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Children with Porencephaly: A Study of Services

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CHILDREN WITH PORENCEPHALY:

A STUDY OF SERVICES

by

DANA KAUFMAN AND ELISABETH MASON

A practicum submitted in partial fulfillment of the
requirements for the degree of

MASTER OF SOCIAL WORK

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Practicum approved by:

Jack Hegrenes, Advisor
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CHAPTER I

PURPOSE AND OVERVIEW

This study was conducted to serve as a follow-up of services received and/or needed by families with children who have been identified by Crippled Children's Division of the University of Oregon Health Sciences Center as having porencephaly, usually a severe form of brain damage. Porencephaly refers to cystic cavities or lesions in the brain caused by a prenatal and perinatal insult to the brain resulting in varying degrees of motor and mental deficits. These children have been seen in general as part of the Cerebral Palsy Clinic. There may be a lack of awareness on the part of the parents and the staff as to what the precise diagnosis and probable prognosis is of this group, therefore, it seemed appropriate to look at specific problems and needs that families might have.

In addition, the information gathered could be useful in planning a specialized clinic for this population.

CHAPTER II

SERVICE LITERATURE REVIEW

Services for children with porencephaly and their families are not a focus of study as reflected by the lack of literature on the subject. Therefore, this is a review of general services for the mentally and physically handicapped. The majority of articles in this area dealt with counseling and counseling techniques; only the minority discussed services.

Writers generally agree that strong supportive services are vitally important to the healthy growth and development of a handicapped child and her family although this has not been tested by adequate numbers of controlled studies. Stifler et al., in the only controlled study found by this reviewer, said that "counseling, therapy, special education and other supportive services do alleviate the conditions and result in a less severely handicapped child."¹ Evans studied people who kept their handicapped children in the home and found that additional services might have reduced their problems.² Mitchell described one of the positive impacts of better services on handicapped children as a lessening of the secondary effects of handicaps.³

Assuming that there is a recognized need for broad supportive services in order for handicapped people to reach their fullest potential, G. Brewer and J. Kakalik reviewed, on a national scale, resources available to handicapped children. They found services to be generally good but in need of improvement. Preventing handicaps, identifying needs, and providing services are done somewhat haphazardly with the following results. If an attempt at prevention through education and other avenues is not undertaken there will be existing handicaps which need not have occurred. Lack of identification implies that children might get no services, inappropriate services, or services too late for effective use; and vague directions mean that children do not receive constellations of services suited to their individual needs.

Services also frequently lack planning, coordination, and provision of information according to Brewer and Kakalik. There is seldom a good mechanism for identifying children's needs at a local level and there is no federal policy coordinating services to handicapped children. Information about individual programs is described as "in disarray, of poor quality or non-existent."⁴

An important area of the literature were those studies which, by directly questioning parents, evaluated individual agencies. There was agreement across these studies by parents about their needs. They wanted comprehensive information explained to them in laymen's terms about their

child's disability. In mourning the birth of a disabled child parents may work hard to gather as much information as possible about their child to maximize her growth and development, and to minimize and expiate their own guilt. This behavior allows them a sense of accomplishment and therefore helps bring back some sense of self-esteem.⁵ But it is important to note that parents may need to have this information given to them repeatedly over a period of time due to their emotional state,⁶ and resultant inability to hear information about their child.

Several authors stressed the point that the parents are the main caretakers of the child and therefore the role of staff in community agencies should be as consultants to the parents.^{7,8} The implication would be that parents should be fully cognizant of all aspects of their child's handicap in order to be able to give them truly comprehensive care.

Parents also wanted to be given information about available services so that when they needed, they would have knowledge about and access to appropriate services. A national service called "Closer Look"⁹ exists for referrals but parents interviewed in other studies thought that their own clinics and physicians should have more knowledge about local services.

Many individual needs of both children and parents were mentioned but few were explored by more than one article. These needs included requests by parents for

referrals or recommendations that are practical and within the parents' resources so as not to increase their frustration;¹⁰ opportunities for parents to pool their ideas about raising handicapped children, particularly so they could measure their own child's progress; and resources made available that might help the parents to understand their child.¹¹ One group found transportation and better intermittent care by a person other than family essential to prevent the family from becoming isolated,¹² and another group wanted professional help and guidance in providing stimulation for their children.¹³ In a particularly clear article Kathryn Gorham, as a parent, outlines what she feels parents should receive from physicians and clinics. Apart from those points already discussed in this review, she encourages maximum support by community agencies and clinic staffs of parents caring for a handicapped child.¹⁴

Finally, a number of people reported the effect of parent groups. The functions of these groups varied from dispensing information to providing counseling. Appell found that a parent's group, which included counseling and discussion, helped parents confront their feelings, created more positive attitudes, and led them to deal more realistically with the problems involved in the care of their handicapped child.¹⁵ Bitter also found evidence suggesting that discussion groups which dealt with various aspects of mental retardation resulted in more positive attitudes in

parents toward their child and to family problems which arose as a result of the handicapped member.¹⁶

Christine O'Connell, in looking for a systematic way in which to disseminate information to parents, set up a class-like group with a program of guest speakers, films, slides, and discussion. She found that parents are "interested in problems other than their own, are supportive of one another and can give as well as receive information."¹⁷ A program described by Flint and Deloach provided information and mutual support, and as a result helped to improve communication between parents of handicapped children. The response by the parents in the Flint and Deloach group was overwhelmingly positive judged by near perfect attendance and good evaluations.¹⁸

In general, the amount of literature evaluating services for the mentally and physically handicapped is limited. Interest in the subject has not yet come into it's own. But the literature which does exist shows quite clearly that parents would feel most effective if they were backed by strong supportive services with an opportunity to learn about their child's illness, and if they joined parents' groups to share their knowledge and experience.

Chapter 2--Notes

- ¹J. R. Stifler, E. Wollin, and A. Krous, "Follow-up Study of Children Seen in the Diagnostic Centers for Handicapped Children," American Journal of Public Health, 53 (November, 1963), p. 1750.
- ²Kathleen Evans and C. O. Carter, "Care and Disposal of Mongolian Defectives," Lancet, 2 (1954), pp. 960-963.
- ³Ross G. Mitchell, "Chronic Handicap in Childhood: It's Implications for Family and Community," Practitioner, 211 (1973), pp. 763-768.
- ⁴Barry D. Brewer and James S. Kakalik, "Serving Handicapped Children" The Road Ahead," Child Welfare, 54 (April, 1975), p. 262.
- ⁵Elva O. Poznanski, "Emotional Issues in Raising Handicapped Children," Rehabilitation Literature, 34 (November, 1973), pp. 322-326, 352.
- ⁶G. Horwood and E. Wolff, "The Organically Handicapped Child, How Can the Family Physician Help?" California Medicine, 110 (1969), pp. 28-33.
- ⁷Merle B. Karnes and Reid Zehrbach, "Matching Families and Services," Exceptional Children, 41 (May, 1975), pp. 545-549.
- ⁸Kathryn A. Gorham, "A Lost Generation of Parents," Exceptional Children, 41 (May, 1975), pp. 521-525.
- ⁹Dorothy Dean, "Closer Look: A Parent Information Service," Exceptional Children, 41 (May, 1975), pp. 527-530.
- ¹⁰Betty Caldwell, Edward J. Manley, and Yael Nissan, "Reactions of Community Agencies and Parents to Services Provided in a Clinic for Retarded Children," American Journal of Mental Deficiency, 65 (1961), pp. 582-589.
- ¹¹B. Bobath and N. R. Finnie, "Problems of Communication Between Parents and Staff in the Treatment and Management of Children with Cerebral Palsy," Developmental Medicine and Child Neurology, 12 (1970), pp. 629-635.
- ¹²J. M. Bryden and A. Tyndale, "Trying to Live Life on Your Terms: The Physically Handicapped Child and the Family's Point of View," Medical Social Work, 21 (July, 1968), pp. 111-117.

¹³A. Barclay, L. R. Goulet, M. M. Holtgrewe, and A. R. Sharp, "Parental Evaluations of Clinical Services for Retarded Children," American Journal of Mental Deficiency, 67 (1962), p. 234.

¹⁴Gorham, pp. 521-525.

¹⁵Melville Appell, "Change in Attitudes of Parents of Retarded Children Effected Through Group Counseling," American Journal of Mental Deficiency, 68 (1964), pp. 807-812.

¹⁶James A. Bitter, "Attitude Change by Parents of Trainable Mentally Retarded Children as a Result of Group Discussion," Exceptional Children, 30 (December, 1963), p. 173.

¹⁷Christine Y. O'Connell, "The Challenge of Parent Education," Exceptional Children, 41 (May, 1975), p. 555.

¹⁸Wallace Flint and Charlene Deloach, "A Parent Involvement Program Model for Handicapped Children and Their Parents," Exceptional Children, 41 (May, 1975), pp. 556-557.

CHAPTER III

MEDICAL REVIEW OF PORENCEPHALY

Parents want to know as much as possible about their child's defect and its treatment. Knowledge of this kind helps to alleviate guilt and to achieve mastery of the situation. If the para-medical staff have an understanding of the ailment they may be able to translate or impart information in layman's terms to the family. This knowledge also tends to sensitize the para-medical worker to the family's problems so that she might be more effective. The following description is intended to briefly explore the historical development of porencephaly, current understanding of its etiology, and treatment. This presentation could be similar to the information imparted to parents of children with porencephaly.

I. HISTORY AND ETIOLOGY

In a comprehensive review of the clinical aspects of porencephaly, Richard Naef¹ wrote that porencephaly was first introduced by Heschl in 1859 to describe lesions in the brain where actual cerebral tissue is lacking thus causing a canal through the brain which begins on the outer surfaces and extends through to the cerebral ventricles.

Heschl thought that porencephalic lesions were the result of a disease of the brain occurring during its development. Kundrat² adding to Heschl's work emphasized that porencephalic cysts were congenital.

Later, it was thought that infection such as encephalitis in infancy or intrauterine encephalitis was responsible for porencephaly. Other inflammatory conditions such as tuberculosis and syphilis also were believed to be related to the development of porencephaly.³

Naef reported that other researchers thought that porencephalies were the result of an arrest of development, or a secondary condition with an unknown cause, or a genetic abnormality of the germ plasm prior to fertilization.⁴

Jaffe emphasized the importance of intrauterine or birth trauma as the most common cause of porencephalic cysts.

The trauma that leads to a porencephaly may affect the brain while the fetus is still in the uterus or it may occur in infancy or in later life. The most common cause is undoubtedly the trauma occurring at birth. In the history of cases of porencephaly there is striking frequency of prematurity, prolonged labor and instrumental delivery.⁵

Marburg,⁶ sixteen years later, stated that birth trauma is the principal cause of porencephaly.

Yakovlev⁷ divided porencephalies into two types:

(1) acquired or encephaloclastic porencephalies which represented defects in the cerebral wall and subsequently resulted in destruction of tissue caused by trauma,

circulatory or inflammatory disturbances, and (2) developmental or schizencephalies which are abnormal clefts formed congenitally in the brain substance due to agenesis or growth abnormalities of the brain.⁸ A recent study by Nixon et al. of patients with congenital (developmental) porencephaly indicated that the primary insult to the brain originated before the twelfth week of intrauterine life.⁹

It has been postulated by Dr. A. Browder, pediatrician at Crippled Children's Division, University of Oregon Health Sciences Center, (CCD), that an intrauterine insult to the brain could possibly precipitate the difficult birth and the ensuing perinatal problems which are reported in many cases of patients with porencephaly.

A child already with extensive brain damage which occurred in the uterus is going to function and tolerate delivery differently. The question becomes, was the brain damage all the result of newborn difficulty related to something already being wrong with the brain? It may be, at times, that we are assuming everything is from a single insult when it is not.¹⁰

Dr. Browder also explained that the defect to the brain probably did not occur during the formation of the brain which takes place at 3-4 weeks gestation since other malformations in other body organs would be present if that were the case. It was likely to have been something happening to the brain circulation during the formation of the vascular system which occurs at about 9 weeks gestation, or any time up to birth or thereafter.

A porencephalic cyst is probably much like an adult stroke except in the adult the brain is fully developed while in the baby the brain and the skull bones continue to get larger while one part of the brain has died. That part of the brain is a dead area of tissue because it did not get blood, oxygen, or nutrition in the tissue. Loss of this tissue may then actually leave a cavity or space.

The concept of the stroke may also be used to describe what could happen in the case of a premature baby who does not have mature lungs, therefore, gets into trouble in terms of lack of oxygen, shock, and poor circulation. These events could produce two phenomena, vascular damage or blood clotting; both could occur separately or simultaneously resulting in destruction of brain tissue.¹¹

II. DIAGNOSIS

Nixon et al. states that:

Knowing the prognostic implications facilitates patient management and parental counseling
A cooperative multidisciplinary approach with correlation of signs and symptoms, transillumination, E.E.G. results and skull film findings will facilitate early diagnosis.¹²

Diagnosis of porencephaly can be achieved through transillumination in which an ordinary flashlight fitted with a rubber adapter is placed against the child's head in a darkened room. Translucency of the head may indicate porencephaly. Ventricular air studies or pneumoencephalography which replaces the cerebrospinal fluid with air in order that

x-ray films might be taken, can determine the specific location and size of the cyst. This procedure is used infrequently as a diagnostic tool since it requires the patient to have a general anesthetic and there is some risk involved.

The electroencephalogram is useful in confirming a diffuse cerebral disorder but does not provide a specific diagnosis. Carmon et al. states that confirmation of porencephaly cannot be based on the type of electroencephalographic abnormality since it does not identify etiology of localized loss of brain substance.¹³ He states, however, that "the type of electroencephalographic disturbances, as well as to the extent to which they develop, may determine prognosis and aid in decision on operative treatment in patients with uncontrolled seizures."¹⁴

Another technique most recently developed is the computerized brain scanner which provides a definitive diagnosis by x-raying the brain in narrow contiguous sweeps or "slices." The narrow x-ray beam scans the head from 180 angles. The scanner revolves around the head taking 28,000 readings of each "slice." These readings are analyzed by computer so that differentiation between cerebrospinal fluid, gray matter, white matter, bone and fat, and abnormal densities is visualized.¹⁵

Ideally, all of the patients in this study would be scanned to determine the extent of their brain damage. Records could be kept relating the degree of neurologic

symptoms and functional handicap to the extent and area of brain damage, in order to begin to predict what the prognosis is of any individual child diagnosed as porencephalic. Hopefully, this might lead to prediction of specific clinic or management programs which would be beneficial to the child.

III. PROGNOSIS

The literature is guarded about the future of children with porencephaly because it predicts that those who survive will, at best, be moderately defective with spastic double hemiplegias.¹⁶ In Nixon's study of eighteen patients with congenital porencephaly,¹⁷ seventeen had motor deficits, twelve presented with signs of delayed growth and development, ten patients had convulsions, and one had hydrocephalus.

In the present study of twelve children from CCD, ten had motor deficits, nine were developmentally delayed, five had seizure disorders, and two had hydrocephalus.¹⁸

IV. TREATMENT

Treatment is primarily symptomatic. It may consist of anticonvulsive drugs for those patients with seizures to prevent further damage. Surgical procedures may be indicated to drain the cyst or to insert a shunt to carry the cerebrospinal fluid from the brain into other parts of the body, where it can be absorbed into the bloodstream. Treatment may

also be in the form of physical therapy to increase and encourage maximum utilization of the child's potential. The authors of this study think that any service provided to patients and their families that enables them to develop the greatest portion of their innate abilities is a form of treatment whether it is medical, special schooling, skilled therapies, or counseling.

V. SUMMARY

Porencephaly can currently be described as the presence of cavities in the brain developed in fetal life or in early infancy. It appears that the defect may be multifactorial in origin. The cause is suppositional. Physicians are able to say it might be due to lack of oxygen, or infection prenatally or perinatally. It would be speculation to give parents a specific cause for the injury to their child's brain, though that is what parents want and what they pressure doctors to give them. Physicians must find a balance between telling parents that they do not know the cause and inundating the parents with all of the possible causes. It is important to note that parents' emotional involvement often gets in the way of their hearing the explanation and understanding it, so it is important to repeat the diagnosis and its explanation many times. With each repetition parents will learn more. Their understanding helps lead to their acceptance of the disability which in turn will benefit the whole family in

their use of services and the ultimate development of their handicapped child.

If we conclude that the children in our study are typical, porencephaly will result in symptoms ranging from mild motor deficits to profound neurologic impairments. Diagnosis may be done through transillumination or brain scanning. Treatment involves use of seizure medication, brain surgery for draining cysts or shunting the cerebrospinal fluid, physical/occupational/speech therapy, and linking the family to needed or desired services.

Chapter 3--Notes

¹Richard W. Naef, "Clinical Features of Porencephaly," Archives of Neurology and Psychiatry, 80 (July, 1958), p. 133.

²Ibid., p. 134.

³Ibid.

⁴Ibid.

⁵R. H. Jaffe, "Traumatic Porencephaly," Archives of Pathology, 8 (November, 1929), p. 789.

⁶Otto Marburg, Ph. R. Rezak, and M. B. Marks, "Porencephaly, Studies in Phlebothrombosis and Phlebostasis," Journal of Neuropathology and Experimental Neurology, 4 (January, 1945), p. 58.

⁷Naef, p. 135.

⁸Ibid.; P. I. Yakovlev and R. C. Wadsworth, "Schizencephalies: Study of Congenital Clefts in the Cerebral Mantle," Journal of Neuropathology and Experimental Neurology, 5 (April, 1946), p. 116; John M. Freeman and Arnold P. Gold, "Porencephaly Simulating Subdural Hematoma in Childhood," American Journal of Diseases of Children, 107 (April, 1964), p. 328.

⁹George W. Nixon, Richard F. Johns, Jr., and Garth G. Myers, "Congenital Porencephaly," Pediatrics, 54 (July, 1974), p. 49.

¹⁰J. Albert Browder, Interview, May 1976.

¹¹Ibid.

¹²Nixon et al., pp. 43, 49.

¹³A Carmon, S. Lavey, and A. Shwartz, "The Dynamics of Electroencephalographic Abnormalities in Porencephaly," Neurology, 14 (August, 1946), p. 761.

¹⁴Ibid., p. 763.

¹⁵"Brain Scanner Avoids Invasive Technique," Pediatric News, 9, No. 9 (September, 1975); "EMI Brain Scanner Should Provide More Answers," Scope, Good Samaritan Hospital and Medical Center Publication (January-February, 1975), p. 10.

¹⁶Thomas Farmer, ed., Pediatric Neurology (New York: Hoeber Medical Division, Harper and Row, 1964), p. 171.

¹⁷Nixon et al. p. 45.

¹⁸See Table VI, p. 28.

CHAPTER IV

METHOD OF INQUIRY

The population for this study consisted of fifteen families. A descriptive case study using an interview schedule (see Appendix B.) was developed to get at formative data concerning services to porencephalic children and their families. Twelve interviews were completed. One family declined participation and two families were not located in time to ask them to participate in the study.

A preliminary interview schedule was completed and given to a family from the Cerebral Palsy Clinic. Upon revision, it was given to the family in the study most recently seen at Crippled Children's Division (CCD). This family had the most current information given to them concerning porencephaly and their child's disability. They provided some input and suggestions regarding the interview and after a few minor alterations the final form was given to the remaining families.

The questions in the schedule were designed to evaluate the family's perceptions surrounding the services they use and need. The content of the questions covered the following areas.

The first group of questions were designed to uncover factors which limited or encouraged use of services. A

demographic profile of the family was obtained as well as the family's general knowledge of services, their financial arrangements, the family support system, and family attitudes toward the handicapped member.

To evaluate services that the child receives or requires, another group of questions covered the amount of understanding parents had about their child's disability. This included information about the presence of perinatal complications possibly indicative of future problems, physical symptoms in the child, and the level of knowledge the parents have of the child's diagnosis. Also covered were the parents' understanding of the causes of the child's disability, the likely course of development, and the range of treatment available.

Parents were asked to review the services they received at CCD in the third section. Again, the concern lay in the level of understanding of the disability. Questions covered their perceptions of the program, the way in which they use it, and their satisfaction with those services they have received at CCD.

Finally, because it was thought there might be some benefit to the parents if a one-time clinic was given by CCD covering aspects of the disability of which the parents seemed unaware, input was gathered regarding their need for such a clinic and their suggestions for possible subject matter.

CHAPTER V

PRESENTATION OF DATA

The twelve children included in this study range in age from 3-23 years, with an average age of 8.7 years and a standard deviation of 5.39. There were six girls and six boys in the group. The age of the children when first seen at CCD ranged in age from 7.5-9 years. Seven of the twelve were seen at CCD for the first time at one year or younger.

The fathers' ages range from 29-55 years with a range of 8-18 years completed of formal education. All fathers but one are presently employed. One father is deceased.

The mothers' ages range from 25-53 years with a range of 8-17 years of education. Three of the mothers work outside the home while the others list housewife as their current occupation.

Four of the twelve parents have been divorced. Of the four divorced families, three children with porencephaly live with their mother. The fourth child has been legally adopted by her maternal grandparents.

Four of the children are only children, two children are first born, three children are second born, and three children are fifth born. (See Table I.)

TABLE I
FAMILY COMPOSITION

Subject	Patient's Age ^a	Sex	Siblings by Age	Parents by Age
				mother/father
1	8	F	-	29/31 ^b
2	6.5	M	2	28/29
3	7.5	M	9,10	35/37
4	5	F	-	30/29
5 ^c	8	F	-	27/32 ^b
6	10	M	21,19,17,15,4	38/40 ^b
7	5	M	-	28/29
8	4	F	6	25/34
9	23	F	19,25	44/41
10	3.5	M	1	29/30
11	14	M	26,23,20,19	46/deceased ^b
12 ^d	10	F	36,34,31,27	53/55

^aAge computed as of 6/1/77.

^bDivorced.

^cAdopted by maternal grandparents.

^dAdopted.

Three families have not moved since their child was born, five families moved to obtain services such as education or medical care for their child, and four families moved for other reasons.

Eight families of the twelve live within the tri-county area surrounding Portland. One family lives in Vancouver, Washington, and three families live in other cities in Oregon.

Nine of the twelve children in the study are presently living at home. One child has been adopted by the child's maternal grandparents and lives in another city while frequent visits with her mother are maintained. Another child spends Monday through Friday at the Oregon State School for the Blind with weekends home, and the third child lives at Fairview Hospital and Training Center, an Oregon State institution for the retarded, with her parents visiting two or three times a year.

All of the children but one are currently involved in some type of education program. Three children attend public school in a regular classroom. Five attend public school in special programs for handicapped children. Three are involved in state programs, two of which are residential and one a day school.

The average age of entering a school program is 4.5 years with a standard deviation of 1.94 years. (See Table II.)

TABLE II
USE OF SERVICES

Subj.	Living Arrangement	Age Started School	Current Education Program	Formal and Informal Services Used Presently or in Past ^a
1	Home	4	TMR Class, Speech therapy, Public Sch.	Good Samaritan Child Neurology Clinic
2	Home	2.5	Spec.Ed., Speech therapy, Public Sch.	Family, Shriner's, Church
3	Home	5	Regular classes, Speech therapy, Public Sch.	Shriner's, Neighborhood children, Grandparents, Swimming, Church Sch.
4	Home	4	Spec.Ed., Public Sch.	Good Samaritan Child Neurology Clinic
5	Grand-parents	4	Wash.State Supported Public Sch. for Cerebral Palsy, Speech and Phys. therapy	Medical services at Military base, Family
6	Oregon Sch. for Blind	9	Program at Oregon State Sch. for the Blind	Grandmother, The Elk's Eye Clinic

TABLE II--Continued

7	Home	2.5	Holladay Center Sch. for the Handicapped Public Sch.	Family, Babysitter
8	Home	-	None	Easter Seals Mobile Therapy, Magazine-- <u>The Exceptional Parent</u> , Grandmother
9	Fairview	3	Program at Fairview	Parents of Retarded Children Organization
10	Home	3	Developmentally Delayed classroom, Clackamas Co. I.E.D.	Family
11	Home	5	Regular classroom, Public Sch. with emphasis on reading	Church School
12	Home	6	Regular classroom, Public Sch.	Family, Holladay Center

^aExcluding CCD or education program.

Each of the children had been seen by a doctor unassociated with CCD and practicing in the community. It was assumed that these doctors gave the parents a reason for referring their child to the Crippled Children's Division, and why the child was having difficulties. The specialties of those professionals seen included six pediatricians, one general practitioner, one obstetrician, three neurologists, and a home health nurse.

The parents reported a variety of explanations. One family was told nothing was the matter with their child, the doctor reportedly stating that the child was thriving and not to worry because it was a miracle the baby had lived. One was told their child probably had hydrocephaly, while another was informed that the left side of the brain was underdeveloped. Three reported Cerebral Palsy, two were told brain damage, one that the child was mentally retarded, and one that there was a cyst which affected balance and had damaged that part of the brain controlling the left side. Porencephaly as a diagnosis was not given.

All but one of the births were unusual and involved perinatal problems. The physical manifestations which contributed to the above diagnosis reported by parents are listed in Table III. Physical symptoms suffered by the children can be found in Table IV and Table V. Diagnosis as recorded in the medical chart appear in Table VI.

TABLE III
UNUSUAL CIRCUMSTANCES AT BIRTH

	No	Yes ^a	Not Known	Description
Unusual labor	4	8	-	4-long labor, 3-induced, 1-false, 1-precipitous
Premature	6	6	-	From 2 wks. to 10 wks. early
Traumatic delivery	3	9	-	
Neo-natal difficulties	6	5	1	2-seemed lifeless, 1-spinal meningitis, 1-cried 24 hrs./day

^aOne or more.

TABLE IV
SYMPTOMS

	No	Yes ^a	Not Known	Description
Hydrocephaly	7	5	-	Diagnosed between 2 wks.-18 mos.
Seizures	5	7	-	Starting at from birth to starting at puberty
Physical deformities	4	8	-	
Affected speech	5	7	-	
Serious illness	6	6	-	
Retarded	5	6	1	

^aOne or more.

TABLE V
COMPARISON OF NUMBER OF PERINATAL PROBLEMS
TO NUMBER OF SYMPTOMS FOR EACH CHILD

Subject	Perinatal Problems	Symptoms per Child
1	0	5
2	3	3
3	4	4
4	2	2
5	2	2
6	3	3
7	1	4
8	3	2
9	1	2
10	4	4
11	3	2
12	2	3

TABLE VI
DIAGNOSIS AS RECORDED IN CHART

Subj.	Diagnosis
1 . . .	Clubfeet, Bilateral dislocation of hips, Multiple congenital abnormalities, Psychomotor delay, Seizure disorder, Atonic diplegia, Porencephaly, Delayed language development, developmental delay
2 . . .	Seizure disorder, Right esotropia, Congenital Malformation of brain with porencephaly and microcephaly
3 . . .	Hydrocephalus, Cerebral Palsy, Porencephaly, RH incompatibility, Meningitis, Esotropia, Premature, Congenital bilateral club foot
4 . . .	Cerebral Palsy w/spastic hemiplegia and athetoid, Right hemisphere porencephalic cyst, Seizure disorder, Asymmetrical involvements, (left and right leg length), Alternating esotropia and hypermetropia
5 . . .	Porencephaly, Spastic quadriplegia, Moderate-severe motor delay, Severe intellectual delay
6 . . .	Mental retardation (moderate-severe), Atonic diplegia, Hypertonia w/trunkal and extremity ataxia (2° to cerebellar agenesis), Speech (nonverbal), Aniridia, Cerebral Palsy ataxic athetoid
7 . . .	Neurofibromatosis, Significant delay in motor development, Porencephaly, Spastic tetraplegia (more marked on right), Sightless in left eye, Myoclonic seizures, Mental retardation
8 . . .	Porencephaly, Esotropia (OD), Developmental delay, Spastic tetraplegia
9 . . .	Developmental defect (cerebral cortex, frontal area) Bilateral and left parietal, Spastic quadraplegic, Contractures (hips and knees), Strabismus (internal)
10 . . .	Left Porencephalic cyst, Developmental delay, Suspected hearing loss, Prematurity, Respiratory Distress Syndrome
11 . . .	Agenesis of corpus collosum, Spastic diplegia, Right hemiparesis, Mild articulation disorder, Mild delay in language, comprehension and expression, Alternating esophoria
12 . . .	Premature, Respiratory Distress Syndrome, Brain cyst (right, cerebral cortex), Left hemiplegia, Hydrocephalus, Borderline mental retardation, Spastic diplegia, Left homonymous hemianopsia (suspect)

The interview asked for the parents' understanding of the patho-physiology of the brain damage, its etiology, its possible developmental effects, and the extent to which it can be treated. Five couples described brain damage, two stated parts of the brain tissue were missing. Five could not describe the nature of the disability. Diagnoses reported by parents are shown in Table VII.

TABLE VII
DIAGNOSIS REPORTED BY PARENTS

Subject	Reported Diagnosis
1	Brain damage
2	Brain had not developed
3	Nerve damage from spinal meningitis
4	None
5	Part of child's brain is missing but called it C.P.
6	Cerebral Palsy
7	Cerebral Palsy
8	Hydrocephalus and Cerebral Palsy
9	None
10	Porencephaly
11	Hydrocephalus, brain damage
12	Cyst that damaged part of brain

Current understanding of etiology of the childrens' handicap varied. Reasons reported ranged from the problem being hereditary, caused by perinatal spinal meningitis,

lack of oxygen at birth, complications during birth or early fetal development, to speculation about the birth control pill. Three people stated they did not know the cause.

When asked about the expected developmental course and the extent of treatment, eight parents understood that their child would have some handicap. Three did not know how the child would develop, and one felt that by the time their child is older she may be close to normal. Seven reported that there was nothing to be done in terms of treatment. Five mentioned physical therapy as treatment to develop the physical potential of their child, and one of those five said that there might be new developments in the future which could help in treatment.

Six parents when asked if they considered their child to be mentally retarded responded affirmatively. Those parents, when asked how severe the retardation was, reported slight, slow in some areas, not educable, do not know yet, and functioning below age level.

To evaluate the parents' satisfaction with their knowledge of the child's disability they were asked whether they had been given enough information by the diagnosing doctor. Four felt they had received just the right amount of information. Eight felt they had been given too little. The four parents reporting that they had received just the right amount of information were four of the eight receiving diagnosis and explanation from CCD.

The doctors who had given the diagnoses and explanations were described in positive terms generally. Few were considered to have treated the parents poorly (see Table VIII).

TABLE VIII

PARENT'S DESCRIPTION OF INTERACTION WITH
DOCTOR WHO GAVE DIAGNOSIS

Subj.	Description	Reason
1	Vague, little tact, confusing	When parents asked what was wrong, each time doctor said they had to do more tests before he could tell them. Then diagnosis was vague, i.e., seizure disorder
2	Blunt, treats parents like idiots, though concerned for child	Calls mother at home, knows name of child, keeps up on children in family
3	Frank, to-the-point comfortable personality	Uses understandable terms, gives total attention, he is specialist
4	Told facts, impersonal, cared for child	Showed she was interested by calling child by name and talking to her
5	Good, thorough	Wasn't rushed, took time
6	Professional in a positive way	Took time to tell them what they were up against
7	Professional in a negative way	Did not explain enough about what they were doing
8	Superficial, hardened	Mechanical, felt she was being talked down to
9	Cruel, excellent doctor	Said parents should send child to Fairview, gave them so much information
10	Warm, seemed to care, sensitive	Understanding, non-clinical, unhurried, relaxed, nice to child
11	Wonderful	Showed concern and interest
12	Gruff	"Look at all of the children whose lives are hanging on the balance, yours is alive," respected parent's views

The last part of the section on understanding dealt with the effect of a disabled child on the family and their relationships. All of the respondents reported positive effects within families but several reported a change in relationships with friends. Two stated they see friends less often, and two said their child adds to their problems. Reasons given were that children were problematic in social situations in that the children were difficult to take out and some friends did not understand. Also, lack of respite care limited families maintaining friendships. Eight families reported no change in relationship with friends (see Table IX).

TABLE IX
PARENT'S REPORTED EFFECT OF HANDICAPPED
CHILD ON RELATIONSHIPS

Subj.	Effect on Relation- ship with Family	Effect on Relation- ship with Friends
1	Mother-family accepts child but overdoes, father-family realistic and good to child generally made marriage difficult	Fewer friends, can't get out as much
2	Family goes out of way to help, involved with child	Has had negative effect on some friends
3	Family concerned with financial resources, doesn't "see" handicap	None
4	Doesn't know, have not had normal child to compare to	None
5	Warm and accepting	None
6	Not much, but draws family closer	Adds to problems
7	Family understanding but everybody feels hurt	None
8	Taught compassion and sympathy for people in difficult circumstances, not enough time for other child	Not as social, friends don't stay as long as they used to when visiting
9	Makes other children more compassionate, moving to area which had school for handicapped best move they made in terms of opportunities for whole family	Made relatives kinder people
10	Family recreation difficult, family closer	Brought people closer
11	Father never accepted child, drawn girls closer together, taught family how to get along with people	None
12	Made children more considerate of handicapped child	None

In the study of services section of the questionnaire, families were asked what kinds of services were available to them, informal and formal, and how many of those they use apart from CCD. Five families use all of the services that they mentioned and seven families generally use less than half of the services of which they are aware. Families were asked to remark on needed services. Their responses are recorded in Table X.

TABLE X
NEEDED SERVICES REPORTED BY PARENTS

Category	Subject	Description
Home	1	Someone to work w/child at home, particularly w/coordination
	2	Respite care, therapy at home
	3	Husband needs to learn to do exercises w/child at home
Counseling	1	Marital--how to cope
	2	Not actively seeking, but would not turn down
	8,3	For child when he is older--how to cope w/being different
	4	Maybe more counseling
	5	Upon occasion, more counseling
	9	Improve communication between us and child--need reassurance that we are doing alright
Educational	1	Desire parent education
	2	Definitely desire education about Cerebral Palsy
	3	Yes for us, later for child
	5	Education for me (mother)
	8	How to cope-for parents and child
	10	Would like to read books on the subject
Financial	1	Definitely need help, no insurance, big medical bills
	3	Money for shoes and braces really sets budget back, would appreciate assistance
	4	Have gotten money for transportation which we appreciate
Medical	3	Need physical therapy and occupational therapy

TABLE X--Continued

Category	Subject	Description
Medical	5	Needs more physical therapy and speech therapy
	6	Need closer medical services
	12	Need someone to check child's legs, physical therapy
Recreational	1	Needs stimulus from normal children and something physical to develop coordination
	3	Child needs more friends
	2	Hope child can go to camp, also needs something to develop coordination
	8	More group activity w/other children
	9	Help in getting child outside, i.e., ways to make it easier
	12	Needs physical education suited to child's disability
Transportation	1,2	Could use transportation to doctors
	10	Help w/transportation would allow child to go to school more days
Vocational	3,5,6,8,11	Vocational training in future
Other	3	How to plan and what to expect in the future
	10	Help in planning for future even after we die
Desirable Services		Respite care, contact with children w/similar disability, parents group, closer schools, parents advocacy, music, transportation or help on and off bus, good babysitting service, better physical education, better/quicker referrals, hydrotherapy

In evaluating the various services received at CCD, the data indicates that parents generally did not remember or delineate between the individual disciplines unless they considered them excellent or very poor. Physical therapy was mentioned most often as being a good service. No one specialty was particularly disliked. Reasons given for why services were rated excellent or good included the staff's attitude and dedication, and the freedom with which they imparted their knowledge to the parents for their use at home. The parents also liked staff who individualized their child. Reasons for rating the services as poor or fair were impersonal treatment, rushing through examinations and explanations, giving no explanation of their treatment of the child, and not giving enough information about the child. An interest in a special clinic or workshop was indicated by nine of the twelve families interviewed (see Tables XI, and XII).

TABLE XI
INDICATION OF INTEREST IN A SPECIAL CLINIC

Possible Topics of Interest	Subject												Total
	1	2	3	4*	5	6*	7	8	9*	10	11	12*	
a. Reevaluation of child		x	x		x			x					4
b. Parent education	x	x	x		x		x	x		x	x		8
c. Availability of community services	x	x	x		x		x	x		x	x		8
d. Counseling		x					x	x					3
e. Opportunity to talk to other parents			x		x		x	x		x	x		6
f. Other topics	x	x	x		x		x	x		x	x		8

* Not interested in special clinic.

TABLE XII
OTHER TOPICS OF INTEREST

Subject	Topic
1	a. Discipline b. What social security benefits are available
2	a. Teach us self help skills for child i.e., learning to tie shoes with one hand so that we can show him b. Discipline c. Ways to help him understand how he's different from others--to understand why other children are so cruel
3	a. Therapy instruction for parents b. Help to start towards occupational/vocational skills c. Chance to talk to parents with older handicapped children for ideas
5	a. Information about certain "tools" children should have--self help skills, equipment, etc. b. Would be valuable to have adult w/Cerebral Palsy to talk about their experiences--coping, etc. c. Find out what books are available on Cerebral Palsy
9	a. Not interested in clinic but would be willing to talk to other parents
10	a. Available equipment, technical things
11	a. Clinic should be for both parents

The last question was an open-ended question which was asked for any information the parents thought was missing in the interview schedule. Most of the responses were repetitions of comments made previously although two parents commented on the importance of their religious faith in

coping and another family commented on a need to increase public awareness generally of handicapped children. One mother related the personal change and growth she has experienced through having a handicapped child.

CHAPTER VI

DISCUSSION AND RECOMMENDATIONS

This study was done to learn how much understanding families with porencephalic children have of the illness and whether the level of their understanding is related to the way in which they use available services. We also wanted to give the parents an opportunity to comment on their experiences with CCD and on other services they use or might need.

In general we found that most parents were confused about the diagnosis of their child. Ten out of twelve gave us one diagnosis when several have been recorded for each child in the medical chart. Only one family actually used the term porencephaly to label the disability. Most of the other families described their child as having brain damage or Cerebral Palsy and were otherwise nonspecific. Two were unable to give us a diagnosis.

There seem to be at least three possible reasons for this lack of awareness: (1) the parents might not have been told that their child had porencephaly, or (2) they were told once or twice but did not hear the diagnosis because of its strong emotional impact, or (3) they were unable to understand the diagnosis from a technical point

of view and so, do not have a clear picture of the etiology, diagnosis, and treatment of their child's disability.

If parents know their child's diagnosis, they will be more likely to seek treatment for their children and they will have realistic expectations for the future. Due to the small number of families who had some understanding of the brain defect, we are unable to clearly support this relationship with data from our study. But there were several parents who probably would have undertaken recommended medical treatment if they had had more conscious information, since their reluctance to do so stemmed from unfounded fears about the medical procedure.

However, there were other results from this study which we feel provide practical information about treatment and services. We have chosen to discuss these results in greater depth.

First, parents do not ask for what they need unless questioned directly, a behavior probably characteristic of most parents. When asked, parents in our study responded with some important needs which could be or already are available. For instance, parents said they would like financial assistance with medical bills, transportation, and braces. Also mentioned was counseling which is a service intermittently offered at CCD. Therefore, more effort should be given to informing parents at the time of diagnosis and periodically thereafter, of all services that are

available. The physician cannot always be expected to know or predict specific services that may be needed by her patient, nor does she have the time to get this information each time she sees the patient. Development of a brochure which contains up-to-date information on all services would be useful to parents as well as more aggressive referral to appropriate services. Several parents wanted a reading list; this could be part of the brochure.

Secondly, due to relief at finding a service which dealt specifically with their child's disability, some parents seemed reluctant to make critical comments about CCD and apologetic when they did so. Again, as a result, they do not ask for services they need. It was evident that parents had needs which were not met due to their reluctance and insufficient knowledge of the programs at CCD, not because such programs do not exist. These feelings also prevent specific programs from starting which otherwise would if more people asked for them.

A third reason for inefficient use of resources results from the exclusion of four of the families interviewed from the Cerebral Palsy Clinic. At present there is discussion over whether porencephaly should be a separate diagnostic category from Cerebral Palsy. As long as the children are not diagnosed as Cerebral Palsy they are unable to receive the benefits of the special Cerebral Palsy clinic. These four families receive uncoordinated

services and fewer services. Despite the risk of the parents mislabeling and misunderstanding the disability it would be better for these children to be included in the Cerebral Palsy Clinic until another clinic or satellite clinic can be set up for them. These clinics are important because a parent who understands all aspects of the brain defect will be able to cope better with the child's handicap.

In voicing their concerns, parents expressed two major needs directly related to their treatment at CCD, which we feel are important enough to be emphasized here. First, they wanted more information about what happens to them when they come to CCD for clinic. They wanted to know what was being done to their child (including routine examinations), why it was done, and what the results were. The parents seemed to be saying that they wanted to be recognized as an important part of the team caring for their child. Some felt they did not have this recognition.

The parents also expressed a desire for groups where parents could get together to share experiences, give each other support, and discover new resources. These groups are available occasionally but seldom to our particular population as a group because they are not all included in a special clinic. There is strong support for such groups from all types of professional literature.

We would like, in closing, to recommend that parents of these children be contacted and given an opportunity to

return to CCD for the most recent knowledge about their child's disability. Many of the parents whose children were seen at CCD a few years ago need to be updated on changes that have occurred in the program as well since CCD policies have changed and become more treatment and management oriented.

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APPENDIX A

COVER LETTER

COVER LETTER

Your family has been selected as one of a number of families in the Cerebral Palsy Clinic in order to do a follow-up study of services at Crippled Children's Division.

The study is being conducted by Liz Mason and Dana Kaufman, two graduate students in Social Work at Portland State University under the auspices and supervision of Crippled Children's Division.

Crippled Children's Division sees this as a valuable follow-up service to you and an opportunity to gather information that will help us to improve our services. Your names will not appear in any report resulting from this study in order to maintain confidentiality. Participation in this study is voluntary on your part and your refusal to participate will in no way jeopardize any future treatment that you might receive at our agency.

We hope that you will choose to participate. You will be contacted by telephone to see if an interview may be arranged with you in your home.

Sincerely,

J. Albert Browder, M.D.
Director of Cerebral Palsy Clinic

APPENDIX B

INTERVIEW

INTERVIEW

FOLLOW-UP STUDY OF CHILDREN WITH MULTIPLE DISABILITIES

As you are aware from our letter we are here to do a follow-up study of some families that have received services from CCD.

Before starting the questions we would like to emphasize once more that all the answers you give us are confidential so no one will know who said what. The answers won't be connected with your name. The answers will not influence or jeopardize your treatment in any way either. We hope that with this assurance you will feel free to answer the following questions as accurately as possible, but if there are any questions you do not want to answer you don't have to. Do you have any questions before we begin concerning this interview? OK, let's start.

I. Demographic Information

1. What is the name of your child who was referred to CCD? _____

His/her date of birth? _____

And age? _____

2. When was s/he first seen at CCD? _____

3. When was s/he last seen at CCD? _____

4. What is your relationship to the child? _____

5. May I have Mr. _____ age _____, highest education level _____, and occupation _____

6. May I have Mrs. _____ age _____, highest education level _____, and occupation _____

7. May I have the names and ages of the other children in the family.

Name

Age

- 1.
- 2.
- 3.
- 4.
- 5.

8. Are you MARRIED DIVORCED WIDOWED SEPARATED ?

9. Where did you live when your child was born? _____

10. Have you moved since your child was born?

NO-go to 14

YES

11. How many times have you moved?

12. Where have you moved to?
(Please list each according to
city) _____

13. What were the general reasons for
the move/s?

1.

2.

3.

4.

14. Do you have active health insurance?

NO-go to 16

YES

15. What is it?

II. Understanding of and reactions to child's disability

16. Did you suspect anything was the matter with your child
before you were told?

NO-go to 18

YES

17. In what way?

18. Was your child born prematurely?

NO-go to 20

YES

19. How premature was s/he?

20. Were you aware of any difficulties during the neo-natal period?

NO-go to 23 YES

22. What were they?

23. Was the delivery traumatic?

NO-go to 25 YES

24. In what way?

25. Did you have an unusual labor?

NO-go to 27 YES

26. In what way?

27. Did or does your child have hydrocephaly?

NO-go to 30 YES

28. Was this diagnosed within the first six months of his/her birth?

29. How was this treated?

30. Has (child's name) had any seizures or convulsions?

NO-go to 33 YES

31. When did they start?

32. How are they being treated?

33. Does your child have any physical deformities?

NO-go to 36 YES

34. What are they?

35. When did you first notice them?

36. Is (child's name) speech affected?

NO

YES

37. Has your child had any serious illnesses?

NO-go to 39

YES

38. What were they and when did they occur?

Illness

Date

39. Is your child mentally retarded?

NO-go to 41

YES

40. How severe is his/her retardation?

41. ARE THERE OTHER SIBLINGS?

NO-go to

YES

42. Have your other children had any of the conditions we just talked about? I will repeat them. (use no names, initials if nec.)

PREMATURE BIRTH_____

TRAUMATIC OR UNUSUAL LABOR_____

HYDROCEPHALY_____

PHYSICAL DEFORMITIES_____

SEIZURES OR CONVULSIONS_____

SERIOUS ILLNESS_____

ANYTHING ELSE_____

[read if checked] (We would like to look at your child's original medical chart. Because the child wasn't born at the University of Oregon Medical School we were unable to see his/her medical chart. In order for us to do this we need to have you sign a release of information form, like this (show form). Would you mind signing this for us?)

43. Did you know something was the matter with your child before you went to CCD?
44. What were you told by any doctors about your child's condition before you were referred to CCD?
45. What was/were his/her/their speciality/ies?
46. What sort of setting did/does s/he/they practice in?
(private office, group practice, agency)
47. How old was (child's name) when the above doctors examined him/her?
48. WAS A CLEAR DIAGNOSIS GIVEN?
YES
NO-go to 58
49. How did you interpret this information?
50. Did the person/people who told you give you
___ a. TOO MUCH INFORMATION
___ b. JUST THE RIGHT AMOUNT
___ c. TOO LITTLE INFORMATION
51. How would you describe the people/person who told you your child had/was (child's illness)?
52. What was it about these/these people's/persons manner or behavior that made you feel this way?
53. When you were first told your child had (child's illness) what were your reactions?

54. What made you feel this way?

55. What effect has having a child with (child's illness) had on your family?

56. Has having a child with (child's illness) changed your relationship with your friends and relatives?

NO-go to 58 YES

57. In what way?

III. Study of Services

58. Is (child's name) living at home now?

YES-go to 62 NO

59. Where is s/he living now?

60. What is the reason that s/he isn't living at home?

61. How often do you visit her/him?

62. Is (child's name) attending school?

NO-go to 65 YES

63. When did s/he start school?

64. How much time does s/he spend at school per week?

65. Is (child's name) involved in any special programs?

NO-go to 68 YES

66. What type?

67. How often does s/he attend this/ these programs?

GO TO 69

68. What is the reason s/he isn't involved?

69. What kind of services are available to you, formal and informal besides CCD?

a.	f.
b.	g.
c.	h.
d.	i.
e.	j.

70. Which services do you make use of that are available to you, formal and informal?

___a.	___f.
___b.	___g.
___c.	___h.
___d.	___i.
___e.	___j.

71. Would you rate those services as excellent, good, fair, or poor? If you want I can repeat your list.

(Use the space before the letters in the above question to designate rating by using the first letter of excellent, good, fair, or poor, E,G,F,P.)

72. How often do you use these services?

73. How did you become aware of the services you use?

74. What is the reason you don't use the others?

- a.
- b.
- c.

75. Could you remark on any services that you need now or have needed in the past from the following areas?

- a. AT HOME
- b. COUNSELING
- c. EDUCATIONAL
- d. FINANCIAL
- e. MEDICAL
- f. PERSONAL
- g. RECREATIONAL
- h. TRANSPORTATION
- i. VOCATIONAL
- j. OTHER

76. We would also like you to describe services which you feel would be desirable but perhaps not essential for you.

77. There may be resources or services that you have used only once or twice. Would you recall as many as you can skipping those that you have already mentioned.

____a.

____b.

____c.

____d.

____e.

78. Would you rate each of the services you just mentioned as excellent, good, fair, or poor? I will repeat the list if you want me to. (Use the space in front of the letter to designate the rating using the first letter of excellent, good, fair, or poor, E,G,F,P.)

IV. Services at CCD

79. Who referred you to CCD?

80. What was their profession?

81. Where did they work?

82. How old was (child's name) when s/he was first seen at CCD?

83. Was the diagnosis given to you by CCD different in any way than what you had been told previously?

NO-go to 86

YES

84. What was the diagnosis at CCD?

85. How was it different?

86. What is your current understanding of the cause of your child's (name of illness)?

87. What is your understanding as to how this will affect your child's development?

88. What is your understanding of how your child's (name of illness) can be treated?

89. WAS A CLEAR DIAGNOSIS GIVEN BEFORE COMING TO CCD?

YES-go to 90

NO-go to 94

90. What services have you received at CCD? Would you rate each service you mention as excellent, good, fair, or poor?

- a. EDUCATIONAL FACILITIES
- b. EDUCATIONAL TESTING
- c. AUDIOLOGY
- d. DENTISTRY
- e. COUNSELING AND/OR PSYCHOTHERAPY
- f. GENETICS
- g. MEDICINE (SPECIALITIES)
- h. NURSING
- i. NUTRITION
- j. OCCUPATIONAL THERAPY
- k. PHYSICAL THERAPY
- l. PSYCHOLOGICAL TESTING
- m. SPEECH PATHOLOGY

91. What makes those services excellent or good?

92. If the services aren't excellent or good, what could make them that way?

93. What services could be eliminated, if any?

94. Apart from the existing clinic would you like or be interested in a special workshop at CCD concerning your child's disability?

NO-go to 96

YES

95. What kinds of things would you like included at a special clinic?

95. (cont.)

- a. re-evaluation of my child
- b. parent education (understanding of causes, how to cope etc.)
- c. learning what services are available in the community
- d. counseling
- e. a chance to talk to other parents of similarly handicapped youngsters
- f. other

96. Is there something we've missed in our questionnaire that you would like to tell us?

Thank you very much for participating. We appreciate your help.