rooms for this class and increase age to 10 years (parents subsidized $10.00 per week and provided own transportation). At 11 started at his present residential/day care private school. School district special education paid part and provided transportation. We paid $110 per month. Now under new bill and fully paid for school year plus 8 weeks at summer school. Son will be 21 this year and will attend same school on a day basis at parent's expense. All three have been very rewarding experiences and have made many true friends along the way. (#642)

We were unable to find any program for our child until he was five years. We wish he could have gotten help earlier; he's in an excellent program now at the grade school level, but I'm very concerned about the program in high school. (#002)

B. RESIDENTIAL OPTIONS

1. Satisfaction with Residential Experience

Of the families in our sample, 48 had children who were or had been in residential placement. Of these, 26 families (54.2%) had children who had been in more than one residential placement. (See Table 32).

Of the 22 families whose children had been in only one residential placement, 5 had their children back at home at the time they responded to the survey questionnaire. Thus, a total of 31 families had experienced a transfer from a residential facility(5 to the families' homes and 26 to another residential facility).

Transfers occured as a result of a new facility becoming available (Waukegan Developmental Center) and associated dissatisfactions with previous facilities. Cost of care was not a factor.

Table 32

How many residential placements has your child been in?	
One	45.8%
Two	37.5
Three	14.6
Four	2.1
	N=48

Table 33

Parents' reasons for transferring their child to another residential facility. (rank ordered by frequency of reason given for transfer, N=31)	% yes
1. I felt she/he was not making any progress.	38.7%
2. A new facility was built or opened.	38.7%
3. I felt she/he was not receiving adequate care.	35.5%
4. She/he was evaluated as needing a different program.	35.5%
5. She/he was evaluated as being able to benefit from a less restrictive environment.	19.4%
6. Became too old for the previous facility.	16.1%
7. I could afford a more expensive facility.	3.2%
8. Our family moved.	3.2%
9. The previous facility became too expensive.	0.0%

Parents Evaluations of Residential Placements

It is a pleasure to have our son closer to home. (#258)

Child was merely cared for physically and his social, physical, and speech development were retarded because of poor environment "stimulation" and no individual love and attention. (#285)

I could not be more satisfied with the personal care my son is getting. There is some frustration with state bureaucracy at a higher level. They filled the center at full capacity quickly. Now they talk about cutbacks and transfers. (#256)

We were afraid until this year that the school doors would close because of the lack of funds to stay open. I and others involved with the school want it reopened for those over 21. We want to keep the school opened for the care of these people for a "lifetime". (#286)

I feel my child is happy in a residential facility. I only wish it could be permanent. (#252)

When residential placement is needed, it is better to place the child in a facility as close to home as possible; keep the child home as long as possible, but not too old for a satisfactory adjustment to the facility. (#659)

Placement enables my child to progress because of the rhythm in her life. Living at home would constantly alter any routine and would interrupt her learning ability. Size is another big consideration since she is getting too large for me alone to handle for any length of time. (#774)

K. will be placed soon. I did not think there were other alternatives in the community. My doctor told me it was for the best. There were no openings in the day programs I investigated. I thought it was best for my child. I thought it was best for my family. (#398)

There is sometimes a lack of proper care and supervision because of a serious staff shortage. (No funds available to pay better and/or hire more aides.) As caring parents, "We are not kept informed of procedures in the medical and dental care." (#651)

2. Anticipated Needs for Residential Care

- Although few children are old and capable enough to look after themselves (3.3%), not many parents have contingency plans for placement in a supervised facility (10.2%) in the event that they became unable to care for their developmentally disabled children. The majority expect other family members or friends would care for their children (63.0%). The remainder, about 1/5, simply trust to the future or leave placement up to the State. (See Table 34.)

- Few parents have long-range plans involving a residential placement. Even if the eventual need for such a placement is anticipated, the timing for such a transition is left vague (see item ranked #2, Table 35).

- Not surprisingly, parents of younger children are more likely to rely on relatives or friends; parents of older children are more likely to have arranged for a supervised facility. The more severe the disability, the more likely a facility is to have been planned.

Table 34

Many parents are concerned about what would happen if for some reason they were unable to care for their developmentally disabled child. What do you think would happen to your child if you were unable to care for him/her? (rank ordered by frequency of future type of care anticipated)	
1. A family member or friend would care for child.	63.0%
2. I pray to outlive child; I live from day-to-day and trust the future will look after itself.	13.9
3. I have planned for placement in a supervised facility.	10.2
4. The State would place and care for child.	9.6
5. Child is old and capable enough to look after him/herself.	3.3
	N=303

Table 35

If your future plans include residential care for your developmentally disabled child, when do you plan to do this? (rank ordered by frequency with which timing of residential placement planned)	
1. Do not plan residential placement	43.0%
2. Other plans (not specified as to timing of placement)	32.9
3. My child is currently in a residential facility.	11.3
4. When he/she becomes 21 years old.	7.0
5. As soon as we can find a place for him/her.	3.0
6. When our child finishes his/her current day program.	2.7
	N=328

Parents Perceptions of Their Child's Need for Residential Placement

The right time is when the family can no longer provide what the child needs effectively--when more help, teaching, etc., is indicated. Family health also should be considered. I feel no one member, retarded or not, should be more important than any other member. However, the retarded person deserves no less than the best opportunity to develop his potential. (#263)

I am looking for a residential home now--My son is 19 and the longer I wait the harder it will be for him to adjust to adult living. It is difficult to find a placement-with waiting lists everywhere we turn-and not much help from outsiders. (#310)

I placed my child 12 years ago because I could not continue to care for her and give her and the rest of the family the necessary time. At that time there were not any programs for after school etc. and I was physically worn down and could not continue as things were. I needed physical help more than anything else. (#776)

We would like, if at all possible, to avoid residential placement, but feel that, realistically, this may have to be considered someday. (#583)

Children who are normal grow up and leave home at about this time. It would be unfair to our child to keep him at home without friends and activities. (#281)

We plan to have our child finish his special education years and then see what the possibilities are for his future. We would like to place him in a permanent home while we are still healthy and able to visit him and have him home for vacations. After his schooling is finished, we feel he will truly miss his friends, all DD individuals, and would be happier in a residential or community living placement before an emergency arises and he has to be abruptly uprooted from home. We don't know at what age this will be. (#508)

Plan to place in early to mid-teens because: 1)We are weary; 2)I feel unprepared to care for a menstruating teen with developmental disabilities; 3)if child is positively going to live elsewhere, this seems to be a fairly natural time to make a transition; 4)considerations of various sorts in regard to adolescent sibling same sex. (#328)

Our child will finish school at 21. Her brother and sisters will most likely not be living at home. He father and I will be in our 50's. I think if a good residential placement could be found it would be to everyone's advantage. I think at age 21, our child will want friends, a social life, etc., that we will not be able to provide and the community cannot provide at this time. (#315).

C. COMMUNITY ACCEPTANCE AND CONSUMER ACTION

1. Community Acceptance

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. If parents are willing to initiate social invitations, most (88.6%) perceive their neighbors as willing to accept (see item ranked #1, Table 36). Fewer perceive their neighbors as willing to extend the invitation (69.2%), to accept the developmentally disabled child as a friend for their own children (60.3%), or to accept the child as a neighbor living in a community living facility upon reaching adulthood (61.3%) (see items ranked #2-4, Table 36). When relationships move beyond neighborliness to collegiality at work, at school and in clubs (see items ranked #5-7), only about ½ of the parents perceive their neighbors as accepting their developmentally disabled children. Finally, least acceptance is perceived for relationships which symbolize adult status in the community, opposite sex friendships and voting privileges (see items ranked #8-9). Thus, social distance is perceived to increase as developmentally disabled children move from their own homes, to the neighborhood, to collegial relationships and to full acceptance with all the rights and privileges of adulthood.

Age of Child. Parents of younger children are more optimistic, perceiving less social distance, than are parents of older children.

Type of Disability. The relationships between perceived social distance and type of disability are quite dramatic. Parents of mildly retarded children perceive the greatest acceptance (65-95% think their neighbors would accept their children in the 9 situations presented; interestingly lowest acceptance is perceived for opposite sex friendships). In general, projected acceptance decreases by type of disability as follows: moderately retarded, epilepsy, cerebral palsy, severely and profoundly retarded, autism. A majority (80%) of neighbors of families with autistic children are perceived as willing to accept only an invitation to the parents' own homes. A minority (0-44%) of neighbors of families with autistic children are perceived as accepting of the other 8 types of situations presented.

Family Income. In general, lower income families perceive neighbors as more accepting.

Sex of Developmentally Disabled Child. Invariably, neighbors are perceived as more accepting of developmentally disabled daughters than of sons.

Thinking of what their developmentally disabled children will actually be doing upon reaching adulthood at 21 years of age, parents most commonly express either a continuation of familial protectiveness (child remaining at home and having a job in a sheltered workshop) or independence (child living on own or with friends and having a regular job in the community). (See items ranked #1-2 in Tables 37 and 38.)

Age of Child. As was the case for perceived social distance, parents of younger children are more optimistic.

Type of Disability. The more severe the disability the more likely parents are to choose a community facility as the most appropriate living situation (see items ranked #3-5, Table 37). Parents of mildly retarded children are most likely to expect their children to hold a regular job (60.0%). Parents of moderately retarded children project either a sheltered workshop (43.6%) or a supervised job (31.8%) as appropriate. A job in a sheltered workshop is expected by parents of children with autism (88.9%), severe and profound retardation (69.4%), epilepsy (50.0%), and cerebral palsy (42.9%).

Family Income. The higher the income the more likely parents are to project a community facility and a sheltered workshop as most appropriate.

Sex of Developmentally Disabled Child. Females are more likely to be expected to remain at home or to live on their own and to work in a sheltered workshop. Males are more likely to be expected to live in a community facility and to work in a regular or supervised job in the community. That is, females are perceived as needing more protection on the job whereas males are perceived as needing more supervision in their living situation.

Table 36

Some people with developmentally disabled children find certain communities more accepting than others. Imagine your own child at different stages in life; how accepting do you think your own neighbors are (or would be) in the following situations? They do (would): (rank ordered by frequency with which community acceptance projected)

	Would	Uncertain	Would not	
1. Visit us when child is at home.	88.6%	6.6	4.7	N=317
2. Invite to visit in their own homes.	69.2%	12.1	18.8	N=315
3. Accept as a neighbor living in a community living facility (upon reaching adulthood).	61.3%	29.8	8.9	N=315
4. Accept my developmentally disabled child as a friend for their own children of the same age.	60.3%	18.8	20.9	N=320
5. Accept as a coworker (upon reaching adulthood).	52.2%	32.5	15.3	N=314
6. Accept as a classmate at the same school for their own children of the same age.	51.7%	24.0	24.3	N=317
7. Accept as a member of a social club with their own children of the same age.	50.5%	24.8	24.8	N=311
8. Accept as a friend for their own children of the opposite sex.	46.8%	25.3	27.8	N=316
9. Accept as a voting member of the community with full legal rights (upon reaching adulthood).	42.4%	32.5	25.1	N=311

Table 37

Which of the following choices of living situations do you think will be most appropriate when your child becomes 21 years old? (rank ordered by frequency with which living situation expected)	
1. With me at home.	34.0%
2. Living on own or with friends.	21.8
3. A private residential facility (like Grove or Lamb's).	19.8
4. A supervised apartment house unit.	12.5
5. A public residential facility (like Waukegan Developmental Center)	11.9
	N=303

Table 38

Which of the following choices of work situations do you think will be most appropriate when your child reaches age 21?	
1. A job in a sheltered workshop.	43.5%
2. A regular job in the community.	32.4
3. A supervised job in a special business program (for example, in a hospital, restaurant, or motel).	24.1
	N=253

2. Consumer Action--Parent Groups

For many parents, a natural process begins with the identification of their child as developmentally disabled. What starts as self-awareness grows into group social action. First comes the sharing of common concerns and information, with 1/3 of the parents having participated in group counseling and educational groups and another 1/3 who report a need for these group experiences (see items ranked #1-2, Table 39). Next comes organization to work for expanding and improving community services as well as for the rights and dignity of all developmentally disabled persons. Fewer parents have actively taken this next step with 16.2% having participated on a governing or advisory board and 12.4% having worked with a political advocacy group (see item ranked #3-4, Table 39). There is a considerable untapped potential here with approximately 1/3 of the parents interested in taking this next step into community action (31.2% have not, but would like to, participate on a governing or advisory board, and 38.1% in a political advocacy group).

Age of Child. It is the parents of younger children who are both more likely to have participated in group counseling and educational groups, and to be interested in doing so if they have not yet participated. Conversely, parents of older children are less likely to have participated and to plan to do so. On the other hand, age of child does not affect participation or interest in participation on governing boards or in political advocacy groups.

Type of Disability. The more severe the disability, the more likely parents are to have participated or to want to participate in all four types of parent groups.

Family Income. Parents with higher family incomes are more likely to have participated in all four types of parent groups. Parents with lower family incomes are more likely not to have participated, but do want to do so. Family income is not systematically related to unwillingness to participate.

Willingness or unwillingness to participate in parent groups raises the question of what barriers to participation exist. Out of a list of 7 reasons commonly given for nonattendance, the logistical problem of arranging for babysitters or transportation was reported as a barrier far more often than negative feelings about aspects of the meetings themselves. (See Table 40.) This finding is similar to that for meetings with teachers (see Table 27 and comments on page 31).

Table 39

Nowadays there are different types of parent groups. How do you feel about participating in the types of parent groups listed below? (rank ordered by frequency of participation)

	Have Participated	Haven't-- would like to	Haven't-- don't plan to	
1. Group counseling (where parents meet to discuss their attitudes and feelings toward their developmentally disabled child).	38.8%	30.9	30.3	N=317
2. Educational group (dealing with techniques of child rearing and development as related to developmental disabilities).	32.1%	39.1	28.8	N=312
3. Governing or advisory board (dealing with the administration of an organization or facility for the developmentally disabled).	16.2%	31.2	52.6	N=308
4. Political advocacy group (working to expand options and services for the developmentally disabled).	12.4%	38.1	49.5	N=307

Table 40

Listed below are a number of reasons parents have given us for not attending meetings with other parents who have children with developmental disabilities. Do you agree or disagree with these reasons? (rank ordered by frequency for not attending meetings)

	Agree	Uncertain	Disagree	
1. It is difficult for me to arrange for babysitters or transportation.	32.8%	7.5	59.6	N=305
2. It is a waste of time to go to parent meetings because they never seem to talk about things related to my child.	17.7%	15.4	66.9	N=305
3. It is a waste of time to go to parent meetings because the real decisions are made elsewhere.	15.3%	17.2	67.5	N=308
4. I do not feel comfortable with the kind of people who attend.	12.1%	14.3	73.6	N=307
5. I do not like to go to parent meetings when they are held in a public place, such as a community center or library.	8.7%	16.8	74.5	N=309
6. The people who run the parent meetings do not seem to care about me.	8.6%	17.1	74.4	N=304
7. I do not like to go to parent meetings when they are held in my developmentally disabled child's school.	6.8%	12.3	80.9	N=310

Parents Comments About Parent Groups

I felt a great need for the support of such a group from birth to age 6. Now, I'm more comfortable. I feel that with the problems of adolescence, I will need the group again. I would like to see some sort of group living available in the community for a greater number of the retarded with meaningful work available. I feel that the parent groups must work toward this constantly. I would like the service of respite care. (#355)

If in Spanish would very much like to attend, but they are all in English (Don't understand too good.). (#060)

Most parent groups need a lot of involvement and time to accomplish anything significant. Most people have other commitments and responsibilities which also require time and interest. This conflict leads to inadequate participation. (#314)

It is hard to find extra time. My husband and I work full-time. We rely a great deal on the printed information from the school and organizations that relate to our child. We take full advantage of activities offered our child. But seldom participate ourselves. (#348)

I'm sure transportation poses serious problems to many people. Also, people uncomfortable with their dev. disabled child have many negative feelings: meeting in public places (embarrassment) or facility (too close to child).(#263)

The best things about parent groups are: 1) the rap sessions between parents--you are not alone; 2) Parent Power--the ability of an organized group to initiate and support special programs. It seems to be necessary to constantly monitor special programs or they're eliminated or altered in a negative manner. (#002)

Parent groups are great if you are objective enough to overlook personalities. Sometimes the parents have so many hang-ups it is difficult for me to realize they are not just feeling sorry for themselves and are sincere in wanting to better the child's future. (#336)

Too many of the parents I have met seem unwilling or unable to help the school or organization helping their child. They seem to expect something for no effort. Other parents work exceedingly hard, so hard they exclude other social activities. Only a few seem able to achieve a middle ground as opposed to extremes. (#753)

3. Consumer Action--Community Needs

- Parents reflect pessimism or at least uncertainty regarding continued support or expansion of community funding of services for the developmentally disabled. This is not surprising given the general climate of increasing costs, taxpayers failure to support rate increases which would maintain current levels of services, declining school enrollments, and lay-offs of educational personnel. (See Table 41.)

- Parents' future goals for their developmentally disabled children are more child-centered than concerned with mode of service delivery (see Table 42). This finding is similar to that for parents' priorities for educational programs (see Table 31 and comments on page 32).

- A wide variety of community services are necessary to provide family support, educational and diagnostic programs, living alternatives, and general community acceptance. Of 19 specific services identified, only special education programs were perceived as adequate by as many as 50% of parents. Looking at the need for services another way, less than 1/5 perceived any of the 19 specific services as unnecessary. (See Table 43.)

Family Support. Family support services--babysitters, crisis lines, referral services, respite care, homemaker/home-health aides, and counseling--are perceived as extremely necessary but woefully inadequate. Only parent or family counseling services were perceived as adequate by as many as 1/3 of parents, with the other 5 specific services identified perceived as adequate by 10% or less. Conversely, only homemaker/home-health aides were perceived as unnecessary by as many as 20% of parents, with the remainder perceived as unnecessary by less than 10%. Parents of older children, of children with more severe disabilities, and with higher family incomes were more likely to favor expansion of family support services.

Educational and Diagnostic Services. Educational and diagnostic services are also perceived as extremely necessary, but as more adequate than family support services. After school day care is seen as the area where increased availability is most needed (by 82.0% of parents), and this is particularly the case for parents of younger children. The more severe the disability, the greater the perceived need for all four services listed. Family income is not systematically associated with perceived need for educational and diagnostic services.

Living Alternatives. Approximately 3/4 of parents perceive a need for expansion of community living facilities, residential facilities, and foster homes. Nursing home alternatives are perceived as most adequate (by 16.0% of parents) but even here approximately 2/3 of parents perceive a need for increased availability. Parents of transitional (19-to 21-year-old) children, those who are most likely to have an immediate need to look for alternatives, report the greatest need to increase availability. The more severe their children's disability, the greater the parents' perceived need for increased living alternatives. In general, parents with higher family incomes perceive the greatest need for expansion of all 4 types of living alternatives; parents with low family incomes (less than

$15,000 per year) similarly perceive a greater need, but for increased availability of foster care only.

General Community Services. Architectural adjustments, news media coverage, and expansion of library acquisitions are identified as the priority areas for service expansion. Religious services and special transportation are perceived as more adequate, but even here over 2/5 of parents report a necessity for expansion. The more severe their children's disabilities, the more likely parents are to perceive it necessary to expand services. Perception of need is not associated with age of child or family income.

Table 41

Community Funding

	Willing	Uncertain	Unwilling	
How willing do you feel your community is to continue funding the existing level of services for the developmentally disabled?	51.7%	39.5	8.8	N=299
How willing do you feel your community is to increase funding to expand services?	24.5%	56.3	19.2	N=318

Table 42

Parents have different goals for their developmentally disabled child. Would you agree or disagree that the following are important for your child's future? (rank ordered by frequency with which goals thought important)

	Agree	Uncertain	Disagree	
1. It is important that our child be happy and content.	99.1%	0.6	0.3	N=322
2. Our child should be encouraged to reach the limits of his/her abilities.	97.8%	1.6	0.6	N=321
3. It is important that our child live normally (or as normally as possible).	97.5%	1.9	0.6	N=320
4. It is important that our developmentally disabled child be assured of a secure lifelong placement.	80.8%	10.2	9.0	N=313

Table 43

Some parents are more satisfied than others with the services that are available to developmentally disabled children in their community. Thinking of your community, please rate the services below according to how important it is to expand or offer them: (rank ordered by need to expand or offer within each type of service)

	Adequate	Expand or Offer	Not Necessary	
Family Support				
1. Babysitters trained to handle developmentally disabled children	2.4%	92.5	5.2	N=291
2. Crisis lines for parents in times of stress	5.8%	88.7	5.5	N=292
3. Community referral service for legal, medical, and financial needs	10.5%	86.8	2.7	N=296
4. Respite care	8.9%	82.1	8.9	N=297
5. Homemaker/home-health aides	6.0%	74.2	19.8	N=283
6. Parent or family counseling services	32.6%	63.2	4.3	N=304
Educational/Diagnostic				
1. After school day care	3.9%	82.0	14.1	N=284
2. Early intervention programs	29.7%	66.5	3.8	N=290
3. Diagnostic services and clinic	31.4%	65.1	3.6	N=303
4. Special education programs	50.9%	49.1	[illegible]0	N=316
Living Alternatives				
1. Community living facilities	14.1%	75.7	10.2	N=284
2. Residential facilities	14.5%	74.8	10.7	N=289
3. Foster homes	10.3%	71.9	17.8	N=281
[illegible] Nursing homes	16.0%	65.1	18.9	N=281
[illegible]eneral Community				
[illegible] Architectural adjustments made so that it is easier for disabled people to get around	7.5%	89.3	3.1	N=292
2. Public education concerning developmental disabilities in the news media	7.8%	88.4	3.7	N=294
3. Reading materials in libraries on child's disability	23.4%	70.7	5.9	N=290
4. Church services	30.5%	[illegible]5.1	14.4	N=292
5. Special buses or vans	43.0%	41.0	6.0	N=302

Parents Comments Concerning the Future of Their Developmentally Disabled Child

Concerning her future--I many times hope I out-live her but the future cannot be ignored and must be planned for. We must try to make it as pleasant for the retarded as we can. (#506)

I feel parents of younger handicapped youngsters, that will need supervised living when they are older, should be concerned about the future, now. It's easy to put it off and hope something will be available in 10 or 15 years. It's very hard to get parents to look into the future. This could be because the future is so uncertain--how far will their child develop, what will be available, etc. (#315)

Can't bear to think about it now. Feel we'll cross that road when we come to it; that it is impossible to cope with something that won't occur for 20 years. (#594)

I would like to see all kinds of "care facilities" available so I could place my child in an atmosphere that is "right" for her. It would be unrealistic to put a child who is not self-sufficient in her own apartment or with friends. Then there are supervised facilities--as to what kind of supervision it would of course depend on how independent my child is at that time. I hope by then there are enough "care" facilities available so a parent could make a caring and educated choice and not have to place the child in an unfit area only because it was the only space available. (#590)

I would feel much better about his chances of a job if he received at least ½ day vocational training beginning at the junior high level. This is not true now. He is a good worker. He wants to "get a job". Training is the problem. (#054)

We are very concerned about our child's future financially. Will there be sheltered work shops? Although a number of family members will take our child if anything should happen to us, the financial burden is a great concern. (#134)

Since we very much want our child to live with us, I forsee a pressing need for respite care. As we get older, it may be physically more difficult for us to meet his needs, and any help in this area will be required. (#643)

Help!! There seems to be little, in terms of counseling and information available. (#328)

INDEX TO TABLES