6-1978

A research project on the developmentally disabled adult

Randi Lynn Hillinger
Portland State University

Recommended Citation

Hillinger, Randi Lynn, "A research project on the developmentally disabled adult" (1978). *Dissertations and Theses.* Paper 2685.
https://doi.org/10.15760/etd.2681

A RESEARCH PROJECT ON THE DEVELOPMENTALLY DISABLED ADULT

by

RANDI LYNN HILLINGER

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

MASTER OF SOCIAL WORK

Portland State University

1978

TO THE OFFICE OF GRADUATE STUDIES AND RESEARCH:

The Advisor approves the practicum of Randi Lynn Hillinger presented June 1978.

Jack R. Hegrenes, Ph.D., Advisor

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER I

INTRODUCTION

In 1963, Congress approved the Mental Retardation Facilities and Community Mental Health Centers Construction Act. This legislation authorized $50 million to be spent on research, training, education, and services development for the mentally ill and retarded. Since that time, the Developmental Disabilities Services and Facilities Construction Act of 1970 was passed.

Recent legislation to meet the needs of the developmentally disabled has primarily been concerned with children and adolescents and vocational rehabilitation. Little attention has been given to the developmentally disabled adult or aged person. In 1976, however, the Department of Health, Education, and Welfare, through the Office of Developmental Disabilities, accepted proposals for projects intending to study this neglected population. Consequently, five University-affiliated facilities (UAF) were the recipients of grants to study the extent and needs of the developmentally disabled population.

A project titled "UAF Training Project about Aging and the Aged Developmentally Disabled at the University of Oregon Health Sciences Center" was awarded to Leroy O.

Carlson, M.D., of the Crippled Children's Division (CCD) at the University of Oregon Health Sciences Center. The amount of the grant was $50,000 per year for three years ($150,000).

Constance Hanf, Ph.D., and John Keiter, Ph.D., are the project's principal investigators. The author of this paper, a candidate for the Master of Social Work Degree, was a member of the Aged Developmentally Disabled Grant Team from January to June 1978.

BACKGROUND AND NEED FOR THE AGED DEVELOPMENTALLY DISABLED GRANT

Section 401(1) of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 defined developmental disability as

> . . . persons whose disability originated before the individual attained age 18, has continued or can be expected to continue indefinitely, constitutes a substantial handicap to the individual and is due to mental retardation, cerebral palsy or epilepsy.

No comprehensive data base concerning the adult developmentally disabled (ADD) population is available. The absence of theoretical formulations about aging, and particularly the aging ADD, make it difficult for service providers or professionals to incorporate a conceptual framework into their work. Communication between agencies and individuals appears rare and the opinions of ADDs themselves are seldom sought when their needs are identified (Hanf, 1977).

In the Program Narrative, Dr. Carlson described the pilot programs for the developmentally disabled (DD) older adult that had been developed and operated by CCD for approximately six years.

In 1970, the training staff developed a comprehensive program geared to meet the needs of older handicapped adults in the community. The program included seminars focusing on needs and resources, interdisciplinary clinics for evaluation and consultation, and field visits to group and nursing homes plus activity and workshop settings.

The interdisciplinary clinics evaluated one client each week who had been previously contacted by a DD coordinator. The staff made an assessment of the client's particular needs and follow-up visits were made to facilitate implementation of recommendations.

This pilot project provided a model for training and service in regard to the older DD person and developed professional interest. Expansion of the program would add to the knowledge and experience of the staff and make it possible to develop and disseminate information on a topic which is currently receiving little attention.

The project objectives of the Adult Developmentally Disabled Grant are:

(1) to develop a model curriculum about older DD individuals for professional and paraprofessional training purposes at this UAF;

(2) to conduct a comprehensive survey of the needs of the aging DD population primarily in Oregon and secondarily in Washington, Idaho, and Alaska;
(3) to provide expertise at this to administrators and supervisors concerning the needs and problems of the aging DD population; and
(4) to expand the pilot project on the older developmentally disabled population (Carlson, 1976).

To accomplish these objectives, the Aged Developmentally Disabled Grant Team undertook a variety of projects. This team is multidisciplinary and consists of representatives from medicine, psychology, social work, education, occupational and physical therapy.

ACCOMPLISHMENTS IN THE FIRST YEAR OF THE ADD PROJECT

The ADD Grant was funded for the period of October 1, 1976 to October 1, 1977 with yearly renewals. The project staff were hired in January 1977 and all projected goals for the first year were accomplished.

During the first three months the curriculum focused on a summer program, tutorial training, and didactic presentations. The ADD Grant Team sponsored "The Adult Developmentally Disabled in Oregon in 1977," a series of case evaluations, field experiences, discussions, and seminars. Two graduate social work students were trained in the use of two survey instruments.

To conduct a comprehensive survey of the needs of the aging DD population, three survey instruments were developed and used: (1) a simple demographic questionnaire to determine the size of the population; (2) a questionnaire to be given to workshops to gain understanding about sheltered employment; and (3) a comprehensive questionnaire designed to collect more intensive data about individual ADDs, particularly their current status (e.g., employment, social activities, dental and health condition, residence, finances, etc.).

The demographic questionnaire has been used widely in Oregon (in ten counties and both the state's institutions). These data are being compiled. The workshop questionnaire has been used in four local centers. One workshop would not cooperate, giving confidentiality concerns as the reason. The forty-seven-item comprehensive survey questionnaire has been used at the United Cerebral Palsy (UCP) Workshop, Clackamas County DD Coordinator's files.

The ADD Team determined that the population studied in this sample could be limited to all aging DD persons over age forty and cerebral palsied individuals from age twenty-one to age forty.

Accomplishments in consultation to the community in the first year of the project included: (1) training students and staff in problems, issues, and needs of the aging DD population; (2) assessment and management procedures which were used with a profoundly retarded young woman; and (3) consultation concerning the referral and placement of a fifty-two-year-old profoundly retarded male.

CHAPTER II

THE SECOND YEAR OF THE AGED DEVELOPMENTALLY DISABLED PROJECT

Objectives for the second year of the ADD project include:

(1) completing data analyses of results of the demographic and comprehensive surveys;

(2) providing more multidisciplinary clinic evaluations of the aging DD population and offering consultations with ongoing staff; and

(3) continuation of the summer adult DD program.

Objectives for the development of curricula for training professionals include: making audiovisual materials and writing a set of papers that will provide input to the formal curriculum. This material will be based on the information that was gathered in the questionnaire and survey.

The state-wide demographic data collection of the adult DD population was completed by March 1978. Statistics from this survey were studied for their contribution to the papers and reports being developed on current issues and problems concerning adult DDs. Numerous presentations have been made to groups and conferences.

In January 1978, formal work on the development of curriculum for training professionals began. The author of this paper joined the ADD Grant Team at this time. It was decided that case studies would be used and data-based issues would determine the general approach. Material from videotaped individual interviews of adult DDs would be used to support the issues and be utilized wherever possible. An integrated perspective would be achieved by focusing on life-span development.

A special training film on aging and cerebral palsy is being made. An orthopedic surgeon who consulted at the Crippled Children's Division for many years had regularly filmed each child seen by him in the cerebral palsy clinic. The availability of these early films made possible current videotape comparing of the status of these individuals as children and as adults.

Objectives continue to be met with papers, articles, and tutorial education with multidisciplinary students, trainees, interns, and residents who are affiliated with this UAF. Further, the interdisciplinary clinics have continued to participate in the diagnosis and evaluation of DD adults.

DISCUSSION OF CEREBRAL PALSY

As a member of the ADD Grant Team, the author participated in projects concerned primarily with the cerebral population. To gain a better understanding of the individuals who would be interviewed and the population to be studied, it was necessary to investigate the facts about cerebral palsy.

Cerebral palsy (CP) is the term describing a group of permanently disabling symptoms resulting from some injury or damage to the brain. The result is loss or impairment of control over voluntary muscles. Difficulty in motor control involves poor balance, awkward or spastic movements, irregular gait, tightness of the muscles, and speech problems.

The relationship CP has to the brain usually results in other handicaps as well. Mental retardation affects 50-75 percent of CP children and adults and 70 percent have especially poor speech. Convulsions and hearing impairments are also common. Visual disorders include strabismus (one or both eyes turning in) or general difficulty with vision. Dental abnormalities such as irregular positioning of teeth and tendency toward many cavities result from insufficient build-up of tooth enamel during prenatal development. An arm or leg may be shortened due to poor growth. A curved back may result from the tilting of one's hip in an effort to compensate for a shortened leg. Excessive pull of muscles around joints may cause abnormal and permanent positioning of the elbow, ankle, or wrist.

CP children with normal or above average intelligence may still have conceptual and perceptual problems or disabilities regarding language development. Difficulty adapting to stress and anxiety may also result from brain damage.

The five major types of CP are: (1) spasticity (muscle spasms which is the most common motor symptom); (2) athetosis (slow, constant, twisting contortions of the arms and legs); (3) ataxia (lack of muscular coordination causing one to walk as if in a drunken state); (4) tremor (involuntary shaking or trembling); and (5) rigidity (stiff, slow cont of muscles) (National Health Education Committee, Inc.).

All four extremities may be invoved in motor difficulties or only an arm or leg. The most common disability, hemiplegia, involves the extremities on one side of the body. Symptoms for one out of seven people afflicted by CP are limited to clumsiness which may be barely noticeable (UCP, New York, New York). Those more severely handicapped may require a wheelchair and assistance with basic necessities of daily living.

Main causes of CP include:

(1) Prematurity
(2) Anoxia (difficulty of the newborn in breathing)
(3) Complications of labor or delivery
(4) Jaundice (yellowing of the skin) of the newborn due to Rh incompatability or incompatabilities of other blood types
(5) Infections of the brain, such as meningitis or encephalitis. Occasionally an inflamation of the

brain may occur after routine cases of measles or German measles and other viral diseases.

(6) Poisonings, such as lead

(7) Accidents resulting in head trauma

In over 1/3 of those individuals affected at birth, the cause is unknown (UCP, New York, New York, as quoted by National Health Education Committee, Inc.).

ONE RESULT OF THE DEMOGRAPHIC SURVEY

Records of over seven hundred individuals with cerebral palsy (CP) who had been followed in clinics at the Crippled Children's Division (CCD) until reaching twenty-one years of age are available to the ADD project. These charts, which cover a thirty-year time span, contain detailed information on medical development and some social and educational data. To incorporate this historical information into a study of service delivery and life-span development of CPs, the twenty-one to forty age group (as mentioned previously) were added to the adult aging sample.

As a result of the demographic survey completed by the ADD Team during the first year of this project, it is now possible to better identify the total CP population of twenty-two of the thirty-four counties in Oregon (the survey also included the mentally retarded population but that will not be addressed by the author). Table I shows the total CP population identified by the survey in both community and institutional settings (Hanf and Keiter, 1977).

TABLE I

TOTAL CEREBRAL PALSY POPULATION IDENTIFIED BY DEMOGRAPHIC SURVEY

Community or Institution	21-40 Yrs.	41-60 Yrs.	61+ Yrs.
Community	105	29	5
Institution	142	28	4

SOURCE: Hanf and Keiter, 1977.

The CP population showed a rapid decline as age increased. It was found that 33 percent of the CPs in the community between the ages of twenty-one and forty disappear between the ages of forty-one and sixty. After age sixty-one, the rate of decline is even higher. Only 17 percent of the CPs remain. The pattern is relatively similar for institutionalized populations.

According to Hanf and Keiter, the rate of this decline does not follow that of the normal population. The causes of this disappearance (or death) pattern must be understood if the needs of the population are to be determined. Life span may be shorter. However, what are the causes of death and could they be prevented with attention at an early age? Are modes of treatment and early intervention contributing factors? Of what significance is severity of condition and neglect?

In an effort to begin answering these questions, the ADD Grant Team dealt first with the seven hundred CPs who had received services at CCD over the past thirty years.

The author compiled a list of those individuals who lived in the Portland area at the time they were seen at CCD. Current addresses and telephone numbers were located, when possible, from the Portland telephone directory. Names of patients and their parents were looked up in an attempt to locate the CP individual. Approximately one-third of all past Portland residents seen at the CCD CP Clinic were still listed in the directory. Those living outside the Portland area must still be located. All will soon be contacted.

The author designed and completed cards on each of the seven hundred past CCD patients which will be used in data collection. Recorded information included: name, diagnosis, parents' names, birth date, address, and date of last contact with CCD. Information yet to be obtained includes: (1) current residence and living situation (i.e., independent, semi-independent, or dependent); (2) marital status; (3) occupation; and (4) (if applicable) date and cause of death, autopsy report (if performed), and death certificate number. Data will be investigated with assistance from the Bureau of Statistics.

INTERVIEWING PROCESS

The author participated in the interviewing process with four graduate social work students and the two principal investigators on the ADD Grant Team. The purpose of the interviews was: (1) to develop material for a training film on CP adults; (2) to compare the status of past CCD patients as children and as adults; (3) to further examine the rapid decline of the CP population as age increased; and (4) to further investigate services received.

Seven of the CP individuals who had been seen at CCD by the orthopedist mentioned earlier were contacted and agreed to participate in the interviews. Two would be bringing their wives. It was explained that an effort was being made to evaluate the services they received at CCD and, if needed, improve services for those children who could be seen in the future.

The questionnaire used for the interviews (see Appendix) (Hanf and Keiter, 1977) was based on the descriptive survey instrument already referred to. That instrument was revised by the Team for a follow-up questionnaire on cerebral palsied adults.

It included questions concerning current status (e.g., financial support, work and living situation, social activity, education), and services received in the past and present. A main focus was on the individual's own perspective about the services he/she received as a child at CCD.

The interviewers were responsible for reviewing the charts (if available) of the individuals to whom they would be talking and familiarizing themselves with the questionnaire.

Four adults with cerebral palsy were present on the first day of interviewing at CCD. There were also four interviewers which made it possible to establish rapport between interviewer and interviewee before the videotaping began. Each interview was conducted by one person while another recorded answers. It was very helpful to have two people interpreting language which was difficult to understand. The interviews lasted between thirty and forty-five minutes.

Following the ADD Team's interview, the orthopedist who knew these individuals as children interviewed them. His interest was in physiological status and long-term effects of surgery and bracing. Films of walking and standing were taken so orthopedic development could be compared to the early-age films.

Second and third groups of interviews took place at the United Cerebral Palsy Office in Portland. The format utilizing one lead interviewer and a recorder was continued. In some cases, the input of all six ADD Team members present was necessary to interpret speech. A final interview took place at CCD and again the orthopedist participated.

DISCUSSION OF RESULTS OF THE INTERVIEWS

These nine interviews are by no means a random sample and thus the information obtained cannot be considered representative of the entire adult CP population. The issues raised, however, are worthy of considerable attention and further investigation. The main focus of this discussion will be on these issues.

Five males and four females, ranging in age from twenty-four to forty-six, were interviewed. Two couples (both CP) participated in the process, but one woman did not want films or information about her included in the study. (Eight participants signed release of information forms.)

Services Received by Those Interviewed

Educational. Six of the seven past CCD patients attended the Holladay Center School (for handicapped children up to fifteen years of age) and seeemd to have maintained positive feelings about that experience. They received most of their physical and occupational therapy there and four people cited the school as the most helpful agency to them. One woman said that the therapists and her foster mother worked together to provide emotional support. Another person felt Holladay was "pretty helpful" and improved over the years.

Surgical-Medical. Questions concerning braces received from CCD in childhood elicited emotional responses. A twenty-four-year-old woman (spastic paraplegic) who is now in a wheelchair stated that she "could not stand the braces" and felt they were a waste of time. She said she would have preferred having the freedom to crawl and use her muscles. A man pointed out that the braces broke easily and were "a headache." Another person said that braces hurt and pinched so much that he finally refused to wear them and decided "I would just work much harder by myself." This thirty-three-year-old man is a functional walker, although he falls occasionally. Putting the braces on was considered the worst part for a man (spastic hemiplegic) who is wheelchair-bound today. "They may have helped," he said, "but they were too heavy to move around in anyway." A young woman named the braces as the least helpful or important assistance she had received in her life.

Many surgeries were performed on the seven individuals at CCD with varied results. Two people believed their hip operations were helpful. One of these men, now in a wheelchair, underwent surgery on his arm. This seemed to have produced little change. A thirty-two-year-old spastic quadriplegic man had extensive surgeries which eventually enabled him to stand in braces, but not to walk functionally. He was reported to have experienced "emotional setbacks" at the time of his operations and is confined to a wheelchair today. A thirty-six-year-old man and a thirty-two-year-old man who walk functionally felt that their surgeries were helpful. The older of the two underwent eight separate operations in his lifetime and is now able to live independently with his wife.

Currently, surgery and bracing appear by professionals to be important and necessary for every CP child.

Documentation in patient charts suggests that these treatments greatly improved the person's functioning. For some clients, however, braces and casts were viewed as tortuous restrictions on childhood which did not keep them out of wheelchairs as young adults. It is often difficult to predict the outcome of treatments, but whether to attempt them rarely seems questioned. Are extensive operations enabling one to better straighten his legs, but not walk, really necessary in all cases?

It is possible that in retrospect, those individuals who endured treatments which were not very successful would rather have had none. For them, the pain was not worthwhile. For those who can walk, however, "it was worth it." When faced with the chance for improvement, it is possible that many people would be willing to take the risk. Only the individual involved can decide if any slight change for the better is worth the suffering which may precede it. In the cases of most children, it is a parent or doctor who makes that decision. The effect of surgery or therapy must be carefully assessed before it takes place.

Although one can argue that a child has no understanding of the importance of medical procedures, basic explanations and being "treated as a person" can certainly take place. Commenting on his childhood treatment, one man stated, "They never asked me about my pain . . . what was happening inside me."

Physical Therapy and Occupational Therapy. Most respondents felt that both physical and occupational therapy were very helpful. One man remembered the patience and understanding of a therapist at Holladay Center, and another felt that help with walking was the most important assistance he had received. Positive feelings about these therapies may stem from the fact that someone worked with them as opposed to having had something done to them.

In addition to the benefits of individualized treatment, a patient can see the reasons for occupational and physical therapy and can usually see results. A man said that learning to dress himself was extremely difficult, but he remembered understanding the importance of the task. Many felt that physical therapy was one of the only things they are not getting now and would like to have. It was also mentioned as something they wished they had more of as children.

Independence. When asked what they would tell a parent who had a child with CP, three people responded, "Let him do things for himself." One man's parents helped him with eating, but "I didn't really learn until they made me do it myself." When asked what help he wished he would have had, another man stated, "People letting me do more things for myself more often."

In The Disabled and Their Parents, Maria French described the limitations others placed on her because of her cerebral palsy. She remembered being told to "get someone else to help" because everything took her "too long" to do. She stated,

> My answer to these attitudes was a line from a poem I read when I was four: "_Querer es poder_" ("To want is to be able to do"). And so I _did_ . . . This was one of the subtle modes with which people through their concern, began to define my capabilities as _they_ saw them. They ignored the necessity for me to have the freedom to fail (Buscaglia, 1975, p. 237).

These comments point to an important observation: people tend to try to help the handicapped too much. It is frustrating to allow someone to clumsily perform a task that would be simple for someone else. The very situation, however, fosters independence and confidence in the disabled person. Many individuals are unfairly robbed in this way of the chance to develop to their fullest potential.

Socialization. According to Bud Thoune, Director of United Cerebral Palsy (UCP) Center of Oregon, the cause for poor socialization among CPs is that parents often stand in the way of advances. Over-protective attitudes prevent people from learning that they have the ability to adapt to their disabilities and problems. When a parent or service agency does all the work, feelings and skills that will lead to independent or semi-independent living are not developed. Thoune believes that "no one should do any more than that person does to help themselves" (Thoune, 1978).

A thirty-three-year-old man lives with his parents and works in the UCP sheltered workshop. His mother handles all his finances. He uses a wheelchair and does not go places in the community unless his parents take him. As an only child, his parents devoted their lives to helping him, but their over-protection may have prevented this man from gaining independence and self-confidence. What will occur when his parents die?

Nancy Wesselman Deibler, coordinator of youth activities for UCP, Inc., points out that,

> The disabled young adult who is physically dependent on his/her parents for transportation or mobility . . . lacks the opportunity for experimentation by which one defines oneself. Opportunities must be made available to young adults for getting out of the house, away from parents . . . They must have the freedom to experiment, to try new behaviors and to find out what they like and dislike.

According to another man, "Someone should encourage CPs to get out and associate with lots of people." He was proud to have been the first handicapped person in his public high school and said people allowed him to do things for himself. Now married and employed in the community, he stated that he feels more "normal" around people who are not handicapped.

Social interaction of those interviewed was confined, for the most part, to a spouse, roommate, or UCP activity. Few respondents had many friends and most only interacted with family members occasionally. One man went bowling regularly with his wife and one friend. Three people were very involved with church or religious groups which comprised their social activities.

One Disabled Couple as Parents

An important issue was raised by a CP couple who live together in an apartment in southeast Portland. After having received sex education and counseling, they decided to have a child.

Bill and Sue are employed at a UCP workshop with income supplemented by social security and SSI. Bill is able to walk unassisted and travels on a motorized bicycle to do shopping and other chores. Sue uses a walker. They are proud that they have lived independently for the last five years and their love for each other is very evident.

Bill has difficulty with numbness in his right arm, uses a hearing aid, and has speech which is difficult to understand. Sue's speech is generally less understandable and she has use of both arms and hands.

Having a child and taking care of her for almost two years was difficult but extremely satisfying for Sue. She proudly showed a picture of their daughter and was eager to talk about her. She nursed the child as an infant and later obtained a helper in the home. When Sue decided to go back to work at UCP, a full-time babysitter was employed. When the child started walking, the parents felt that foster placement was necessary because they could no longer keep up with her. They were able to visit her frequently.

Sue sought help from the Children's Services Division (CSD). The caseworker assigned to the family believed that the child would be harmed if she was not taken from their custody. The staff at UCP and a pediatrician from Kaiser Hospital were convinced that Sue and Bill would eventually give their daughter up for adoption because they wanted what was best for her. The caseworker and CSD felt that the girl was in an inadequate environment and threatened to involve the courts if she was not given up for adoption <u>immediately</u>.

The child was adopted by a family in Portland (the foster parents) and Bill and Sue are allowed to visit her every couple of months. They were not, however, given the opportunity to make the decision for themselves. The separation has been extremely painful for them.

Without risking harm to the child, the couple was able to experience having and raising a daughter. Sue has the traditional role of a woman to identify with, which was extremely beneficial to her. However, when people have children they cannot care for, the responsibility falls on the government. The issue is this: are physically handicapped adults to be prohibited from conceiving children they will be unable to care for? In a time when the disabled are finally being seen as people with rights, the issue becomes more emotionally charged. The answer to the question is not easily found and there are arguments and facts which must be considered.

A child needs the physical care and stimulation handicapped parents may be unable to provide. Bill and Sue's caseworker reported seeing a spastic movement which caused their child to fall to the floor. Moreover, the added expense of children for those on a fixed income may be difficult to handle. It may be very beneficial and rewarding for disabled couples to be parents. For the child, however, the confusion of adjusting to new parents or a variety of living situations is not likely to be beneficial.

At present, any American with the physical ability can have children. Handicapped individuals, just as many other adults, have raised healthy and happy children. Children with a multitude of problems, on the other hand, have been raised by physically normal parents. To deny one the privilege of having children is taking away a basic human right.

The physically disabled must be respected as human beings. It is important for disabled couples who want children to have straightforward and supportive counseling to examine all aspects of parenthood. A university professor in the field of special education points out that marriages for the handicapped are usually more successful without the additional strain of children (Buscaglia, 1975). He suggests that individuals expose themselves to situations involving children (e.g., volunteering in a nursery or day care center) for several weeks to gain full appreciation of all the implications of having children.

The opinion of a genetic counselor to determine the hereditary components of a disability is vital. Most cerebral palsy, as in the case of Bill and Sue, is not hereditary. Other disabilities are. It is certainly likely that a handicapped adult would decide not to risk having a child with the same disability he or she had.

Physically disabled individuals are certainly capable of making intelligent decisions. Bill and Sue's feelings were not ever considered by CSD and they were not trusted to do what was best for their child. Even though everybody associated with them was sure they would release the girl for adoption, the decision was made <u>for</u> them by the state.

Education and counseling are valid ways of addressing the question of disabled adults having children. People often imagine the joys of loving and raising a child without realizing or accepting the difficulties involved. Some individuals may find they do not relate well to children, while others may become aware of how physically <u>and</u> emotionally demanding a child can be. Handicapped couples may reconsider becoming parents when the facts are made available in a non-threatening manner. People can be educated and guided, but they must be free to make their own decisions.

CHAPTER III

CASE STUDY: LIFE SPAN DEVELOPMENT

The following case study traces the development of an individual the author interviewed.

HISTORY

Rick was born in 1946 two months premature and weighed three pounds. His mother reported "family problems during the pregnancy." He was kept in an incubator and later received medication for anemia for one year. His eyes were crossed at birth.

At age two, Rick's mother noticed retarded development. He was brought to Shriner's Hospital when he was three years old because he could not walk and stood only on his toes when held up. There were no convulsions noted but he could say no words. He drooled constantly, had no bowel or bladder control, and cried uncontrollably when disturbed. The diagnosis was spastic paraplegia with probable mental deficiency. The mother was advised to consult a family physician and psychiatrist regarding Rick's mentality.

When Rick was four years old he could say one word: "Mama." He could crawl and express needs through motions and had general spasticity of the lower extremities. By the age of four and one-half, Rick could use both arms fairly well and tried to walk with assistance.

At age five, Rick started kindergarten at the Hospital School in Eugene, Oregon. He was described as quite negative when corrected and did not know how to work in a group. His attention span was short and he seemed to fall more than he used to. Speech was barely understandable and he used his own jargon to speak in sentences.

Due to family problems, Rick was placed in a foster home. His foster mother described his behavior as generally negative. He could feed himself, but did so quite sloppily. He was independent in toileting and was reported to imitate a two-year-old child in the home to get attention.

Doctors noted satisfactory progress in speech and physiotherapy. Heel cords were tight because Rick walked on his toes, and the continuation of physical therapy was recommended. It was also suggested that he be discharged to the public school system. Rick had learned color and number concepts by the age of six and had quite a bit of understandable language. Speech therapy, it was believed, could be carried out by his mother (with whom he was living again).

In 1954, the family moved to Portland so Rick could attend Grant School. He was seen at Crippled Children's Division at the University or Oregon Medical School. At their Cerebral Palsy Clinic, it was learned that Rick had remained in the home between the ages of five and seven with no outside treatment. He immediately underwent surgery to correct the muscle imbalance that caused him to look cross-eyed. His performance at Grant School was fair and he was described as a healthy-looking, well-developed boy who walked unsteadily on his toes with a broad gait. He held his head forward and squinted but seemed to be able to identify objects at a distance. Upper extremities were spastic but without marked deformities.

Ricks's parents were separated on and off many times due to his father's serious drinking problem. His mother was anxious for any help Rick was able to get, yet it was the assistance of a public health nurse that got Rick to the Cerebral Palsy Clinic. Rick's father was very strict about disciplining his son and it is likely that tension at home greatly affected Rick. His mother noted excessive bed-wetting when there was added pressure at home or at school.

It was recommended that Rick have psychological and speech testing at CCD and begin regular physical therapy. Parents were told to carry out exercises at home for Rick's hip extension and dorsiflexion of the feet. Diagnosis was spastic quadriplegia, moderate. Psychological examinations showed marked intellectual retardation and a speech and hearing team diagnosed severe dysarthria. Speech was mostly unintelligible but vocabulary appeared near normal.

At age eight Rick started school at the Holladay Center and did very well. The Cerebral Palsy Clinic noted that his gait remained the same and danger of muscle contracture was not indicated. For that reason, physical therapy (PT) was discontinued in the summer to be resumed when school started again in the fall. Around this time, Rick's parents were divorced and it was reported that the household was much happier.

Rick continued at Holladay Center. He had improved, but gravity muscles remained spastic. It was doubtful whether the improvement was due to PT or simply a maturation process, so PT was discontinued temporarily. He grew considerably by age ten and the CP Clinic noted that he tightened up, walked on his toes, and carried his left arm more flexed than the right. The absence of PT for nine months appeared to have no marked difference in his broad gait.

Little progress was made learning to read or do other academic work. At age ten and one-half he could read at a first grade level and was described as happy and cooperative. Progress physically had been almost nonexistent in the last two years. Drug therapy (Disipal) was started at this time and he received weighted shoes to lower the center of gravity. After few improvements and no side effects were noted with the drug, the dosage was increased to its limit (50 mlg. three times daily) and Rick's condition improved.

Rick was fitted with short leg braces at age eleven and PT began again. The braces proved not to be effective and his condition remained the same even when medication was discontinued. When he was twelve PT was discontinued for a year an one-half. At that time (age thirteen and one-half) the staff at Holladay Center saw no decrease in function but Rick experienced fainting spells. He began to fall more frequently. Nothing was done about these incidents at the time.

Progress had been satisfactory in speech therapy and Rick had fairly understandable speech and sentence structure. He was now fifteen which made it his last year at Holladay Center. He was assigned a home teacher and was to begin a workshop at UCP. His mother remarried around this time.

Two years later, Rick was in an automobile accident and suffered a dislocation and fracture of the right femur. Because of his spasticity and the stability of the fracture fragment, it was elected not to openly repair the injury. He had equinus deformities of both heels and flexation deformities of both knees and hips and surgery might impair prior functioning. PT began following six weeks of traction. After two months he could ambulate satisfactorily with a walker.

Rick was examined at the CP Clinic for general progress when he was nineteen years old. He was able to walk, still on his toes, and had an extremely tight heel cord on the right side. Heel cord lengthening was recommended and his mother was told that any surgery was speculative. He was put in two short leg casts to see if they could be tolerated. He was able to walk fairly well although he bent his knees so he could walk on his toes. The surgery was done and after two months in casts, the equinus had been overcome. It was difficult for Rick to control his leg, but after one year he was able to walk with his heels down. He was seen for the last time by CCD when he was twenty years old.

Current Status

Rick was referred to the CP Clinic at age thirty-two for an interdisciplinary evaluation in collaboration with the adult program. The focus of the evaluation was to assess his health state and level of adaption to independent living.

Rick lives alone in a well-kept and efficient apartment in Portland. He is currently unemployed and receives SSI and welfare. He has been living independent from his family for five or six years and said he was just tired of living at home. When asked if anyone encouraged him to move, he said that everyone was rather surprised and "I just did it by myself." He stated that he would not move back because he enjoys living alone. "I wanted to learn more and I did!" Rick reported infrequent contact with his family and indicated having friends through the Divine Light Mission. He reported doing a large amount of walking and uses public transportation to "get around town," to do shopping, and visit health care facilities. He is treated weekly by an acupuncturist and said his balance has improved.

Health Condition and Functional Abilities. A medical examination revealed Rick to be a healthy man with obvious cerebral palsy, mixed, with athetosis and spasticity of all four extremities. He has tightness in the joints, walks on his toes, and has a balance problem with occasional falling. Language is halting but easy to understand. There is considerable facial grimacing and occasional drooling.

Results of an assessment by Occupational Therapy revealed more than adequate abilities to respond to the demands of daily life for gross motor activity. Major strengths were seen as his pace of locomotion and endurance. Rick has adequate hand function ability.

A nutritional assessment indicated that despite low intake of protein, Rick's diet is not inadequate and he is currently satisfied with his weight. He supplements his diet on the advice of a naturopath, with vitamins and bee pollen and considers himself a vegetarian.

Recreational activities center around the Divine Light Mission. He is more often a passive member of that group and has traveled extensively with them. He attends the group's functions every evening and likes the people he associates with.

Educational and Intellectual Functioning. Rick has good practical skills and functions overall at mid-grade levels. Despite some difficulties with time concepts and perception (possibly a reflection of life style), Rick is able to apply skills at a concrete level and if necessary or interested, is capable of increasing his educational achievement. He expressed no interest in pursuing further education at present. Speech is intelligible in spite of articulation errors and small vocabulary.

Results of a psychological assessment found Rick functioning within the borderline range of intellectual abilities, although it was difficult to determine the reliability of this estimate due to his disability. His strengths were in tasks measuring common sense, practical judgment, and the ability for abstract thinking.

Life Perspective. Rick shows good social judgment, motivation, and has developed strength and coping skills. He has a basic life philosophy of "one day at a time." His very positive and present-oriented outlook may reflect his exposure to certain philosophies (such as those of the Divine Light Mission), but his life perspective seems to provide him with the strength to continue.

Summary. In summary, Rick is a thirty-two-year-old mixed CP male who had an extensive history of care through the facilities of CCD and other resources. His adjustment to his handicap and to independent living appear to have been satisfactory and he has shown initiative and developed coping skills. He is presently in good health and is capable of pursuing vocational and personal growth and development.

The consensus of those present at the interdisciplinary evaluation recommended that Rick: (1) work on developing more of a future orientation through involvement with community resources such as Vocational Rehabilitation or CETA. This would allow him to investigate alternative opportunities, develop new interests, and meet other people; (2) consider CCD as an "advocate" for his continued pursuit of educational or vocational options; and (3) contact CCD if necessary to confirm referral to local resources. The recommendations were discussed with Rick and he was eager for feedback and other information. He indicated a need "to think" about all the opportunities he could encounter.

CHAPTER IV

CONCLUSIONS

Through the efforts of the ADD Grant Team, the long neglected and seldom researched adult DD population is being studied. The size of the population in Oregon has been identified and intensive data about the current status of individual ADDs has been collected. A comprehensive survey provided information about sheltered workshops and employment for the handicapped adult. Summer programs for the adult DD, tutorial training, didactic presentations, and consultations have taken place. Curriculum about the older DD individual has been developed and will continue to be developed for the training of professionals and paraprofessionals.

The author gained valuable experience as a participant in this project. Research on the ADD population provided the background necessary to be a member of the interdisciplinary team. It was possible to develop a better understanding of the many facets of a grant such as this and directly experience the satisfaction and frustration that accompany it. Organization of data collected on the demographic survey was time-consuming yet rewarding because of its importance to the Team's work. Knowledge of those procedures is important in any research project.

The interviewing process proved to be extremely educational and gratifying experience. Initial information gathered on CP stimulated interest in a previously unfamiliar group of people. Interaction with these adults encouraged awareness of problems and issues faced by physically handicapped adults. Historical information on the lives of CPs made it possible to examine services received by these individuals from a new perspective and to consider alternatives. The feelings and emotions conveyed when asked about the past will not be forgotten by any of the interviewers present. Interpreting the language of those with speech problems, and the patience with which their words were repeated will long be remembered.

The variety of projects undertaken by the ADD Grant Team have brought a better understanding of needs and issues concerning the developmentally disabled adult. Their objectives have been and will continue to be met.

REFERENCES

REFERENCES

Buscaglia, Leo. The Disabled and Their Parents: A Counseling Challenge. New Jersey: Charles B. Slack, Inc., 1975.

Carlson, Leroy. Program Narrative. Portland, Ore.: University of Oregon Health Sciences Center, 1976.

________. Project Progress Report. Portland, Ore.: University of Oregon Health Sciences Center, 1977.

Deibler, Nancy Wesselman. "Service Needs and Problems of Developmentally Disabled Young Adults." DD Themes and Issues (January 1977). Chapel Hill, N.C.: University of North Carolina Printing Department.

Denhoff, Eric, and Robenault, Isabel. Cerebral Palsy and Related Disorders. New York: McGraw-Hill Book Company, Inc., 1960.

Hanf, Constance, and Keiter, John. Aging among Individuals with Developmental Disabilities: A Project of National Significance. Portland, Ore.: University of Oregon Health Sciences Center, 1977.

________. Oregon ADD Population: Getting It Together from a Data Base. Portland, Ore.: University of Oregon Health Sciences Center, 1978.

National Association of Social Workers. The Encyclopedia of Social Work. New York: National Association of Social Workers, 1971.

National Health Education Committee, Inc. New York: United Nations Plaza, 1971.

National Society for Cripple Children and Adults, Inc. Cerebral Palsy. Illinois: October 1971.

Thoune, Bud, Director of United Cerebral Palsy Center of Oregon, Portland, Oregon. Personal interview, May 1978.

United Cerebral Palsy Association, Inc. "Cerebral Palsy." New York.

APPENDIX

APPENDIX

CCD UN: ____-____-____ Date________________

CP Follow-up Questionnaire

______ 1. Your birthdate: ______Month ______Date ______Year

______ 2. Sex: 0. Male 1. Female

______ 3. Deceased: 0. Yes 1. No
Cause of death:____________________________
Date 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
01. With roommate
02. With spouse
03. Supervised apartment
04. With parent or relative
05. Foster home
06. Group home
07. Nursing home or home for aged
08. Halfway house
09. State institution
10. Other: please specify____________________
99. Unknown

______ 6. Where did you receive your education?

0. None
1. Special education classroom
2. Home tutored
3. Regular classroom
9. Unknown

______ 7. Your general education level:

00. None
01. 1st through 4th grades
02. 5th through 8th grades
03. Some high school
04. High school graduate
05. Vocational training school
06. Attended junior college or college
07. Junior college or college graduate
08. Graduate school
09. Other: please specify_____________________
99. Unknown

______ 8. Your current work status:
0. Employed in community
1. Employed in sheltered workshop of activity center
2. Student in vocational training program
3. Student in academic program
4. Houseperson
5. Not employed
6. Retired
9. Unknown

______ 9. Your ability to get about (locomotion)

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

______ 10. Your sense of direction

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

Do you have use of

		0. Full use	1. Some use	2. No use	9. Un-known
______ 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
1. Interacts occasionally
2. Never interacts with others
9. Unknown

______ 17. Your social interaction with others outside your residence

0. Interacts frequently
1. Interacts occasionally
2. Never interacts with others
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

______ 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 <u>all</u> 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 at CCD	Before 21 not at CCD	After 21	Receiving now
21. Vision-eyes				
22. Hearing-ears				
23. Dental-teeth				
24. Surgery				
25. Bracing				
26. Counseling				
27. Other				

Please indicate by checking <u>all</u> 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 at CCD	Before 21 not at CCD	After 21	Receiving now
28. Walking				
29. Feeding				
30. Dressing				
31. Toileting				
32. Grooming				
33. Speech				
34. Menstrual Care				
35. Sex Education				
36. Family Planning				
37. 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

____

____

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 <u>now</u> 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

57. Urinary or bowel ____Yes ____No

58. Other (specify) ______________________________

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