

PARENTS' KNOWLEDGE OF THE CONDITION AND TREATMENT PROGRAMS  
OF THEIR CEREBRAL PALSIED CHILDREN

A Research Paper

Presented to

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## Chapter 1

### INTRODUCTION

The understanding and cooperation of parents plays an important part in the treatment and management of children with cerebral palsy. In fact, Cardwell (1956) described the habilitation of the cerebral palsied as a family, not an individual problem. Several authors have commented that the parents exercise a degree of influence on the outcome of habilitation (Barsch, 1968; Cardwell, 1956). The parents' understanding of the nature of the disability, the meaning of the diagnosis, and the purpose of the treatment programs is crucial. However, Hersov (1963) found that the majority of parents of cerebral palsied children did not appear to understand the nature of cerebral palsy, were confused as to the meaning of the diagnosis, the absence of a cure, and the poor prognosis. He found that only a small proportion of the parents felt they understood the nature and cause of the disability to their satisfaction. Bobath and Finnie (1970) also found that despite repeated advice on treatment and training, there still remained a lack of understanding about the problems and needs of their children, which pointed to a lack of communication between parents and staff.

The nature of cerebral palsy and its treatment programs can be very difficult for the parents to understand. Yet, as the above comments indicate, the ability of the parents to become informed about

the condition and treatment programs has an important influence on the course of habilitation. Although there has been some comment on the importance of the parents' understanding of the condition and treatment programs, systematic investigations of the problem are lacking. Consequently, the purpose of this study was to survey the parents of cerebral palsied children in order to determine their knowledge of the condition and treatment programs for their children. Another purpose was to obtain information as to whether there is a communication problem between parents and professionals.

## Chapter 2

### PROCEDURE

A 12-item multiple choice and short answer questionnaire designed by the author was used to survey the parents' knowledge of the condition and treatment programs of their children. For purposes of this study, treatment programs can be defined as any therapies the child is receiving as part of his habilitation. Physical therapy, occupational therapy, and speech therapy are the treatment programs often used with cerebral palsied children.

The questionnaire used in this study was designed to cover three general areas. First, parents' knowledge and understanding of their children's treatment programs. Second, parents' knowledge and understanding of their children's specific problems, such as eating, walking, speaking, and hearing. Third, in what areas communication problems exist between parents and professionals. The Appendix contains a sample of the questionnaire used in this study.

The questionnaires were administered in March, 1977, to a group of 38 parents of cerebral palsied children. The parents were randomly selected from a group of parents whose children were being treated in an out-patient clinic for cerebral palsied children at an orthopedic hospital in St. Louis, Missouri. One parent of each child selected was asked to complete the questionnaire. Seven fathers, twenty-nine mothers, and two parents completed the questionnaires.

The children in this study had all been diagnosed as having cerebral palsy by a medical doctor. They came from a seven state area, and ranged in age from 2 years to 16 years. Each of the children was being treated at the hospital out-patient clinic for cerebral palsy children.

## Chapter 3

### RESULTS

I feel that the publication of the questionnaire, together with a description of the parents' replies, may prove helpful to other workers in the field, who may be unaware of the possible need for more communication to occur between parents and themselves. Therefore, the replies to the questionnaires are summarized in this section.

#### Question 1 (a)

What age was your child when you were told of his medical condition?

##### Replies

At birth	4
During the first 6 months	5
Between 7-20 months	16
2 years	10
3 years	2
4 years	1

#### Question 1 (b)

What were you told?

##### Replies

Cerebral Palsy	23
Brain Damage	4
Retarded	3
Other ( heel cord, etc. )	4
No Answer	4

#### Question 1 (c)

Did you understand this explanation?

##### Replies

I did	22
I did partially	11
I did not	4
No Answer	1

Question 2 (a)

Please check the treatment programs that your child has received at this hospital:

Replies

Physical Therapy	14
Occupational Therapy	1
Speech Therapy and Physical Therapy	2
Occupational Therapy and Physical Therapy	1
Braces	5
Surgery	3
Yearly Check-Up	2
I don't know	6
No Answer	4

Question 3 (a)

Is your child receiving therapy away from this hospital?

Replies

Yes	23
No	15

Question 3 (b)

If yes, what type of therapy is he receiving?

Replies

Physical Therapy	7
Speech Therapy	2
Occupational Therapy and Physical Therapy	2
Speech Therapy and Physical Therapy	4
Speech, Physical, and Occupational Therapy	3
Shoes	1
I don't know	1
No Answer	3

Question 3 (c)

Where is he receiving his therapy?

Replies

United Cerebral Palsy School	2
School	10
Institution	2
Community Center	3
Home	5
No Answer	1

Question 3 (d)

How did you find out about this service?

Replies

From professionals at this hospital	2
Therapist	1
School	8
United Cerebral Palsy Association	1
Doctor	1
Community Services	3
No Answer	7

Question 4 (a)

Do you feel you are given good explanations about your child's current treatment program and prognosis?

Replies

I do	27
I do partially	9
I do not	2

Question 4 (b)

What would you like to know more about?

Replies

Child's future prognosis and recovery	11
Cause of child's condition	2
Research and new procedures	2
Meetings parents can attend	1
Program of CP Clinic at Hospital	1
Child's disabilities	1
Explanations of medical terms	1

Question 5 (a)

Please check the therapies that you provide at home:

Replies

Occupational Therapy	1
Physical Therapy	16
Speech Therapy and Physical Therapy	10
Occupational Therapy and Physical Therapy	2
Occupation, Physical, and Speech Therapy	1

Eight of the parents indicated that they did not provide therapy at home. Reasons why therapy was not provided at home included not required, not been contacted, and lives in an institution away from home.

Question 5 (b)

How much time do you devote to the home treatment program?

Replies

1 hour per week	8
2-4 hours per week	9
5 hours per week or more	12
No Answer	1

Question 5 (c)

Do you understand the things that you are asked to do at home and why you should do them?

Replies

I do	27
I do partially	2
I do not	0
No Answer	1

Question 6 (a)

Does your child have difficulty crawling, walking, or moving from place to place?

Replies

Yes	25
No	12
No Answer	1

Question 6 (b)

Do you understand the reasons for his difficulties?

Replies

I do	20
I do partially	4
I do not	1

Question 6 (c)

Do you feel you can give your child help in making these movements?

Replies

I do	14
I do partially	5
I do not	4
No Answer	2

Question 7 (a)

Does your child have difficulty with his hand movements (picking up objects, using his hands to help himself, etc.)?

Replies

Yes	22
No	16

Question 7 (b)

If yes, please explain:

Replies

One hand affected	6
Can't use hands normally	2
Spastic	4
Quadraplegic	1
Difficulty making movements to help self	6
No Answer	3

Question 7 (c)

Do you understand your child's difficulty in making hand movements?

Replies

I do	16
I do partially	3
I do not	1
No Answer	2

Question 7 (d)

How do you help your child make his hand movements?

Replies

I do the movement for him	2
I help him do it himself	12
I do not help him	5
No Answer	2

Question 8 (a)

Does your child have difficulty eating?

Replies

Yes	7
No	30
No Answer	1

Question 8 (b)

If yes, please explain:

Replies

Child chokes	2
Difficulty using spoon	3
Does not keep food in mouth	1
No Answer	1

Question 8 (c)

Do you know how to help your child with his eating problems?

Replies

I do	4
I do partially	2
I do not	1

Question 9 (a)

Does your child have difficulty speaking?

Replies

Yes	16
No	19
No Answer	3

Question 9 (b)

If yes, please explain:

Replies

Difficulty forming words & getting them out	4
Slow in learning sounds and words	1
Communicates with voice tones	1
No Speech	2
Can't speak plainly	3
Stutters	1
Has difficulty with a few sounds	1
No Answer	3

Question 9 (c)

Do you understand what you can do to help your child with his speech?

Replies

I do	10
I do partially	4
I do not	2

Question 9 (d)

How much of your child's speech do you understand?

Replies

All of it	6
Some of it	8
None of it	2

Question 10 (a)

Does your child have difficulty hearing?

Replies

Yes	0
No	23
I don't know	13
No Answer	2

Question 11 (a)

Is your child old enough to go to school?

Replies

Yes	31
No	7

Question 11 (b)

If yes, where does he go to school?

Replies

Residential institution	2
Private School	1
Special School	3
Public School	25

Question 11 (c)

Is your child in any type of special class?

Replies

Yes	14
No	13
I don't know	2
No Answer	2

Question 12 (a)

What is your biggest concern or problem with your child at this time?

Replies

A variety of replies was received to this question. The majority of parents expressed concern about future prognosis and walking. Others expressed concern about their child's mental attitude and happiness. Still others said their biggest problem was feeding, taking care of toilet needs, or speech. Other parents expressed the concern of their children living normal lives.

Some of the replies to the questions were quite interesting. Their implications will be discussed briefly.

When asked if they understood the medical explanation of the condition of their children (Question 1 c), 22 parents stated that they did understand it. However, 11 parents said that they only partially understood it, and 4 parents said that they did not understand it at all. Since the parents' understanding of the child's condition is vital to the child's successful habilitation, this finding is disappointing. It points to the need for professionals to give clear explanations in simple terms that can be understood by parents.

When asked what type of treatment their children had received at the hospital, 6 parents did not know (Question 2 a). This demonstrates a lack of communication between professionals and parents. Parents should be told in simple language the goals of all therapy programs.

On Question 4 (b), the parents were asked what they would like to know more about. A large majority of the parents stated they would like to know more about their child's prognosis and chances of recovery. Again, this demonstrates the need for professionals to provide more information to the parents concerning their child's prognosis.

When asked if they provided therapy at home (Question 5 a), 30 of the 38 parents indicated that they did provide therapy at home. Of the 30 parents who provided therapy at home, 27 indicated that they understood what they were to do, and why they should do it. This finding indicates that therapists are instructing parents about home treatment, and that the parents are carrying out the program.

As a speech pathologist, I found two of the parents' replies to Question 9 (a) interesting. Two parents of children, age 7 and 8½ years, stated that their children had no speech. Neither of the parents said that their children were receiving speech therapy at home, school, or at another facility. This demonstrates unawareness of the need and availability of speech therapy services for the cerebral palsied population. Too often, speech problems are overlooked in cerebral palsied children, while physical problems such as walking are emphasized.

Thirteen parents indicated that they did not know if their children had a hearing problem. Parents should have their children's hearing tested at any early age, so if a loss is present, amplification can be provided. Since the cerebral palsied population is known to have an increased incidence of hearing loss (Cruickshank, 1976), early audiological testing is especially important.

## Chapter 4

### SUMMARY AND CONCLUSIONS

Questionnaires were administered to 38 parents of cerebral palsied children seen in an out-patient clinic at an orthopedic hospital in St. Louis, Missouri. The multiple choice and short answer questions were designed to survey the parents' knowledge and understanding of the condition and treatment programs of their children. The questions were also designed to determine if a communication problem existed between professionals and parents.

To the extent that the data in this study represents parents' knowledge and understanding of their children's condition and treatment programs, it seems reasonable to conclude that there is some good communication occurring between parents and professionals. However, the parents need more specific information about treatment programs and prognosis. In general, the parents recognize their children's problems, but do not understand their implications. The speech pathologist, physical therapist, and all other professionals who deal with the habilitation of the child must do more counseling in order to increase the parents' knowledge and understanding of their child's condition, and especially his treatment program and prognosis.

Increased communication between parents and professionals is one way in which parents can become more knowledgeable about their child's

condition and treatment programs. Pamphlets designed for parents of cerebral palsied children, explaining in simple terms the meaning of cerebral palsy, the goals of speech, physical, and occupational therapies, and the value of their cooperation is another way. Parent meetings where parents can discuss their problems and share ideas may be another solution to the parents' need for additional information.

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APPENDIX

Questionnaire

Age of Child \_\_\_\_\_ Your Relationship to Child \_\_\_\_\_

Please answer the questions by placing a \_\_\_\_\_ in the space provided or by writing a few sentences to answer the question. Thank you.

1. What age was your child when you were told of his medical condition?

\_\_\_\_\_ What were you told? \_\_\_\_\_  
\_\_\_\_\_

Did you understand this explanation? \_\_\_\_\_ I did  
\_\_\_\_\_ I did partially  
\_\_\_\_\_ I did not

2. Please check ( ) the treatment programs that your child has received at this hospital:

\_\_\_\_\_ Occupational Therapy  
\_\_\_\_\_ Physical Therapy  
\_\_\_\_\_ Speech Therapy  
\_\_\_\_\_ I don't know

3. Is your child receiving therapy away from this hospital? \_\_\_\_\_ Yes \_\_\_\_\_ No

If yes -- What type of therapy is he receiving? \_\_\_\_\_

Where is he receiving this therapy? \_\_\_\_\_

How did you find out about this service? \_\_\_\_\_

4. Do you feel that you are given good explanations about your child's current treatment program and prognosis?

\_\_\_\_\_ I do \_\_\_\_\_ I do partially \_\_\_\_\_ I do not

What would you like to know more about? \_\_\_\_\_  
 \_\_\_\_\_

5. Please check the therapies that you provide at home:

\_\_\_\_\_ Occupational Therapy

\_\_\_\_\_ Physical Therapy

\_\_\_\_\_ Speech Therapy

\_\_\_\_\_ None Why not? \_\_\_\_\_

How much time do you devote to the home treatment program?

\_\_\_\_\_ 1 hour per week

\_\_\_\_\_ 2-4 hours per week

\_\_\_\_\_ 5 hours per week or more

Do you understand the things you are asked to do at home and why you should do them?

\_\_\_\_\_ I do

\_\_\_\_\_ I do partially

\_\_\_\_\_ I do not

6. Does your child have difficulty crawling, walking, or moving from place to place?

\_\_\_\_\_ Yes \_\_\_\_\_ No If Yes -- Please Explain \_\_\_\_\_

Do you understand the reasons for his difficulties?

\_\_\_\_\_ I do

\_\_\_\_\_ I do partially

\_\_\_\_\_ I do not

Do you feel you can give your child help in making these movements?

I do

I do partially

I do not

7. Does your child have difficulty with his hand movements (picking up objects, using his hands to help himself, etc.)?

Yes       No      If yes -- Please Explain \_\_\_\_\_

Do you understand your child's difficulty in making hand movements?

I do

I do partially

I do not

How do you help your child make his hand movements?

I do the movement for him

I help him do it himself

I do not help him

8. Does your child have difficulty eating?       Yes       No

If yes -- Please Explain \_\_\_\_\_.

Do you know how to help your child with his eating problems?

I do

I do partially

I do not

9. Does your child have difficulty speaking?       Yes       No

If yes -- Please Explain \_\_\_\_\_.

Do you understand what you can do to help your child with his speech?

\_\_\_\_\_ I do

\_\_\_\_\_ I do partially

\_\_\_\_\_ I do not

How much of your child's speech do you understand?

\_\_\_\_\_ All of it

\_\_\_\_\_ Some of it

\_\_\_\_\_ None of it

10. Does your child have difficulty hearing? \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ I don't know

If yes -- Please explain \_\_\_\_\_.

11. Is your child old enough to go to school? \_\_\_\_\_ Yes \_\_\_\_\_ No

If yes -- Where does he go to school? \_\_\_\_\_.

Is your child in any type of special class?

\_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ I don't know

12. What is your biggest concern or problem with your child at this time?

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