

1978

# Issues for Professionals Working with Cerebral Palsied Individuals

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## Recommended Citation

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<https://doi.org/10.15760/etd.2676>

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ISSUES FOR PROFESSIONALS WORKING WITH  
CEREBRAL PALSIED INDIVIDUALS

by

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

MASTER OF SOCIAL WORK

Portland State University

1978

The practicum of Joan Marquis, Beth Thompson  
and Wendy Girdlestone, presented in  
June 1978 and approved by Jack R. Hegrenes

ISSUES FOR PROFESSIONALS WORKING WITH  
CEREBRAL PALSIED INDIVIDUALS

Practicum Advisor



Jack R. Hegrenes, Ph.D.

*[Handwritten signature]* June 6, 1978

## ACKNOWLEDGMENTS

We wish to acknowledge two people who have been very helpful in the development of this practicum. We are thankful for the assistance of Constance Hanf, Ph.D. in Psychology, Professor of Medical Psychology and CCD and John Keiter, Ph.D. in Philosophy of Education, Research Associate at CCD. Discussions held with them led to the concept of issues professionals have to deal with in working with cerebral palsied individuals. We are grateful for their suggestions and encouragement.

We also wish to thank our interviewees who gave of their time to help us broaden our understanding of cerebral palsy.

Finally, we extend our thanks to Bud Thoun, Adult Service Director of United Cerebral Palsy, Portland, Oregon for helping us to arrange the interviews and for answering our many questions.

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## CHAPTER I

### INTRODUCTION

This practicum is the result of our participation with a grant of national significance from the Developmental Disabilities Office. The project's inquiry is to describe the aging and aged developmentally disabled and to develop professional curricula based upon the findings. This grant was awarded to the Crippled Children's Division of the University of Oregon Health Sciences Center in 1976. Our involvement with the grant occurred in conjunction with our field placement at Crippled Children's Division, hereafter abbreviated as CCD. During two quarters work on the project we touched on one segment of the broad scope of this three year grant. A brief overview of this grant will indicate our learning experience on it.

This grant is one of five awarded to University Affiliated Programs. The project has had a primary staff of two individuals: Constance Hanf, Ph.D. and John Keiter, Ph.D. These individuals directed and supervised our activity as described below.

There are three major objectives for the grant: 1) to conduct a comprehensive survey of the aging and the aged population, 2) to develop curricula for the training of health-care professionals and 3) to consult at the supervisory level with national, state and community agencies. The developmentally disabled population studied by the grant includes cerebral palsied individuals over twenty-one years of age and mentally retarded

individuals over forty years of age. Since other groups are already investigating the epileptic population, this project does not include them. Our practicum thrust specifically dealt with cerebral palsied, sometimes abbreviated CP, adults.

The Crippled Children's Division of the University of Oregon Health Sciences Center (UOHSC) has been conducting outreach efforts, evaluations, and providing specific services for cerebral palsied individuals for almost fifty years. Using this vast resource of information about Oregon's cerebral palsy population we began our efforts toward locating the adult cerebral palsy population from old files at CCD. We recorded demographic data on all patients who were diagnosed as having cerebral palsy and whose birthdates indicated that they were over twenty-one. Approximately 700 individuals, with birthdates from 1928 to 1951, were recorded.

Our efforts to find current addresses for these people took us through phone books for the state of Oregon, lists of patients at Fairview and Eastern Oregon State Hospital, and assistance from the United Cerebral Palsy Association of Northwest Oregon. Meanwhile, we were working on a questionnaire that would describe the lives of these individuals. The search for these adults has not yet been completed.

CCD records were also used to obtain a picture of how different disciplines affected the CP individuals they encountered. Using a random sample of the cerebral palsy cases found, we went through the medical records tallying the types of comments and actions recorded and the profession of the person recording. This will be used to ascertain what facets of the patients' lives were of concern to which people.

Over the years, George Cottrell, M.D., an orthopedic surgeon involved



with CCD, recorded on film some of his patients' gait problems. It was decided that these films would be useful in the development of training curricula, especially since he was interested in contacting these same individuals to video-tape them as adults. Taping sessions provided an opportunity for us to meet adults with cerebral palsy and to use our questionnaire.

Prior to interviewing each person, we read their medical charts. All of these individuals had been seen at CCD during childhood. These records provided medical, social and educational history from pre-school years to age twenty-one. We condensed the immense amount of material contained in these records into case histories. A background was gained that was updated during interviews. The childhood histories were of extreme benefit in giving a perspective on the life circumstances unique to having cerebral palsy. From the childhood background and eventual functioning as an adult we were able to learn about problems, realities and needs of these CP individuals. Access to these often dramatic life histories provided an important learning experience for us.

Additionally, we interviewed other adult CP individuals, some who were married. The information and impressions gathered from these interviews brought out many issues. Although hardly a research sample, the nine adults we interviewed did share some similar problems and experiences. Through the information obtained, responses to the questionnaire, and the life histories of these adults, we raised the following issues: 1) Birth of a child to a handicapped couple, 2) Rights versus privileges of the handicapped, 3) Sexuality of the handicapped, 4) Mainstreaming, 5) Social retardation of handicapped individuals, 6) Benefits versus deficits in

the provision of services, 7) Schools for the handicapped versus public school settings, 8) Rights of the child, 9) The result of health services provided over the years and 10) Societal responsibility for the handicapped. From these issues we selected: 1) Services for Cerebral Palsied Individuals, 2) Communication Difficulties and Other Barriers to Normalization for Cerebral Palsied and 3) Birth of a Child to a Cerebral Palsied Couple, as being the areas most pertinent to health professionals attempting to serve the cerebral palsied person.

## CHAPTER II

### SERVICES FOR CEREBRAL PALSIED INDIVIDUALS

#### INTRODUCTION

The main focus of the questionnaire used in the interviews with the adults having cerebral palsy was on the services they received in the past and were receiving at the time of the interview. The questionnaire attempted to determine not only what services had been available, but also which ones were considered to have been most or least helpful by these individuals. This approach allowed us to be aware of the human side of the provision of services instead of the quantitative side. It brought out individual feelings about and reactions to services, which in turn raised some questions and issues about what service is offered, who determines what the person with cerebral palsy will receive in services, what the best alternatives are and what the present needs of adults with cerebral palsy appear to be.

This chapter addresses these concerns as it reviews the services the interviewed CP's received as children and as adults. Some of the information discussed here was obtained through review of University of Oregon Health Science Center, Crippled Children's Division charts of those we interviewed, but most of the information was provided by the individuals themselves based on their recall of what they experienced. Therefore, the information is often subjective and may differ from what actually occurred. In some cases this difference could be identified

and clarified by a review of the person's CCD chart, whereas in other cases we found no difference between what was reported by the person and what was in the chart. Often we relied solely on the person's memory and were not able to determine the accuracy of the report. It is our belief that this will not detract from our findings because it is what was significant to each individual that is of concern here, not the exact count of every service received. Also, much of the information on services presently available to adults with CP was provided by Bud Thoune, Adult Service Director of United Cerebral Palsy (11).

Because there were interviews with seven individuals and one couple this chapter does not attempt a comprehensive review of the services offered to the CP adult population in this metropolitan area. It is an attempt to raise issues, as mentioned above, and to highlight the human side of service provision. After reading this chapter perhaps professionals and para-professionals who deal with children and adults who have CP will be more aware of the implications of their decision regarding services for these individuals and more sensitive to the right each CP person has to be treated as a feeling, thinking individual with likes and dislikes, one who may well be capable of contributing to decisions that are being made about him/her.

## SERVICES RECEIVED AS CHILDREN

### Surgery

All of the individuals interviewed had undergone surgery to correct CP-related physical impairments when they were children. The surgical procedures were often attempts to straighten legs to enable them to walk,

while some of the operations were performed on the arms in the attempt to make them more functional. Several of these people underwent a series of operations which entailed not only time spent in the hospital but time spent in leg casts. One man underwent sixteen operations before the age of twenty-one years and one woman underwent three major operations as a child, each followed by a month in leg casts. The man is able to walk independently, however, the woman relies on a wheelchair although she will use crutches at home.

The difference between the outcomes of these two individuals raises the question as to how helpful the surgical procedures were. The authors do not have medical backgrounds and will not attempt to judge the success of these or other operations. However, the overall effect of these operations upon the individual as a person should also be considered. The goal of many of these surgeries was to achieve ambulation, but at what price? These children underwent innumerable separations from family and friends during their stay at the hospital, undoubtedly experienced much pain as a result of the surgery, and then were placed in leg casts for up to a month, limiting their movement. In the case of one boy, surgery caused him an emotional setback which returned him to a previous painful state. It took six months for this setback to begin to disappear and eighteen months until he felt relatively secure again. The second operation was cancelled because of his reaction to the first one. Some of the people who had these surgeries are now basically confined to wheelchairs. Were these surgeries unrealistic attempts to get CP children to walk? What about the surgeries that did help individuals to walk? Was the trauma of separation from family and the endurance of leg casts

worth it?

Some of the reactions of those who experienced such surgery were that it was helpful, somewhat helpful, or that one operation was useful while another was not. One person considered surgery the most helpful assistance he received. One woman's comment was that she had no idea whether the surgeries were important, but she went along with the doctor because he said they were. Another comment was that the surgeries were experiments and that the doctors were still learning about what was helpful.

It seems fair to summarize these views by stating that the medical profession was, at the time, trying to do what it believed necessary to enable these children to walk. The questions raised are whether that is the most important goal and whether it is a realistic one for each CP child. The likelihood that the child will be able to walk after the operation or operations must be evaluated against the trauma they entail.

### Braces

Wearing braces was another common experience for all of our interviewees. Their reactions to the braces ranged from the thought that they were a little helpful to the comment that they were a waste of time. Other comments were that the braces broke easily, that getting them on was the worst part and that they were too heavy. One woman stated strongly she would rather have had the freedom to crawl and to move her muscles herself. Another person said that they pinched, hurt and were a headache. He added that he finally said, "Forget it," and decided to work harder at walking without them. Another man said when he was young he had braces but he took them back because they were uncomfortable and cut into his

skin. Although there was a variety of responses to this experience of braces, the attitudes were generally negative. The negativism appeared related to both discomfort and physical limitations. This suggests that professionals might well take the feelings of the children into consideration when prescribing braces or determining the extent to which they should be worn. Again, the issue appears to be how much good the corrective measures will have in comparison to the limitations and discomfort they produce.

### Physical Therapy

Physical therapy, essentially help with walking, was received by all those interviewed. Reactions to it were positive. Only one person said that the physical therapists did not know what they were doing...a remark that raises a question as to whether physical therapists should force individuals who may shortly be in wheelchairs to walk. The limitations of a person's actual physical capability may have to be considered. However, most of those interviewed believed it was helpful and some considered it to be the most helpful assistance they received. A comment from one man was that he was glad the physical therapists forced him to walk. It seems that physical therapy was considered useful because positive results could be experienced and because there was no resulting limitations or discomfort to counterbalance the positive aspects. Consideration should also be given to the fact that physical therapy occurred over extended periods of time and relationships may have developed between the individuals with CP and the physical therapists -- relationships that probably were important to these youngsters who had fewer people with whom they came in contact than did nondisabled children. These relation-

ships may have added to the positive attitude toward physical therapy.

### Occupational Therapy

Many of those we spoke with also received occupational therapy in such areas as feeding, dressing, toileting and grooming. We did not receive many comments regarding these services although one person believed that, along with physical therapy, it was the most helpful assistance he received. Our assumption about the lack of response to occupational therapy is that since it was received when these individuals were very young, they did not recall what it was like.

### Speech Therapy

Speech is another area of therapy about which we received few comments. About half of the adults we talked with had help with speech. The one comment we got was that it was the most helpful assistance received. The issue to be considered here is the usefulness of speech therapy. Some of the people had received extensive speech therapy over a number of years and yet they were essentially unintelligible. In our interviews it took several people and a great deal of concentration to understand what they were trying to communicate. This is not to deny that many people with cerebral palsy are indeed helped by speech therapy. The question is whether it can be determined who will be helped by speech therapy and who will not make noticeable gains. Is speech therapy provided to some of these youngsters because professionals believe an attempt must be made to improve their speech even if it seems hopeless? Could the time of these children and therapists have been better spent on something else?



### Medical and Social Services

There were other services these people received as children. For our interviewees, medically-oriented services included assessment and/or correction of vision, dental care for most of the interviewees, and hearing for some of them. Social services, particularly those dealing with foster care, were extensive in one case, which will be briefly discussed here.

This was the case of a young girl with CP who developed in a poor home environment, including alcoholic parents, an unemployed father, and a brother who was a juvenile offender. Social services had her placed in a foster home, basing this action on parental neglect and alcoholism. The girl went to several foster homes and ended up in one in which the people truly cared about her. This lasted up to the time of the foster mother's illness. At that time Fairview was considered as a possible placement until it was ruled out as inappropriate because of her average intelligence. She was then placed in a boarding home, followed by more foster placements, and finally returned to the one foster home in which she had been cared about so much.

The reason for reviewing this social history is to highlight the issues it raises for social service providers. First, the current home environment of a child with CP must be evaluated. Not only was this girl in a detrimental home environment, but the negative attitude of the mother toward doctors and hospital personnel caused the girl to miss appointments and kept the mother from following through on some of the suggestions on home therapy. In another case, a mother had to be told to quit threatening and prodding her son because his lack of functional improvement was thought to be psychological and the boy's father had to

be worked with to try to keep him from contributing to the boy's infantilism. These parents also showed no interest in working out an exercise program for their son at home. Social services should determine if the child's environment is affecting the therapy the child is receiving, as well as determine the adequacy of the overall home environment. A second issue is the availability of alternative living situations for a child with CP. It is alarming that a Fairview placement would be considered for a girl of average intelligence who is physically disabled. Was this one of so few alternatives that it had to be considered? It is difficult to find foster homes for disabled children and, although this situation may change in the near future, other alternatives need to be available. The goal is to find the best solution for each child. Where do handicapped children go when the home does not provide a suitable environment? Hopefully, not from one foster home to another, as in this case: surely such changes affect one's sense of security. It is entirely likely that this woman's present preference for staying at home with her foster parents rather than seeking companionship among her peers relates as much to her past unstable living situations as it does to her cerebral palsy.

### Education

Several alternatives may need to be available in the area of education as well. The people we spoke with all had received some education, ranging from approximately upper grade school through high school graduation. The difficulty in assessing those at the lower end of the range is due to the fact that many of these individuals were in special education classrooms which do not correspond to standard grade levels. It

was interesting to note that the interviewees usually received their education in more than one type of setting. Several people were in special education classrooms and had home tutors, one person was in a special education classroom and later in a regular classroom, and some people experienced all three settings. This seems to point to the need for differing educational opportunities for CP individuals according to needs. One issue which this raises goes along with the current controversy over placing children in the least restrictive educational environment. What are the educational needs of CP children and how are they best met?

We obtained no negative reports about any of the three educational settings that people had been in: special education classrooms, home tutoring or regular classrooms. However, Holladay Center, which would fall in the special education category, consistently was regarded by our interviewees to have been a pleasant and positive experience. Attending Madison High School, which has regular classrooms, was also considered to be a good experience by two men. The common denominator of these two different educational situations, one which gave support and attention to the physically handicapped child and the other which forced the person to perform up to his capacity, seems to be the respect for the individual. Holladay Center communicated to its students a concern and a caring for them, whereas Madison High School treated the individual with CP as "normal" and expected him/her to meet all the basic educational requirements. Perhaps both of these aspects are needed by the child with CP. Each one needs to learn to accept his/her handicap and to gain a sense of worth, then to move on to be challenged to get along in regular classrooms and to be forced to find his/her potential by competing with "normal" students.

One man's comment was that being the only handicapped child in his school made him feel more "normal" and that he would forget about his handicap at school. He was treated equally and was allowed to do things for himself. Whether the best solution is to have CP children in special schools to learn how to cope with their handicap and to gain their feeling of self-worth and then to move them into regular schools, or whether to get them into regular schools as soon as feasible and possibly supplement that with a special classroom has yet to be determined. Another concern is whether it is best to have one CP child by him/herself in a regular school or to have several handicapped youngsters together in a regular school so they can provide support for themselves. There are many possibilities to be explored and it seems that several alternatives should be available to accommodate each child's need. The alternatives need also to include home tutoring because this may best meet the child's need, but it should be considered as a last resort because it severely limits the child's chance to learn socialization skills as well as the opportunity to be with and enjoy his/her peers. The main consideration in any of the possibilities is that the person with CP be respected as an individual.

The type of education the person with CP receives is also a consideration. Should the focus be on academic, self-help, vocational, social or other skills? The focus which seems to have prevailed is a complex one. All of the people with whom we spoke needed education in all of these skills, each to a different degree. Self-help, social, vocational and academic orientations are each valuable and in order to determine which should be the focus of an individual's educational program it is necessary to decide what the goal for an individual is. One person may require

concentration on self-help skills, others may need vocational and academic training or may be able to address themselves solely to academic study. Social skills are important for learning how to get along in several situations and may need to be integrated as part of the education of a CP person. The prime considerations should be to know what the person is capable of and what he/she wants. One man was offered the opportunity by the State of Oregon to go to a typing class. He went for a while, having been encouraged by others to try it, but he quickly stopped because of lack of interest. No one had taken the time to ask him what he might like to do for a job. People who make educational and vocational decisions for CP individuals may not see accurately the capabilities of the person with CP. It also seems necessary to involve the CP individual in the decision about his/her education and then base the vocational goals on accurate and realistic assessments of the person's capabilities.

#### Interviewees' Remembrances

To get some understanding of what adults remembered about the services they had received as children we asked several open-ended questions. The first question was, "What was the most helpful or important assistance you received?" There was a variety of responses: physical and occupational therapy, help with walking, speech therapy, and surgery. Support from people was also mentioned, more so than any one therapy. One man said the patience and understanding from some of the therapists was his most important assistance. The emotional support from the people at Holladay Center was mentioned by a woman who said they were the first people she trusted. She also said her foster mother was of tremendous assistance, particularly for helping decrease her fear of doctors.

According to these adults, the support from professionals and family members as well as having received a variety of services were the most helpful assistance received.

Another question we asked was, "Which agency was the most helpful?" Holladay Center received the overwhelming response -- it was the only agency actually named. The other responses were that all the agencies were the same, they all were helpful. The person considered to be most helpful was the orthopedic doctor who performed the surgeries. Two specific physical therapists and a specific occupational therapist who were at Holladay Center were named. One man could remember a woman at Holladay Center who was most helpful although he could not remember her name or position. One woman rated her foster mother as most helpful. These adults with CP did remember specific agencies and people who were helpful to them, which indicates that services and people have different effects on children with CP. Their responses also show that Holladay Center was a most valuable experience for them.

The request to recall the least helpful assistance brought only two responses. These were braces and helpful suggestions for walking that did not help. The person who received the suggestions expressed the viewpoint that the therapist did not know his limitations or capabilities and that he was pushed too hard. Most could not recall any "least helpful assistance." It is not possible from this to determine whether this was because they felt positively about all their experiences, because they were afraid to label a particular type of assistance as negative in front of professionals or because they simply did not remember is not clear.

This lack of response was also the case when we asked, "What help do

you wish you had gotten as children that you did not receive?" One man answered that he wished he could have had more physical therapy when he was younger because his muscles were more flexible then. Another comment was that he wanted people to let him do more things for himself. Another said that professionals never asked about his pain and that no one took the time to know what was going on inside of him.

### Summary

These comments tie into what was previously discussed, i.e., that people with CP have thoughts and feelings they want to express and will express if they are asked. This goes for educational or career choices, whether to wear braces or to continue therapy, for the individual's assessment of his/her capabilities and for feelings about him/herself. If there was one thought which came across strongest in our discussions with these CP adults about their childhood, it was that they wanted to be treated as whole people and this included contributing to the decisions that were to affect their lives.

## SERVICES RECEIVED AS ADULTS

### Introduction

As children with cerebral palsy move into adulthood the services they receive change. Less emphasis is placed on services that deal directly with their CP and more emphasis is put on providing assistance to help them function as independently as possible.

### Surgery and Braces

No CP-related surgeries were performed after the age of twenty-one

years on any of the interviewees although a few of them had other types of operations. Also, no one wore braces after the age of twenty-one years. It appears that operations and braces are not considered helpful to CP adults by the medical profession. On the other hand, perhaps these services were not continued because these individuals no longer were eligible for them under the Crippled Children's Division and no other agency provided these services. Braces generally were discontinued when the child was still young, so it seems their usefulness ended long before adulthood. Surgeries appear to be different. In two cases an operation was performed just before the individual turned twenty-one, seemingly an attempt to assure this service was performed before the person became ineligible under the Crippled Children's Division. These operations were performed on people who were, and still are, independent walkers. An operation was discussed for a girl in her late teens who was in a wheelchair, but it was never performed. These few cases suggest that surgeries may be helpful to some CP adults, probably those functioning physically at a higher level, but that this type of service is not available to adults. Cerebral palsy is not followed medically in adulthood as it is in childhood, so even if a surgical operation would benefit an individual, there is no one to make this assessment. Also, there is no agency for CP adults to help cover the costs of such an operation. A general medical insurance plan or government medical coverage may not recognize the need for such an operation and, therefore, refuse to help pay for it.

#### Medical Care

Medical care received by the interviewees since becoming adults



were: care for eyes, e.g., eye examinations and glasses, received by half of the people; hearing examinations and hearing aids received by two individuals; and dental care received by three of them. It seems most people received care on an emergency basis and there was a lack of preventive medical care. It is not clear whether this lack was due to the cost of these services, the unavailability of physicians comfortable working with handicapped adults, or the need to educate CP individuals about the worth of preventive medical care. The problem may likely be due to a combination of these possibilities. It is an issue which needs to be investigated.

#### Occupational Therapy and Physical Therapy

One interviewee received help with walking and another help with grooming, each after the age of twenty-one years. With these exceptions we found that no occupational or physical therapy had been received by individuals after they were twenty-one years old. Is this due to a lack of services or because CP people will not benefit from occupational or physical therapy when they get older? Two interviewees mentioned physical therapy as the help they wish they were receiving now. One individual wished she would have physical therapy to exercise and added that no one will explain to her why she cannot. These requests add to the question of why occupational therapy and physical therapy are not available to CP adults.

Bud Thoun, the Adult Service Director of United Cerebral Palsy (UCP), gave us some insight into this question (11). He said occupational and physical therapy had been provided full-time for four years at UCP, funded by the Developmental Disabilities Office. He doubted seeing any improve-

ment in the participants during those four years and he was not sure what benefits these services might have for CP individuals after eighteen years of age. He does not see CP adults getting much benefit from daily occupational therapy, yet he thinks that physical therapy for exercise may be beneficial and that the service should be provided if the person has the motivation to walk. If a doctor refers an individual for occupational or physical therapy, welfare will pay for this service. Although Bud Thoune does not believe these services should be provided by UCP on a regular basis, he does believe these services should be available on a consultant basis to offer assistance in a less traditional way. He sees these disciplines providing suggestions on ways to adapt an environment, for living or working, to the needs of a CP individual. Assessing the need for equipment, e.g., grab bars or ramps for a house, are examples of ways a consultant would help a person. Mr. Thoune suggested that services such as occupational or physical therapy should not be discontinued for adults with CP, but that innovations in the provision of these services may best meet the needs of CP adults.

### Speech Therapy

Speech therapy follows the pattern established by occupational therapy and physical therapy: none of the interviewees had received speech therapy after the age of twenty-one years, this service was provided by UCP for four years with no apparent benefits, and the optimum approach perceived by Bud Thoune would be to have the service available on a consultant basis. It appears that new approaches to speech therapy for CP adults may need to be created. This issue of communication is discussed in Chapter III.

### Equipment

There does not seem to be a problem getting equipment for CP adults. Bud Thoun addressed this topic and said equipment is paid for by Adult and Family Services or by Vocational Rehabilitation. If these two agencies fail to provide the funds for the equipment, Easter Seals will provide them. Types of equipment needed include orthopedic shoes, grab bars, walkers, and wheelchairs. The piece of equipment which is difficult to obtain is a motorized wheelchair because of the high cost. The agencies will provide electric wheelchairs in the case of a quadriplegic who can move only by propelling him/herself backwards, which is bad for posture. Bud Thoun pointed out that a motorized wheelchair is harmful to people who are lazy because it demands less movement and gives them less exercise.

The ease with which equipment can be obtained provides a sharp contrast to the less available services of occupational, physical and speech therapies. It seems as if the objective and observable results from equipment provide more justification for their provision. Other services have not been evaluated to determine if they are worthwhile for adults. An evaluation of the different services must be completed to offer evidence for whether such services should be provided. These evaluations should look beyond the traditional ways these services are carried out by examining innovative techniques and offering suggestions for modifications of services to best meet the needs of adults with cerebral palsy.

### Additional Services

Consideration should also be given to services needed by all adults. These include housing, transportation, employment, recreation and counseling. What is available to CP adults and what is being utilized

by them?

### Living Situations

The housing situations were varied among the people we interviewed. Half of them were living with their spouses, most likely an indication of our biased sampling rather than a representation of the CP adult population. The other half included one man living alone, another man living with a roommate who also had CP, a woman living with a sister, another woman residing with foster parents and one man living with his parents. All were in apartments except the two who lived with natural or foster parents.

This information points out the variety of living situations for CP adults and the change which has occurred over the years. We spoke with Bud Thoune regarding housing and he agreed there was not one type of situation in which a majority of CP adults lived. He showed us a conceptual continuum about living situations which began with living with parents and progressed upward through nursing homes, group homes, foster homes, training for independent living, independent living with minimum assistance (housekeeping, attendant care, etc.), and reached the goal of totally independent living. He noted that five years ago more adults with CP were in the lower half of the continuum, but the UCP program of training for independent living has challenged individuals to try living independently rather than staying in the comfortable environment of a parents' home. The issue here is not merely the necessity of making housing available so CP adults can live independently or semi-independently, but also the need to motivate them to leave a secure living situation to try a new and challenging one.

The training for independent living program at UCP is a good example of a method by which CP adults are gently encouraged to be on their own. Bud Thoune said it may take several small steps for a person to reach independent living, so the participants in the program get the support they need but no more. For example, if a person has a severe speech problem, a staff member will go to the landlord with him/her to make the rental arrangements. Another factor which makes this program successful is Section Eight of the Housing Authority of Portland. This section provides for a low-cost rental contract. A person certified by the Housing Authority pays one-quarter of the rent while the Housing Authority pays the other three-quarters. Since many CP individuals qualify for this arrangement, it enables them to live independently on what would otherwise be too small an income.

It appears that the number of adults with CP living independently or semi-independently is increasing. This has been made possible by different types of assistance: programs which challenge and support, staff who provide necessary guidance, financial assistance, the removal of physical barriers, and minimum assistance such as housekeeping. Although this increase is encouraging, these types of assistance probably need to be expanded. Are present programs reaching only a select population of CP adults, such as those in workshops? Are they getting information about independent living to individuals in nursing homes, group homes, and foster homes -- places where people may be living because they are unaware of the alternatives? Should these programs reach CP individuals at a younger age to motivate them earlier? These questions need to be explored to determine the most effective way of enabling adults with CP

to achieve their maximum possible independence.

### Employment

Because most of the interviewees were referrals from UCP, we found that two-thirds of them were working in the sheltered workshop at UCP. Two other individuals were unemployed and one man was employed in the community. Although our sample is undoubtedly biased, it provides a beginning for a discussion on employment.

We talked with Mr. Thoune, who gave us an interesting perspective on employment for CP adults. He said the difficulty is not getting employers to hire adults with CP, but getting the adults aware of their ability to work in the community. He showed us a continuum which began with day care, moved up through activity centers, the beginning phase of sheltered workshops, the latter phase of sheltered workshops, skill training, and ended at community placement. He noted that individuals will begin and top out at different points along the continuum, but that the goal is for a job in the community. To get a person to reach his/her highest potential, he/she must receive not only skill and vocational training, but also counseling, support and encouragement.

One should acknowledge the right of CP people to determine the type of work they would like to do. This choice will need to be based on their physical and mental capabilities, but it should be as close to their wishes as possible. For the greatest range of possibilities they will need to look toward the community. This may necessitate not only convincing the people that they are capable, but also providing certain types of assistance. Many CP individuals would be capable of working

in the community if they had an attendant to help them with feeding and/or toileting. Flexibility may be required of the employer since some CP individuals may not be able to fit into certain time frameworks, such as only a half-hour for lunch. Other people with CP might be able to work in the community if they were not required to work an eight-hour day or up to a set capacity. If they could do an efficient and effective job at their own pace, they should be allowed to do so and have their pay negotiated accordingly. The goal is to have people with CP find a job in the community. This will require counseling to convince them of their ability, opportunities which allow them to choose the type of job they want, and flexibility and adaptations which will facilitate the CP person's integration into community employment.

### Transportation

Transportation may affect a person's ability to work in the community. The one man working in the community was able to drive and was not limited by lack of transportation. Another man used public transportation to get around, however, many people with CP would not be able to use regular public transportation due to the degree of their handicap. The other interviewees either relied on people to drive them, used special public transportation vans or rode motorized bicycles for going short distances. One man even rode a lawnmower for transportation.

The effect of the lack of transportation is seen in several ways. As a teenager, one woman was unable to attend a workshop because of transportation problems. Most severely limited, perhaps, is the social interaction of people with CP. In this mobile society it is necessary to be able to get out in the community to attend social or recreational

functions. Even when special transportation is provided it usually goes only between the person's home and work or school. This limits a person's chance to participate in social activities. Due to the lack of transportation most of the interviewees stayed at home or went only short distances. Their lack of personal friends may also be due to their inability to visit people they meet. Those who did have friends had met them at work or in their residence.

Transportation is a current need of persons with CP. Existing special transportation should be expanded to enable people to get to social and recreational events to alleviate their social isolation. New types of transportation also need to be explored. Are there modifications which could be made on public transportation, making it easier for a physically handicapped person to use it? Are there adaptations for cars or motorized bicycles to meet the special needs of individuals with CP and enable them to drive or go longer distances safely? These and other alternatives should be investigated to try to meet the transportation needs of people with CP.

### Social Interaction

We have briefly mentioned the social isolation of CP individuals. Most of the interviewees had no participation in a group. Of the few who did, one was a passive member in UCP group activities and two were active members in religious groups. One man walked to a church to participate several nights a week. One woman went four times a week to a church a considerable distance from her home. The church members picked her up in a van each time. Neither of these churches would fit into the category of "traditional religions," each having a fanatical orientation.



These "fanatics" are the people who would accept, and even go out of their way, to bring CP individuals into their group. A lesson can be learned from this: people with CP want to participate and may go wherever there is an open door. Could not the rest of society open a few -- or several -- doors? These opportunities for socializing should not be just for handicapped people, but an integration of handicapped people into regular activities. As one man said, "I feel less handicapped when I am with non-handicapped people."

#### Counseling and Advisement

None of the interviewees said they currently were receiving counseling. The only interviewees who had previously received it were the couple who obtained sex counseling and family planning before they had their child (see Chapter IV). Although formal counseling was not received by other interviewees, they did obtain some of what Buscaglia (2) calls advice. He points out that developmentally disabled adults need advisement in such areas as legal assistance; sex information including family planning, contraception and voluntary sterilization; vocational training and employment; recreational activities; management of finances; public assistance and services available; family relationship; and child care.

When asked about sex education and family planning, all but the one couple said they had not had these services. The general reaction was embarrassment along with an occasional look which seemed to express surprise that a person with CP should consider sex or that anyone would give them sexual counseling. One married man had chosen to have a vasectomy, so he probably did receive some counseling in connection with this

surgery.

The management of finances is an area where help is needed. About one-third of the interviewees handled their own finances, but the others either needed assistance or had someone else handle the budget entirely. Learning to handle finances is a necessary step toward independent living. If the goal is semi-independent living, it may suffice to have someone help with the budget. It appears that two types of financial assistance need to be developed: one to teach the skills of budgeting to enable the CP person to be independent, the other to provide ongoing guidance and advice in budgeting for CP individuals who are unable to learn these skills.

Advice with legal issues, recreational activities, public assistance, family relationships and child care is needed by some people with CP and these services should be readily available to the. Counseling about personal problems should also be available. Because of speech problems, special training may have to be provided to counselors and therapists to facilitate communication.

### Summary

Adults with CP have several service needs. They need assistance with problems relating directly to their CP and with adjustments that will help them to function as independently as possible. With short-term help many of them would be able to live a more "normal" life.

### CONCLUSION

In reviewing the services the interviewees received as children it seemed that, with a few exceptions, the services were adequate. Services which may have been lacking were: 1) social services to determine the

adequacy of the home environment and the effect of the family on the child's therapy and 2) education to help integrate these children into varying social situations and to challenge them to their fullest potential. The issue was raised on how services for each child were determined. Surgery, braces and speech therapy were services that seemed to be provided indiscriminately and with varying results. The results of these services should be evaluated against the time and trauma involved. There needs to be a way to evaluate the potential usefulness of these therapies on each child.

The interviewees remembered their most important assistance to be the support provided by a variety of adults. The impact of this support points to the need for professionals and parents to be aware of the fear, pain and joy which may be experienced by CP children. Youngsters with CP should be as involved as possible in making decisions about their therapy, education and vocation. They need to be listened to and to be treated as whole people.

Services available to people with CP drop drastically after the age of twenty-one years. The usefulness of surgery for CP adults should be evaluated. Preventive medical care is needed, as is some form of physical therapy, occupational therapy, and speech therapy. These therapies may require innovations in service delivery and may rely more on environmental adaptations. These possibilities should be explored.

Services are needed which will motivate CP individuals to become part of the community and convince them of their ability to do so. Modifications are necessary in living situations and in work environments to facilitate the CP individual's integration. Special transportation

should be expanded and new methods of transportation explored. Opportunities for socialization are scarce and should be made available. The same goes for counseling, be it didactic advice or a chance to express feelings and discuss personal problems.

Services for CP children need to be evaluated for their effectiveness while services for CP adults need to be expanded and modified. They should encourage and support individuals so they gain a sense of worth and are able to become integrated into their community. The goal is normalization.

## CHAPTER III

### COMMUNICATION DIFFICULTIES AND OTHER BARRIERS TO NORMALIZATION FOR CEREBRAL PALSIED

#### INTRODUCTION

Many issues evolved through the course of interviewing cerebral palsied adults. At the conclusion of a particular interview with two cerebral palsied adults with severe language impairment we discussed the unique problems this situation presented. Later after all the interviews were completed, when going over themes we would engage for these papers, the interviewing experience was brought up again. Interviewing cerebral palsied adults with severe speech involvement seemed pertinent to trainees and professionals confronting communication with CP persons. We wish to share some of the difficulties we encountered and what approaches we found useful.

While thinking about the issue of communication, and in talking with two professionals who work with cerebral palsied persons regularly, we noted other barriers that are prevalent due to being handicapped with CP. Factors such as socialization skills, mobility, and identity all contribute to blocking or enhancing normalization. Those issues which present barriers to community integration and independence will be explored in conjunction with a discussion of communication.

## COMMUNICATION

### Speech

Those developmentally disabled adults with speech difficulties whom we interviewed had received speech therapy in childhood, usually in connection with attendance in a special school. This was reported by these persons to be quite helpful. In reviewing CCD medical charts of those persons we interviewed, we found documentation on the progressive acquisition of speech over their childhood years. Several of these adults had no speech until age five or eight when they finally began using words. This progressed to sentences, and eventually toward expressing themselves to others.

There arrives a point when the cerebral palsied person reaches the limit of his/her capability and speech therapy is no longer beneficial. Having been able to acquire speech, the still remaining impairment in articulation may be a life-long handicap.

### Barriers

Many cerebral palsied persons lack opportunities because of speech impairment. Communication is a basic means to forming relationships. Through speech we communicate our needs and feelings to others which promotes the formation of identity. Speech is a necessary function for participating in society, and certainly the CP adult with speech difficulties finds him/herself in social isolation.

Lacking this tool of communication presents a barrier toward participation in society and independent self-sufficiency. Tasks such as speaking to a landlord about renting an apartment are prohibitive without

outside assistance. An interpreter is often required for facilitating such transactions and this necessitates reliance on others. Without such an intermediary false assumptions can be made about the cerebral palsied person involved.

In reviewing the medical charts of those adults we interviewed we noted several instances where service professionals had assumed that these physically handicapped persons were mentally retarded. This appeared to be linked with their lack of speech, and/or generalized atonia, and listlessness that some cerebral palsied persons possess. Individuals with these characteristics were regarded with little hope for the future. This view leads to lowered expectations and fewer opportunities for the CP person. In speaking with professionals in the field, it was observed that this is not uncommon, people often associate speech impairment with mental retardation.

Social isolation from childhood on is a reality for the CP individual with little or no speech. Inability to be understood blocks the interactional opportunities available to most persons. What are the possible long term affects of this social isolation? The CP adults we became familiar with who lacked speech in early childhood were able to make their needs known. Yet, this was usually a highly individualized process between mother and child. The intimacy of that relationship prompted the mother to be sensitive to nonverbal expressions not easily translated by others.

Pseudo-retardation has been shown to be directly related to social isolation. As a developing child, CP persons with speech impairment are not able to participate in the learning process between mother and child

that provides the learning of syntax and gives meaning to words. How language relates to cognitive development is explained from two positions: 1) language is viewed as the precursor to thought and 2) thought is seen as essential before language. These theories lead to many ideas regarding the role communication plays in the acquisition of intellect, social skills and identity.

The inability to express oneself by relaying ideas, feelings and beliefs thwarts the creation of an identity. This critical role played by language in human development leads one to wonder how an individual can express him/herself completely through non-verbal methods or with limited speech.

### Interviewing

One can envision the conflict of having normal auditory and receptive capacity with impaired expressive ability that is present for many CP persons. When faced with the task of interviewing adults with speech problems one learns quickly how frustrating this process can be for both interviewer and interviewee. Speech requires extended effort for the cerebral palsied. In turn, the listener must be alert to interpret what is being said. During the interviews we conducted there was usually one CP adult to three or four interviewers. Every interviewer was needed in discerning the individual's communications.

Our situation was that of naive listener, but as the interviewing progressed the speech patterns became more familiar. While speech patterns became more familiar during every session, each CP person presented new obstacles to understanding due to his/her own particular pattern of speech. Even professionals who work with CP persons daily



still encounter problems in understanding their speech. Extended contact with particular individuals, we learned, lends itself to easier communication and understanding. This was demonstrated by a couple, both of whom had speech difficulties yet seemed adept at understanding each other. For them nonverbal communication and knowledge of another person seemed helpful in their communication effort.

### Strategies

Several impressions emerged at the conclusion of our interviewing experiences, impressions which could be applied to communication with CP persons in general. One of the primary factors is the need for patience. It takes time for CP individuals to speak, and time to process what they are saying. It was necessary to slow down our fast pace of normal speaking. CP persons usually need more time to accomplish what non-CP individuals would do quite quickly. For example, when a question was asked during our interviews the person would reply and then we would interpret this back to see if we understood correctly. This often necessitated guessing until we had the message right, and at times it was necessary for the CP person to write down what he/she was attempting to say. Listening in this situation requires patience without preoccupation. When one hurries or pushes anxiety can result and this further impedes communication. A relaxed posture should be aimed for, and more time allocated.

When first trying to interview a CP individual with speech impairment we attempted concentrated listening. This was not productive. It was impossible to understand every word. The most effective method was to relax and listen to the flow of speech. As different parts were

heard it enabled one to fill in words that were not understood at all. By listening for the general content the listener could fill in and add to what was heard. This is a way of building on the communications presented. It is difficult for a CP person to give a long complex answer. In this situation the professional will probably talk more than with other populations.

The usual easy interchange among people which we take for granted is not present when interviewing cerebral palsied persons. We found specific questioning to be essential. Short specific answers should be aimed for. It is also beneficial to elicit yes or no type responses. Those we spoke with did not usually engage in any communication that was not in response to our direct questioning. Both social isolation and a lack of information regarding social trends leaves the CP individual with little to talk about. The interviewer needs to question, elicit feelings, thoughts and interests. These areas are often untapped and unknown to the CP person with limited social interaction.

Noting body involvement in the CP person can also be a way to learn the emotional content of the exchange. Being alert to this requires an awareness of the involuntary movements characteristic of the different CP conditions.

### Professionals

Another difficulty in communication that we learned about during our interviewing concerned the communication of health professionals with the CP individual during childhood. Throughout their early years most of the adult CP persons had continual medical appointments -- for diagnostic assessment, surgery, braces and therapy. Much of their

growing years were spent in contact with these service providers. Undergoing six to eight operations each followed by wearing casts and bracing was not uncommon. Physical therapy was an ongoing necessity for improvement. This involved many hours of physical therapy appointments and follow-up exercises at home.

One young woman we interviewed recalled the unpleasant restriction of wearing braces, doing daily exercises, learning to walk with crutches, and the many operations to counteract disfigurement and enable her to stand upright. Her experience was characteristic of those we interviewed. She is now in a wheelchair and wonders what good all the efforts were. Some we interviewed believed all the medical procedures were worth it while others disagreed. Yet, the trauma of surgery, the frustration of exercises, and the restriction of braces recall painful memories for all.

Two factors for health professionals were pointed out: 1) the emotional reactions surrounding the medical procedures and the meaning these had to the individual were ignored: more professional sensitivity in this area would have been welcomed by the CP individual, and 2) the CP child was seldom included in the decision making process nor asked how he/she felt about the services being planned or given. These conclusions were derived from the CP adults we interviewed.

An example encountered in one chart that was reviewed at Crippled Children's Division dramatizes the factors presented above. One young man, now in a wheelchair, had a leg operation in his early teenage years and was in full leg casts lying down for many weeks thereafter. This in combination with the painful bracing and exercises that followed

caused an emotional set-back for him. A severe regression in self-help and physical abilities accompanied his reaction. He did not regain his capabilities for approximately one year.

A critical issue for service professionals dealing with CP children and adults emerges: if we are to encourage cerebral palsied persons to develop self-sufficiency then we must facilitate expression of feelings and participation in the planning of one's own future. A person with a physical handicap is helpless in many regards, yet not being consulted regarding one's own body surely must further the feelings of helplessness and lack of control over one's life. It is important to explain to the CP individual what medical procedures are being used and why, to elicit their feelings about this, and mandate their inclusion in decision making. Those interviewed wished people would allow cerebral palsied persons to do more for themselves. This implies normalizing the childhood experience of the CP individuals as much as possible and gradually promoting independence rather than viewing this as occurring immediately upon becoming an adult.

When we asked the adults to remember individuals who helped them most it was common to choose those who responded with sensitivity to the experience of the CP person. Taking time to listen, encourage and convey empathy was highly valued by those we interviewed.

## PROBLEM AREAS

### Socialization

Being isolated and set apart from peers is a common experience for the severely handicapped person. From home teachers to special schools

there has been little opportunity for joining in the mainstream of society. The capacity to move out and venture on your own is fostered gradually throughout normal childhood development. For the CP child much of this development takes place only within the confines of one's home. This is a limited socialization experience for the severely handicapped person.

### Dependency

From childhood many CP individuals have learned dependent behavior. While a certain amount of dependency may be inevitable, the way in which this is handled can prove crucial. Dependency can be an attitude. Well-meaning parents and professionals often intervene for the handicapped person in areas the handicapped could handle themselves. If a person is used to having everything done for him/her, he/she may lack motivation for self-help. One professional indicated that the best stance to take is to do for the cerebral palsied person only what that person cannot do for him/herself. A CP person expressed this by explaining that he believed his parents were correct in realizing that he had to do things on his own. He is one of a few totally independent CP individuals, yet he has a pronounced impairment. Another man whose parents have devoted their lives to his care still remains at home more handicapped by emotional than physical barriers.

### Separation

Emotional and psychological restraints may offer greater barriers than do societal attitudes in achieving independence. We initially thought that the greatest obstacle towards integration with society for

the handicapped would be prejudices against them by society. This may be a false assumption. Even with more opportunities now available many individuals are unable to take advantage of them due to fear and lack of confidence in their ability to be self-sufficient.

Separation-individuation is a task which many CP persons are still attempting to achieve in adulthood. Possible dependency on the family prevents this from ever occurring. Self-assertion, expression of ambivalence, anger, and striving for separateness could be frightening emotions to individuals dependent on the family for their entire emotional and physical survival. Such dependency could contribute to the passivity and lack of ambition we noted in the cerebral palsied persons we interviewed.

There is little opportunity for individual accomplishment if one is dependent on another for feeding, toileting, dressing, and mobility; and more so if this extends into adulthood. Staying at home and attending schools for the handicapped may not provide the range of opportunities to experiment and develop confidence in non-handicapped society.

There are few role models for the parents and the handicapped persons themselves to look to for achieving success in the community. Parents find it difficult to let go of their offspring when they ponder how life will be for their handicapped son or daughter. Role models are critical for increasing the confidence for handicapped and their families to take the steps towards independence.

There are risks involved in separating from the family. Yet, without allowing the handicapped child the suffering inherent in experimentation, personal growth cannot take place, and adaptive coping mechanisms will not be tapped. The people we interviewed lived in foster homes, lived

independently, and also at home with parents. Their living situation did not always seem suited to the degree of their handicap.

### Independence

There was a suggestion, in the limited material we gathered, that the social interaction available through attendance in the public school system might have been important in their self-sufficiency in adulthood. Several of those we interviewed who had attended public high school are now living independently. One CP man, now married and employed, talked on this issue. One school district would not admit him to public high school because there were too many steps in the building. His family then moved to another district and he graduated from the high school in that area. He was the first handicapped person in that school and finished in the top of his class. The competition he had in high school, he claimed, improved his general condition; it made him work harder. Being with non-handicapped persons made him feel more "normal." Of course, the role his family played in his achievements cannot be overlooked.

Perhaps daily interaction with non-disabled persons contributes to learning about social roles and realities. Those who only attended special schools or had home teachers missed the opportunity to interact with non-disabled peers. They missed the chance to develop the social skills and confidence it takes to go out on your own.

### Mobility

Yet another factor contributing to independent functioning is mobility. Some CP adults were able to drive, others have power vehicles

or a motorized bicycle of some type. There are vehicles, it seems, that can be adapted for most anyone's needs. Many had no vehicle for independent travel and were dependent upon others for transportation. This added to their becoming more dependent on others for social and recreational activities. People in this position have very limited social interaction. Even those with independent transportation seem to have limited social contacts. It appears as though these handicapped adults have not been able to develop relationships with many people.

### The Future

We asked the CP adults what their future goals were and their answers show a pattern that contrasts to that of non-handicapped persons. Common answers were, "Just keep living," "Take one day at a time," or they "had not given it any thought." What does their future hold without any job skills? For some the relevant question is what would their future be without parents or caretakers.

With little experience in sheltered workshops during their teenage years and no other job-related training for possible employment in the community or for a career, the future does not hold a great deal of hope. Today many participate in sheltered workshop activities which provide some purpose and social outlet. For some this setting will be life-long. Others may move gradually to more independent work and living situations. With more role models living independently and being employed in jobs other than factory related workshop positions the numbers of CP adults in the mainstream could increase.



## CONCLUSION

The issues presented in this paper address specific points of professional intervention. While it is important to educate the public toward accepting and providing for the special needs of CP individuals, it is just as important to work with parents and providers. Service professionals and parents must implement the task of increasing normalization and independence for the cerebral palsied. Two courses of action seem appropriate to accomplish this: 1) provide opportunities for their inclusion in the mainstream of society, 2) teach and encourage self-sufficiency where the potential exists. These goals require stepping back and letting the CP make mistakes that are necessary for growth and mastery. Showing that we have confidence in the cerebral palsied will help them in attaining confidence for themselves. This could instill more hope for the future.

## CHAPTER IV

### BIRTH OF A CHILD TO A CEREBRAL PALSIED COUPLE

#### INTRODUCTION

Recent trends in the human services have moved beyond deinstitutionalization to normalization of the lives of handicapped persons. The cerebral palsied adults that we interviewed were all seriously physically handicapped but varied greatly in their social adaptation. Some live in rather sheltered environments with parents or foster parents, while others have learned to live independently. Locomotion and communication problems naturally affect the level of independence attainable. But the disabled person's self-image and society's expectations are also major factors.

Bill and Alice (pseudonyms) are married cerebral palsied adults; both have varying yet marked involvement in all limbs and labored speech. As we interviewed Bill and Alice, we were immediately impressed by their pride in achievement. Now middle-aged, they live independently in an apartment not too far from their employment site in a sheltered workshop. They have learned to manage household chores, finances, transportation, shopping and other self-care tasks. They were proudest when they showed us photos of their daughter. They were parents and that little girl represented a major step in the normalization of their lives. Having a child seemed a natural part of their life together; furthermore, they conceived a healthy and active child. After her birth, the couple

encountered a mixture of reactions from professionals and friends around them. Few had been involved with a situation like this before and, therefore, did not have models or precedents to follow. Some people were supportive as the parents made difficult decisions concerning the care of their child. Others saw only danger for the girl and used whatever influence or threats they could to remove her from her home. Conflict was resolved and adequate care insured when arrangements were made for the girl to be adopted by the family who had been caring for her on a temporary basis. They all live in the same neighborhood and Alice and Bill are able to visit their daughter often.

Cerebral palsy does not necessarily affect sexual functioning. Pregnancy is possible. It is not a heritable disorder, therefore, there is as much chance for having normal children as for non-CP couples. Delivery may be difficult because of muscle spasms but the physical handicap alone does not stop conception and birth. Having babies is generally expected when people marry. Yet we do not see many CP parents. As a society, we barely acknowledge the disabled as sexual beings, and when we do it is usually just long enough for sterilization procedures to be used so that we do not have to deal with the issue. And then we are surprised and unprepared when a child is born to a couple with CP.

The probability is that increasing numbers of physically handicapped adults will be in situations that permit sexual relations and procreation. Are health and social service providers prepared to react more thoughtfully than emotionally? Anticipation of some possible problems and availability of support services can help us to better serve those who come to us for help. When a child is diagnosed as having cerebral palsy, experience

has provided a network for the probable medical, educational and social resources to be suggested to the family. But if the reverse happens, i.e., a normal child is born to parents with CP, we have not yet established networks to aid the parents and the child.

The following sections of this paper will explore some of the individual and community questions raised by this issue, in an attempt to encourage consideration of the attendant problems before we are faced with the actual situation in professional practice. The opinions expressed are our own, yet based on conversations with handicapped individuals and professionals who work with them. But most of the questions do not have concrete answers and we present our thoughts to encourage others to also look at the many facets involved.

#### WHAT BURDEN DOES THIS SITUATION PLACE ON SOCIETY?

United States' social policy lies somewhere between pure socialism, where the entire community works toward community goals, and pure capitalism, where a laissez-faire attitude greatly limits government involvement in private affairs. While we do tend to acknowledge a basic need to care for the victims of unfortunate circumstances, our social policies lead to plans which stigmatize recipients. We have developed an income maintenance system that grudgingly will minimally support families and handicapped individuals who are unable to do this for themselves. Financial assistance for the handicapped was moved from the welfare system to the social security administration because it would seem less humiliating to receive social security than welfare. The disabled are therefore deemed more worthy of assistance. And certainly many

physically and mentally handicapped persons are at least partially, if not totally, supported by the state.

If taxpayers accept responsibility for these adults, then we are burdened with the cost of their children. Whether the child remains in the parental home or is placed elsewhere, it costs us money. This raises questions as to the most equitable use of public funds. Should people be allowed to have children they cannot raise themselves? Can we afford all these children?

Or perhaps the question is, "Can we afford to allow anyone to attempt to decide which persons can procreate?" Whom could we trust with such a vital decision? There are so many people who fit into the "normal" category who are destructive parents: why, then, are the disabled singled out? We really do not see sexual restrictions on procreation as an option for a country as dedicated to individualism as this one is. Overt restriction is unthinkable to us. What remains then is the question of ways to insure adequate parenting for all children. This is not a problem solely facing the handicapped population. National policy must recognize that there are irresponsible parents in all physical, ethnic and social groupings.

#### WHO HAS LEGAL RESPONSIBILITY FOR THESE CHILDREN?

Oregon law guarantees to physically and mentally handicapped persons "the fullest possible participation in the social and economic life of the state" (7). It is unlawful to discriminate against a handicapped individual in housing or employment, unless the handicap prevents the performance of the duties involved. It is the intent of the legislation that disabled

people have access to an independent, productive life within society. We view the status of being a parent as one of the basic self-image builders in one's life and to deny that status to anyone, without carefully showing evidence for his/her unfitness, is criminal.

When Bill and Alice approached the Children's Services Division for resources to help them care for their daughter, their caseworker decided that it was unthinkable that this disabled couple should be parents and the agency threatened legal action if the couple did not immediately arrange to give up their child. If the case had gone to court, advocates for the couple could cite ways which the parents were arranging for child care assistance in areas that they were unable to perform. The intent of the legislation concerning grounds for termination of parental rights is to see that the needs of the child are met. Parents are responsible for meeting these basic needs or seeing that they are taken care of. It is analogous to the grounds for involuntary commitment to a state hospital -- termination of individual rights. The state must show that the mentally ill person is "unable to provide for his/her basic personal needs and is not receiving such care" (8). If one is unable to care for one's needs but the needs are being met by someone, then no government intervention is warranted. The concern should be with the quality of care rather than with who provides it.

In a situation with disabled parents, a little resourcefulness and observation of varying life styles today show that a child need not be raised by just one or two people in one home all day. In fact, some claim that the type of care provided through an extended family or neighborhood helping systems may be better for all. There are child-rearing

alternatives.

But for those who are concerned about the quality of care a child can receive in a home with disabled parents, there are some very real problems. Infants need fondling and carrying -- are the parents' arms strong and steady enough to do this? Toddlers require a caretaker who can keep up with them. Language development is important for development of mental capacity and communication skills -- can the parents' speech stimulate language formation? Disabled adults may require extra training to learn some child care skills just as they may have required some extra help learning personal care tasks. Duties that are hampered or prevented by a parent's handicap will have to be done by someone else. Alice and Bill arranged for another couple to help them toilet-train their daughter. Medical and social service personnel may have to be in regular contact with this type of family as the child grows and as conditions change. Removal of the child from the home is one option. There are alternatives.

#### WHAT IMPLICATIONS DOES THIS SITUATION HAVE FOR SEX EDUCATION CURRICULA?

Realization that the physically handicapped can and may want to have children presents primary implications for those involved in sex education and counseling. The so-called "sexual revolution of the 70's" has actually been a slow process of increased public verbalization on formerly taboo topics accompanied by minor acceptance of variations in life style. Codes of acceptable behavior still depend upon geographic location, age, sex, appearance, social status, sub-cultural mores and other locally defined criteria.

Historically, sex education services for the physically handicapped have been largely non-existent, especially for the congenitally affected. Spinal cord injured males were the first to be recognized as in need of special services when World War II returned so many of these men to their home communities. Gradually, females who have lost the use of limbs were included in this consideration. Only recently has the need for sexual counseling for the broad range of physically handicapped been explored.

Some argue that there is no proper sex counseling on a practical level for anyone; the handicapped are not unique in this area. But the disabled are generally less mobile and have fewer social outlets. They have less opportunity to "pick it up" than others. Television is a source of information but the view can be too distorted and unrealistic. An adolescent who is constantly sheltered at home or in special environments at school is likely to grow up believing that at eighteen years of age everyone magically falls in love and gets married, has babies, and life is immediately happy and bright. Through our visits with CP individuals, we came to see their lack of social skills as the real disability.

It is recognized that people with CP may need "therapy" to help them learn developmental tasks such as walking, feeding, speaking. Likewise, they may need training in meeting people, building relationships, protecting themselves from strangers, and housekeeping. It seems wise to avoid assuming that someone cannot learn something until you try to teach him/her. If he/she cannot adequately perform the task, then alternative means for accomplishing the task need to be examined.



Sex education for the handicapped involves more than naming genital parts and describing actions. Based on the belief that responsible sex relies on knowledge of self, nature of relationships, alternative life styles, and the responsibilities associated with close contacts, teachers deal with the skills necessary for normalization of social contacts. For example, a lesson on masturbation is incomplete if it omits when and where performing the activity is acceptable. And presentation of a realistic view of marriage can help prepare couples for the liabilities of living together. Too often the handicapped look and act "retarded" when they are out in public because they have not been taught the appropriate code of conduct. Many habits that are accepted in the individual's sheltered environment look strange in public places. Hugging everyone you meet may be considered cute and may be reinforced in a helpless-looking ten year old boy, but he can get into serious trouble if he continues this behavior as an adult male. Normalization involves creating the usual life patterns for the handicapped individual. Education of the community and the individual should ease the acceptance process.

Anna Freud is quoted as saying, "Sex is something we do. Sexuality is something we are." Every person has some kind of self-image which generally includes a sexual component. This is part of the socialization process. We need to recognize our myths about the disabled and how we express these expectations to the people we meet. Are handicapped persons really helpless and continually asking for assistance? Imagine being in a wheelchair and having a stranger come up from behind and push you along without even asking. High self-esteem is based on a feeling of some control over one's own life. Are the handicapped sexless? Do we

encourage stylish clothing selection and grooming? Few group homes or institutions can handle sexual activity between inmates. A commitment to normalization seems to force us to raise our expectations and encourage the handicapped to experience, to learn, to make mistakes and grow from them. Independence rests on independent decision making. Development of this ability takes practice. Sexuality is a matter of self-image; unfortunately, handicapped persons have a difficult time developing a positive self-image and the personal resources to deal with a world that denies the status. We think our complex society requires sex education curricula that meet the varying social needs of all adults.

#### CAN HANDICAPPED INDIVIDUALS BE GIVEN FREEDOM OF CHOICE?

These authors believe that all people have a right to be involved in decisions about their lives. And also that this freedom carries the right to have a chance to learn enough to make responsible decisions. From this basis, and realizing that the fertility that comes with puberty has been a constant concern of parents and child caretakers, we have pondered the question of sterilization of the mentally and physically disabled.

Legislators are now in a controversy over the sterilization of the mentally deficient. There have been times when numbers of these people were sterilized without their knowledge or consent. Advocates for individual freedom have greatly reduced this practice. Some people argue that for persons who have shown gross disregard for societal standards, sterilization is like taking a loaded gun away from a murderer. A real problem arises over who is legally responsible for such decision

making for a mentally handicapped person. By definition, he/she is not competent to make the decision, even if he/she has learned about family planning and wants to make a choice. However, it is an infringement upon his/her rights for someone else to authorize sterilization. And we are still in this legal stalemate.

Skirting the legality issue, some parents have been able to have their children sterilized during their teen years to avoid unwanted pregnancies. A physician can give a medical reason to justify a hysterectomy and no one investigates. This solves the problem for the parents. But, besides the moral question, they have not solved the issue of the young person's sexuality. Sterilization denies the handicapped individual a chance to be involved in the decision making process later on in life when he/she has more information and experience.

From our orientation, there are many valid reasons to have oneself sterilized including concern for overpopulation, medical conditions that make pregnancy dangerous, genetic concerns, and the decision not to raise children. But to find out that you were sterilized before you knew what it meant accents your own vulnerability and can present positive reasons to distrust those closest to you. It can be destructive to relationships and to personal growth. There are ways to avoid pregnancy which are not permanent. When made, the decision concerning sterilization should be based on knowledge, guidance, and discussions between the individual and someone he/she trusts.

#### WHERE DOES ALL THIS LEAVE US?

Acceptance of disabled individuals as full participants in community

life requires a look at the physical barriers to community services and activities. We wonder how accessible family planning services are to people in wheelchairs, on crutches, or those with limited verbal ability. Will the staff be surprised that a disabled person is sexually active? Handicapped persons generally have less income, less education, less employment thus creating a greater need for subsidized health care. It is important that gynecological exams be part of every women's health care. This may be omitted if, consciously or unconsciously, health professionals deny the handicapped woman her sexuality. When disabled people request our services, are we ready to respond to their special needs?

If a handicapped person is sexually active, the couple should understand that there is a good chance she will get pregnant unless measures are taken. Eighty percent of the women using no contraception and having intercourse regularly will become pregnant within twelve months (Planned Parenthood, 1977). The decision to have a child is a serious one and should be based on many criteria.

As social service professionals, our discussions with couples can include an understanding of the responsibilities of parenthood; an exploration of resources, both personal and material, that are available to them; and a consideration of gaps between what the couple has and what they may need. The steadiness of the couple's relationship is another factor. Genetic counseling may be indicated if the medical or family histories show a significant risk. And any woman with special medical concerns would be advised to consult a physician before she risks a pregnancy. Child management requires a good deal of physical and mental exertion that prospective parents do not always plan on. Thusly, the

right to choose to be parents can be based on information and alternatives.

Does child rearing have to be part of every marriage or intimate relationship? Is it possible to be a productive adult without being a parent? It appears that individuals who can feel fulfilled and satisfied with themselves as people can accept a decision not to have children comfortably. And there are other ways to have significant relationships with children without having your own: being a big brother or sister, "aunting" or "uncleing", volunteering time at a nursery school or playground. We see the freedom to be a parent as linked to the freedom not to be a parent.

When a disabled couple has a baby, they need support and understanding just like other parents. They should be judged on their abilities, like other parents. They will probably have some special needs, but parents are special people.

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APPENDIX

CCD UN: \_\_\_\_\_

Date \_\_\_\_\_

## CP Follow-up Questionnaire

- \_\_\_\_\_ 1. Your birthdate: \_\_\_\_\_ Month \_\_\_\_\_ Date \_\_\_\_\_ Year
- \_\_\_\_\_ 2. Sex: 0. Male 1. Female
- \_\_\_\_\_ 3. Deceased: 0. No 1. Yes Date, if known \_\_\_\_\_  
Cause of death: \_\_\_\_\_
- If deceased, please stop here.
- \_\_\_\_\_ 4. Since your 21st birthday, has your cerebral palsy problem  
0. Improved 1. Stayed the same 2. Gotten worse
- \_\_\_\_\_ 5. Your current residence:
- |                          |                                   |                                 |
|--------------------------|-----------------------------------|---------------------------------|
| 00. Alone                | 04. With parent or relative       | 08. Halfway house               |
| 01. With roommate        | 05. Foster home                   | 09. State institution           |
| 02. With spouse          | 06. Group home                    | 10. Other: please specify _____ |
| 03. Supervised apartment | 07. Nursing home or home for aged | 99. Unknown                     |
- \_\_\_\_\_ 6. Where did you receive your education?
- |                                |                      |            |
|--------------------------------|----------------------|------------|
| 0. None                        | 2. Home tutored      | 9. Unknown |
| 1. Special education classroom | 3. Regular classroom |            |
- \_\_\_\_\_ 7. Your general education level:
- |                                |  |
|--------------------------------|--|
| 00. None                       | 06. Attended junior college or college |
| 01. 1st through 4th grades     | 07. Junior college or college graduate |
| 02. 5th through 8th grades     | 08. Graduate school                    |
| 03. Some high school           | 09. Other: please specify _____        |
| 04. High school graduate       |  |
| 05. Vocational training school | 99. Unknown                            |
- \_\_\_\_\_ 8. Your current work status:
- |  |                                |
|--|--------------------------------|
| 0. Employed in community                             | 3. Student in academic program |
| 1. Employed in sheltered workshop or activity center | 4. Houseperson                 |
| 2. Student in vocational training program            | 5. Not employed                |
|  | 6. Retired                     |
|  | 9. Unknown                     |



## 9. Your ability to get about (locomotion)

- |  |   |
|--|---|
| 0. No difficulty                             | 3. Uses wheelchair or other wheeled means |
| 1. Limp or walks unsteadily (may use cane)   | 4. Crawls only                            |
| 2. Walks only when assisted (may use walker) | 5. Unable to locomote self                |
|  | 9. Unknown                                |

## 10. Your sense of direction

- |   |  |
|---|--|
| 0. Does not get lost                                  | 2. Leaves own area only if accompanied |
| 1. Can go about in familiar area without getting lost | 3. Never leaves own area               |
|   | 9. Unknown                             |

Do you have use of

|                | 0. Full use | 1. Some use | 2. No use | 9. Unknown |
|----------------|-------------|-------------|-----------|------------|
| 11. Left arm   |             |             |           |            |
| 12. Left hand  |             |             |           |            |
| 13. Right arm  |             |             |           |            |
| 14. Right hand |             |             |           |            |

15. Your participation in group activities (Other than religious service attendance)

- |                   |                               |
|-------------------|-------------------------------|
| 0. Leader         | 3. No participation in groups |
| 1. Active member  | 9. Unknown                    |
| 2. Passive member |                               |

## 16. Your social interaction with others in your residence

- |                           |                                |
|---------------------------|--------------------------------|
| 0. Interacts frequently   | 2. Never interacts with others |
| 1. Interacts occasionally | 9. Unknown                     |

## 17. Your social interaction with others outside your residence

- |                           |                                |
|---------------------------|--------------------------------|
| 0. Interacts frequently   | 2. Never interacts with others |
| 1. Interacts occasionally | 9. Unknown                     |

## 18. Frequency of your interaction with family (either visits or by phone)

- |   |
|---|
| 0. Lives with family, interacts frequently      |
| 1. Lives with family, interacts seldom          |
| 2. Lives away from family, interacts frequently |
| 3. Lives away from family, interacts seldom     |
| 4. Never interacts with family                  |
| 9. Unknown                                      |

What do you think of the treatment(s) you received during your life in \_\_\_\_\_ and where? (Please specify where you received treatment in parentheses.)

41. PT ( ) \_\_\_\_\_
42. OT ( ) \_\_\_\_\_
43. Bracing ( ) \_\_\_\_\_
44. Surgery ( ) \_\_\_\_\_
45. Other ( ) \_\_\_\_\_  
Please  
specify ( ) \_\_\_\_\_  
( ) \_\_\_\_\_

46. What was the most helpful or important assistance you received in your life?

47. What was the least helpful or least important assistance you received in your life?

48. What help do you wish you had that you didn't receive?

49. What help do you wish you were getting now that you don't get?

50. What agency was most helpful to you?

51. What person was most helpful to you?

Do you have any of the following health or physical difficulties now?

52. Heart-lung \_\_\_\_\_ Yes \_\_\_\_\_ No

53. Vision-hearing \_\_\_\_\_ Yes \_\_\_\_\_ No

54. Cancer \_\_\_\_\_ Yes \_\_\_\_\_ No

55. Epilepsy \_\_\_\_\_ Yes \_\_\_\_\_ No

56. Retardation \_\_\_\_\_ Yes \_\_\_\_\_ No

Please indicate by checking all appropriate boxes for areas of training you received. If you received no training in an area, do not check any boxes for that area.

|                 | Before 21<br>at CCD | Before 21<br>not at CCD | After<br>21 | Receiving<br>Now |
|-----------------|---------------------|-------------------------|-------------|------------------|
| Walking         |                     |                         |             |                  |
| Feeding         |                     |                         |             |                  |
| Dressing        |                     |                         |             |                  |
| Toileting       |                     |                         |             |                  |
| Grooming        |                     |                         |             |                  |
| Speech          |                     |                         |             |                  |
| Menstrual Care  |                     |                         |             |                  |
| Sex Education   |                     |                         |             |                  |
| Family Planning |                     |                         |             |                  |
| Other           |                     |                         |             |                  |

\_\_\_ 38. Can you get to places in your community?

0. Yes      1. No      9. Unknown

\_\_\_ 39. Can you type?

0. Yes      1. No      9. Unknown

\_\_\_ 40. Do you have plans for your future?

0. Yes (please specify below)      1. No      9. Unknown

19. What is the basis of your current financial support

0. Family supports entirely
1. Family supports with outside supplement (SSI, Medicare, Food Stamps, etc.)
2. Receives outside support entirely (SSI, Medicare, Food Stamps, etc.)
3. Supports self with outside supplement (SSI, Medicare, Food stamps, etc.)
4. Supports self with family supplement
5. Is completely self-supporting
9. Unknown

20. Your money handling ability

0. Can handle all, credit, checking or savings, and cash
1. Can handle cash, checking or savings only
2. Need others to help budget
3. Realize money has value but cannot understand amounts
4. Has no idea of the value or use of money
9. Unknown

Please indicate by checking all appropriate boxes for areas of service you received. If you received no service in an area, do not check any box for that area.

|                  | Before 21<br>at CCD | Before 21<br>not at CCD | After<br>21 | Receiving<br>Now |
|------------------|---------------------|-------------------------|-------------|------------------|
| 21. Vision-eyes  |                     |                         |             |                  |
| 22. Hearing-ears |                     |                         |             |                  |
| 23. Dental-teeth |                     |                         |             |                  |
| 24. Surgery      |                     |                         |             |                  |
| 25. Bracing      |                     |                         |             |                  |
| 26. Counseling   |                     |                         |             |                  |
| 27. Other        |                     |                         |             |                  |

59. Are you receiving counselling? \_\_\_\_\_ Yes \_\_\_\_\_ No

60. Are you married? \_\_\_\_\_ Yes \_\_\_\_\_ No

If married, how many children? \_\_\_\_\_

61. Are you generally

\_\_\_\_\_ Happy

\_\_\_\_\_ Neutral

\_\_\_\_\_ Sad

62. If appropriate, is your caretaker generally

\_\_\_\_\_ Happy

\_\_\_\_\_ Neutral

\_\_\_\_\_ Sad