THE FAMILY AS A CONTROL AGENT IN THE LABELING OF THE HANDICAPPED CHILD

By

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ABSTRACT

Adherents of labeling theory have accused the formal agents of control -- those who identify, diagnose, and treat deviance -- of providing the individual with a negative "label" and reinforcing the individual's negative self concept through agency procedures. This research has sought to investigate the "labeling" of handicapped children and specifically the family's role in the labeling process.

Through the comparative analysis of the sequence of negotiations which families of children with different kinds of handicap undertook in the identification, diagnosis, and treatment of the handicapped child, the role of the family in the labeling process was explored and described. Five studies from the literature of the family and the physically deviant child were reviewed and a process model was constructed from the sequences of stages identified in these studies. A sample of twenty-seven parents of fourteen learning disabled teenaged children was non-randomly selected and interviewed. Typescripts from the interviews were coded by units of negotiation. Using these negotiations as units of comparison, the experiences of these parents were compared with those of the parents of the physically handicapped children described in the studies from the literature.

The parents first identified that the child was "different" through evaluating information offered from significant others. When the parents decided to seek help, they sought a diagnostic category from an agent of diagnosis which would explain the child's "different" behavior and would offer hope for remediation. As the parents consulted professionals, they negotiated the meaning of the child's handicap for themselves and therefore for the child. Families were dependent upon the larger society for resources of remediation and for opportunities in which the child could participate meaningfully. Often the deviance of the handicapped child was reinforced by placement in special education classes where he was isolated from his neighborhood peers and normal children. When he entered adolescence this isolation became more critical because the child was unable to establish the peer relationships essential for developing his identity outside of the family setting. Often children developed symptoms of secondary deviance manifest in withdrawal into psychosis, apathy or suicidal episodes.

The learning disabled children were not diagnosed as learning disabled *per se* by professionals because of the ambiguity of the term and the policy on the part of some professionals against "labeling". Instead, parents of these children sought the label for their child by joining the Manitoba Association for Children with Learning Disabilities. By developing expectations for their child as learning

disabled, these parents, not the professionals, "labeled" the child.

It was concluded that labeling the handicapped is a three stage process of 1) identification, 2) diagnosis, and 3) remediation and that deleting the diagnosis only deletes a stage, or a part, in the labeling process. The research supported previous observations that the physically deviant person might benefit from a "label" and the person with resources might seek such a label and the services and exemptions from obligations which the label afforded. Finally it was found that handicapped children were not labeled by the formal agents of diagnosis alone but rather by a negotiated process between parents, professionals, and the community.

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Science has the tools to diagnose a child's disability but has little to offer to help the child and family cope with the problem. A gap exists between the life the child must lead and its effect on the family and the spelling out of the disability.

We have to help the client; we have to help both parents; we have to keep seeing them, and we have to write things down for them--they can't be expected to get all at one time.

Marg Corey
Montreal Children's Hospital

CHAPTER I

INTRODUCTION

Terms such as delinquent, emotionally disturbed, or retarded have been used to categorize and to assign services to individuals who deviate in some aspect from the norms of society. Recently concern has arisen about the consequences of the use of some of these terms because these terms seem to have far-reaching, severely stigmatizing effects. The process by which an individual is identified, categorized, and treated within a specific deviant category and is propelled into accepting the term as a basis for a deviant self-concept, has been called labeling by scholars studying deviance from this perspective.

In this thesis the researcher proposes to investigate the role of the family as an agent of control in the labeling process of handicapped children. Six comparison groups have been selected according to the strategies for qualitative research outlined by Glaser and Strauss.[1] Five were from process studies in the literature of the family and the handicapped child and one was obtained by

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[1] Barney G. Glaser and Anselm L. Strauss, The Discovery of Grounded Theory, (Chicago: Aldine Press, 1967) pp. 49-65.

interviewing parents of a group of learning disabled teen-aged children. The process by which the families negotiated with other agents of control--those in charge of identification, categorization and remediation--was identified for each of these groups of families so that their experiences could be compared. Through a comparative study of these processes this study aimed to 1) contribute to the literature of an underdeveloped aspect of labeling theory, that of the family as labeler and 2) integrate labeling theory with a growing number of process studies on the family and the handicapped child.

Definition of Terms Used

Learning Disability: is a special type of handicap related to deviant school performance which has been attributed to a neurological condition. Though these children score within the normal range on an I.Q. test and suffer no uncorrected hearing or vision loss, they are unable to process language in the same manner as the normal student. Often school performance and the presence of certain types of hyperactive behavior are the only indicators of the presence of the condition. Yet the problems these children present in the classroom and at home are often severe, and if ignored may develop into such secondary deviations as delinquency and psychosis.

Research in this area was initially conducted on

children who were retarded. Alfred Strauss and Heinz Werner collaborated on a series of research studies which culminated in the identification of two populations of mentally retarded children--the endogenous or mental retardate whose condition was due to "familial factors" and the exogenous retardate whose condition was due to neurological damage.[1] In 1940 Strauss working with Kephart developed a behavior rating scale and found that the exogenous children could be differentiated from the endogenous children on the basis of a number of behaviors. The former were described as disinhibited, erratic, impulsive, socially unaccepted, and uncoordinated. These observations led to experimentation with an educational program geared to the particular problems of brain damaged children. Since the exogenous child was abnormally responsive to extraneous stimuli, every effort was made to render the teaching environment a therapeutic one with a minimum of distractions.

From these studies the concept of a minimal type of brain damage emerged. It seemed logical to postulate a continuum of brain damage with severely impaired individuals such as the cerebral palsied at one end of the continuum and the youngsters manifesting learning problems accompanied by the behavior syndrome at the other end of

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[1]A.A. Strauss and L.E. Lehtinen, Psychopathology and Education of the Brain Injured Child, (New York: Grune and Stratten, 1947).

the continuum. This concept of minimal brain damage (MBD) was given further credence by a study of reproductive causality, a term used to describe harmful events occurring during pregnancy and birth which damaged the fetus or the newborn infant.[1] It was hypothesized that because fetal and neonatal deaths could be traced to complications of pregnancy and/or prematurity, likewise brain damage of a minimal degree could result even though the child did not suffer a severe neuropsychiatric disorder. Such conditions as poor nutrition, failure to secure oxygen because of delayed respiration after birth, and maternal infections were recognized as possible factors in shaping the neurological well-being of the child.

In the 1960's a number of conferences were held to debate the scientific and educational problems posed by these children. It was necessary to establish diagnostic criteria, to explore methods of teaching, and to agree on terms. In 1962 the International Study Group on Child Neurology held a conference devoted to problems of definition and diagnosis at which it was decided to discard the term "minimal brain damage" in favor of the term "minimal brain dysfunction" because it was inaccurate to imply brain

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[1]Benjamin Pasamanik and Hilda Knoblock, "The Epidemiology of Reproductive Causality" in Selma G. Sapir and Ann G. Nitzburg, (eds.) Children with Learning Problems: Readings in Developmental-Interactional Approach, (New York: Brunner/Mazel, 1973), pp. 193-199.

damage on the basis of behavioral signs alone. Attempts to further subdivide this term into more specific syndrome labels such as hyperkinetic syndrome, dyslexia, congenital aphasia, etc. were not productive. In 1963 the Easter Seal Research Foundation sponsored a series of conferences at which terminology and identification were debated again. Eventually two reports, one a comprehensive statement of the neurological frame of reference and the other a review of the remedial educational approach, were produced. The medical researchers preferred the term minimal brain dysfunction; the educators suggested adopting the term learning disability. Subtle variations in definitions have marked the evolution of a term for this group of children. Strauss and Lehtinen defined the brain injured child as:

> A child who before, during or after birth has received an injury to or suffered an infection of the brain. As a result of such organic impairment, defects of the neuromotor system may be present or absent; however, such a child may show disturbances in perception, thinking, and emotional behavior, either separately or in combination. These disturbances prevent or impede a normal learning process. Special educational methods have been devised to remedy these specific handicaps.[1]

Samuel A. Kirk, a psychologist who became involved in research techniques for testing children with learning

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[1] Strauss and Lehtinen, Psychopathology and Education, p. 4.

problems, was approached to select a term for the child with these deviant behavior and learning problems. He insisted that the term should not include children with sensory handicaps such as the deaf and the blind nor those who were mentally retarded. He recognized that there were two approaches to classifying these children with learning problems: one referring to biological causation and etiology such as brain injury, cerebral dysfunction, organic driveness etc. and the other referring to behavior manifestations such as hyperkinetic behavior, perceptual disorders, conceptual disorder, catastrophic behavior, and a host of other terms which describe the specific behavior deficit of the child. He insisted that the terms given children were of little help to the child unless they were diagnostic and provided an assessment of the child in such a way that led to some form of treatment, management, or remediation. Accordingly he suggested the use of the term learning disabled in preference to minimal brain dysfunction, and he defined the condition as follows:

> A learning disability refers to a retardation, disorder, or delayed development in one or more of the processes of speech, language, reading, writing, arithmetic, or other school subjects resulting from a psychological handicap caused by possible cerebral dysfunction and/or emotional or behavioral disturbance. It is not the result of mental retardation,

> sensory deprivation, or cultural or instructional factors.[1]

The term, learning disability, proposed a shift from emphasis on neurological-injury and etiology to remediation and education. It sought to elicit a positive response with a promise of programs and progress, but the term meant different things to different people. As the learning disability field was invaded by specialists from a number of disciplines, diverse theories of remediation were experimented with and discarded, but a definition of the term learning disability was never delineated. For the purposes of this study the definition used by the Manitoba Association for Children with Learning Disabilities (MACLD) will be used.

> Learning disabled children possess normal or above average intelligence but exhibit certain behavioral or learning disabilities resulting from deviations in the function of the central nervous system. The child may demonstrate behavioral problems such as excessive hyperactivity, lack of attention, and poor control of impulses and motor functions. He may be deficient in understanding or using language, spoken or written, and he may be imperfectly able to listen, think, speak, read, write or do arithmetic. When there is a significant discrepancy between his educational ability and achievement, the child may be identified as "learning disabled". This category includes

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[1] James J. McCarthy and Joan F. McCarthy, Learning Disabilities, (Boston: Allyn and Bacon Inc., 1969), p. 1.

> such conditions as perceptual handicap, minimal brain dysfunction, dyslexia, and developmental aphasia. It does not include those children whose learning problems result primarily from visual, hearing, or motor handicaps, from mental retardation, emotional disturbance or environmental disadvantage.[1]

The Negotiation Process: involves proposals and counter proposals offered in an attempt to reach an agreement on a special problem. The process has been recognized in a number of settings, for example, the tuberculosis ward,[2] the psychoanalyst's office,[3] and the school.[4] Techniques for utilizing negotiation in solving conflicts in industrial settings[5] as well as the family[6] have been systematized and applied with enthusiasm because

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[1]Pamphlet, Services for Learning Disabled Children Manitoba Association for Children with Learning Disabilities - Lions' Learning Centre.

[2]Julius A. Roth, "The Treatment of Tuberculosis as a Bargaining Process", in Arnold Rose (ed) Human Behavior and Social Processess, (Boston: Houghton Mifflin, 1962) pp. 575-588.

[3]Michael Balint, The Doctor, His Patient, and the Illness, (New York: International Universities Press, 1957).

[4]Wilfred B. W. Martin, The Negotiated Order of the School (Toronto: MacMillan of Canada, 1975).

[5]Richard E. Walton, Interpersonal Peacemaking: Confrontations and Third Party Consultation, (Reading, Mass.: Addison-Wesley, 1969).

[6]Thomas Gordon, Parent Effectiveness Training (Scarborough, Ontario: The New American Library, 1975) pp. 236-264.

organizational development researchers have found that when all concerned negotiate, the solution usually will be more acceptable to all participants. The parent consulting a professional about her child usually is asking that person to "make sense" of the child's deviant performance and to suggest some remediation. The parent will offer information in the form of a list of behaviors or symptoms, and the professional is expected to arrive at a diagnostic category for the child and recommendations for treatment. The willingness and ability of the parent to comply with the recommendations may be dependent upon the professional's ability to involve her in a treatment plan.

Crisis: Behavioral scientists have become increasingly interested in periods of rapid psycho-social change brought about by stressful circumstances. Coelho, Hamburg and Adams define a crisis situation as one in which "one or several individuals are confronted with adaptive tasks that demand the mobilization of new resources in psychological competence and social skills."[1] The crisis may be situational and brought about by events in the person's world such as a severe illness or a bereavement, or the crisis may be developmental as when the individual faces the various stages of personality development during his life.

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[1]George V. Coelho, David A. Hamburg, and John E. Adams, Coping and Adaption, (New York: Basic Books, Inc., 1974) p. 128.

Thus families who realize that a child is handicapped are faced with a situational crisis brought about by the exigencies of managing the particular problems of the handicap. As the child moves toward maturity they are faced with handling each developmental stage within the limitations of his handicap--the developmental crises.

Categorization and Labeling: For the purpose of this study the term labeling will be reserved to designate a three stage process. The stages of this process are recognition, categorization, and remediation. During the recognition stage the parents become aware that "something is wrong with my child". They consult a diagnostition who may categorize (diagnose) the condition and make recommendations for some remediation. Haber and Smith[1] have recommended that the disabled role should be differentiated from the sick role on the basis that the disabled person is not expected to recover and assume normal obligations as is expected of the sick person. The diagnostitian by categorizing the disability, legitimizes the performance failure and establishes the cause of this failure as beyond the control of the individual handicapped person.[2] Alternate

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[1]Lawrence D. Haber and Richard T. Smith, "Disability and Deviance: Normative Adaptions of Role Behavior," American Sociological Review, 36, (Feb., 1971) p. 88.

[2]Ibid., p. 91.

standards of performance become acceptable for this person.

Thesis Organization

Chapter II reviews both the literature of labeling theory--particularly as it pertains to the physical or biological deviant and the literature of the handicapped child and the family.

Chapter III presents the agents of control, the agencies which process the learning disabled child. There has been a bitter struggle between the school and school-related agency, The Child Guidance Clinic with the voluntee-er parent's organization, the Manitoba Association for Children with Learning Disabilities (MACLD). The basis of this inter-organizational struggle is analysed.

Chapter IV is concerned with the methodology, including the qualitative research design, a description of the interviews, and the coding of the interviews by negotiation unit.

Chapter V is devoted to interpreting the information gathered from both library research and interviews with parents and is presented within the framework of labeling theory.

A summary and an examination of the implications of this research are incorporated in the last chapter.

CHAPTER II

LABELING THE HANDICAPPED: A LITERATURE REVIEW

In 1951 Lemert[1] explored the relationship of personal disorganization to the social milieu in which the individual interacted. He classified deviation into three groups: the behavioral (mentally ill, juvenile delinquent etc.), the biological (physically handicapped, and the demographic (minority racial or cultural populations). Subsequent theorists and researchers have explored the effects of labeling in creating and reinforcing deviance, but the majority of research undertaken from this perspective has been concerned with the behavioral deviant. The application of labeling theory to the biological deviant has been less well explored and may be best understood as a negotiated process as suggested by Haber and Smith.[2]

Labeling Theory: The labeling perspective was first described by Tannenbaum as early as 1938 when he focused

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[1] Edwin Lemert, Social Pathology, (New York: McGraw-Hill, 1951).

[2] L.D. Haber and R.T. Smith, "Disability and Deviance: Normal Adaptions of Role Behavior", American Socio-logical Review, Vol. 36, (Feb. 1971), pp. 87-97.

upon the importance of societal reaction in producing criminality. According to Tannenbaum "the process of tagging, defining, identifying, segregating, describing, emphasizing, making conscious and self-conscious eventually caused the person to become the thing he was described as being."[1] Later theoreticians incorporated and elaborated upon Tannenbaum's observation. Lemert suggested a progressive, reciprocal process which led the individual from primary deviance to an entrenched secondary deviance. As long as the individual reacted to his chance deviant act by rationalization or other mechanism of a socially acceptable role, the deviance remained primary. If he began to "employ his deviant behavior or a role based upon it as a means of defiance, attack, or adjustment to the overt and covert problems created by the subsequent societal reaction to him, his deviation (became) secondary."[2] Lemert theorized a progressive, reciprocal relationship leading to this secondary deviance evolving as follows:[3]

1. Primary deviation.
2. Social penalty.
3. Further primary deviation.
4. Stronger penalties and/or rejection.
5. Further deviation.
6. Crisis reached in which the community stigmatizes the deviant.
7. Strengthening of deviant conduct as a reaction to stigmatizing and penalties.

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[1]Frank Tannenbaum, Crime and the Community, (Boston: Ginn, 1938), pp. 19-20.

[2]Lemert, Social Pathology, p. 76.

[3]Ibid., p. 77.

8. Ultimate acceptance of deviant social status and efforts to adjust on the basis of the associated role.

Other labeling theorists have stressed the societal exacerbation of deviant behavior and minimized the dialectical approach set forth by Lemert. Howard Becker studied the jazz musician and the marijuana user in order to find out the process by which these people became to perceive of themselves as different. These studies were compiled into a book, The Outsiders,[1] published during the turbulent period of the 1960's. Becker used much of Lemert's theory and tacked a name on the process described--Labeling Theory. Then he attacked the "Rule Creators", the "Moral Crusaders", and the "Rule Enforcers", who labeled the individual as deviant. These people who discovered, identified, apprehended, convicted, and treated deviants were accused of creating the deviance they sought to erradicate. They were[2] "meddling busybodies" interested in "forcing their own morals on others, representatives of a dominant class who hope to help those less favorably situated". His scathing attacks on those involved in the labeling process caused many social workers to squirm! To Becker, deviance was created by society which formulated rules and organized cadres of rule enforcers. Deviance was the "infraction of

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[1]Howard S. Becker, The Outsiders: Studies in the Sociology of Deviance, (New York: Free Press, 1963).

[2]Ibid., p. 147-163.

some agreed-upon rule." Social groups created deviance by making the rules whose infraction constitutes deviance and by applying those rules to particular people and labeling them as outsiders.

Schur integrated additional concepts to sharpen the existing labeling theory.[1] He used the concept of stereotyping previously used to describe reactions to racial and ethnic statuses, to account for the extremely negative stigma attached to certain categories of deviants. Because stereotyping involves a tendency to jump from a simple cue or a small nucleus of cues of actual or rumored behavior to a general statement of the "kind of person" being referred to, stereotyping can have an overwhelming impact on the individual so that that person may find himself "unable to sustain any alternative definition of himself."[2]

Becker has used the term master status to account for the societal reaction to a specific master cue.[3] He noted that individuals often possessed one key trait which distinguished them. Thus if he were designated as a doctor, he would be expected to have a number of auxiliary traits such as upper middle class status, male, white, and protestant. Similarly one deviant trait might symbolize a cluster

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[1]Edwin M. Schur, Labeling Deviant Behavior, Its Sociological Implications, (New York: Harper and Row, 1971).

[2]Ibid., pp. 38-52.

[3]Becker, The Outsiders, pp. 31-34.

of undesireable traits assumed to be associated with that particular key category, and the individual would be judged accordingly. The homosexual might be discharged from a job he previously performed competently because his activities as a homosexual were discovered and this master status carried with it the assumption of unreliable character.

Labeling the Disabled: Other theorists have addressed themselves to the type of deviant Lemert called the biological deviant--too fat, too tall, too ugly, or perhaps blind, deaf or crippled. Erving Goffman described these people as:

> (those who) in ordinary social intercourse possess a trait that can obtrude itself upon the attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated...those who do not depart negatively from the particular expectations at issue are normals.[1]

Friedson[2] analysed the labeling of the disabled--the identification of the impaired person as a special type of deviant and the process by which this person is categorized and treated. He noted that incurability creates severe problems to society because these forms of deviance pose barriers to normal social and career development. These

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[1]Erving Goffman, Stigma: The Management of Spoiled Identity, (Englewood Cliffs, N.J.: Prentice-Hall, 1963) p.5.

[2]Eliot Freidman, "Disability as Social Deviance", in Marvin Sussman (ed.) Sociology and Rehabilitation (American Sociological Association, 1965) pp. 71-99.

people remain deviant and "the task of rehabilitation is to shape and form their deviance," a process which according to Friedson poses moral problems "more severe and poignant than...with any other type of deviance control" because the "idea of adjustment" can be used in a mechanical and profoundly conservative way".[1]

The disabled according to Haber and Smith have lost the ability to perform expected role activities because of a chronic physical or mental impairment.[2] "Disability... is a form of social adaption to incapacity which organizes behavior in terms of a distinctive pattern of expectations similar to the behavioral adaptions characterized by Lemert. The diagnosis is a legitimation process which exempts the individual from the usual role requirements. However, the individual may persist in claiming role exemptions which are beyond those exemptions appropriate to the actual capacity impairment. An "overadjustment" to a disability is a deviant adjustment, and the researcher suggests that overadjustment is a form of secondary deviance in which the handicapped person organizes his life about his incapacities rather than his residual capacities.

Physical handicap is primarily a medical problem, usually diagnosed with reasonable accuracy by a physician.

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[1]Ibid., p. 95.

[2]Haber and Smith, "Disability as Process", pp. 88-92.

Other disabilities have a physical basis but are not visible. Retardation and learning disability both fall within this category. Jane Mercer[1] has described the process of labeling the mentally retarded, a "school-specific" handicap which develops out of the inability of the child to perform the academic role. Usually the child has no physical deformity and is not easily identified as deviant. Mercer has suggested that if a person does not occupy the status of mental retardate, is not playing the role of mental retardate in any system, and is not regarded as mentally retarded by any of his significant others in his social world, then he is not mentally retarded. She described socially competent people who had been labeled retarded in school situations, who had escaped the category of retarded when they moved out of the school system into the adult world. In the words of the labeling theorist, their deviance did not become secondary! She identified a seven stage process in labeling a school child as mentally retarded:[2]

Stage 1	School enrollment
Stage 2	Student assigned "normal status"
Stage 3	Student retained in grade
Stage 4	Academic-problem status in which special teacher-principle consultation was used.
Stage 5	Case-to-be-evaluated status when the child is evaluated and given psychological tests.
Stage 6	The diagnosis in which the child is categorized as mentally retarded.

[1]Jane Mercer, Labeling the Mentally Retarded: Clinical and Social System Perspectives on Mental Retardation (Berkeley: University of California Press, 1973) p. 8.

[2]Ibid., p. 24.

Stage 7 Achieved-mentally-retarded status when the child is placed in a special education class.

Stage 8 Vacating the mentally retarded status by surrendering the label through graduation, reassignment to a regular class, or leaving school.

Retardation is a diagnostic category primarily established by statistical measurement. If the child scores more than two standard deviations below the mean on an I.Q. test, he is classified retarded. "Stupid" is an informal assessment lacking the relative precision of a professional diagnosis but of no less consequence. Dexter suggests that "many influential people in our society including particularly classroom teachers show more repugnance toward stupidity than toward anything else except dirtiness."[1] He was referring to the high grade retardate in his article, but many learning disabled children have qualified for the term "stupid" because of their inability to grasp the skills of reading or spelling. Certainly the pre-school aphasic child who cannot talk appears very stupid to anyone who asks him his name and receives a garbled reply! Although stupidity is not a category used by professionals, it may be implied and made real by the child's class placement. Professionals may decide against classifying a child retarded or learning disabled, but the informal term describing his deviant performance i.e. "stupid" is not so easily squelched.

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[1]Lewis Anthony Dexter, "On the Politics of Stupidity in Our Society" in Howard S. Becker (ed.) The Other Side: Perspectives on Deviance, (New York: The Free Press, 1964) pp. 37-47.

The Handicapped Child and the Family: A group of process studies has been written which describe parental reactions to becoming aware of a physically deviant condition in a child. These studies chronicle the steps these families pursue in gathering information about the child and the resources they use in searching for a diagnosis and remediation. The family becomes the principal agent of control and detection by contacting professionals about the child's condition and by deciding how to implement the professional's recommendations. If the child is pre-school aged, the reality of the disability will be interpreted to the child by the parent. If the parents perceive the child as incapable, they will treat him in this way and promote the expectation of incapacity. If they perceive the child as handicapped in some aspects but capable in others, they may encourage him to use his capacities constructively. If on the other hand, the child is allowed to use his handicap to avoid accomplishing developmental tasks leading toward independence, his deviance may become secondary.

Davis[1] studied families of polio victims--their reactions to the hospitalization of a child and the adjustments which were necessary when the child returned home.

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[1]Fred Davis, Passage Through Crisis: Polio Victims and Their Families, (New York: The Bobbs-Merrill Co., Ltd. 1963.

Meadow[1] analysed the parental search for a diagnosis in the cases of children afflicted with congenital deafness. Hewett[2] analysed the experience of families with a cerebral palsied child; Roskies,[3] the families of Thalidomide children, and Voysey[4] families with children of various handicaps. Though the handicaps varied in severity and visibility, the process of diagnosis was remarkably similar. Parental reactions to diagnosis varied from optimism to dispair and were not related to the severity of the handicap. Thus children with a comparatively mild handicap might be perceived by parents as severely handicapped while other parents might not be overwhelmed by a very burdensome disability. None of these studies followed the child longer than two years, and none of the studies were concerned with the handicapped child's transition from childhood to adolescence or from adolescence to adulthood.

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[1]Kathryn P. Meadow, "Parental Response to the Medical Ambiguities of Congenital Deafness", Journal of Health and Social Behavior, Vol. 9, pp. 299-309.

[2]Sheila Hewett, The Family and the Handicapped Child: A Study of Cerebral Palsied Children in Their Homes, (Chicago: Aldine Publishing Company, 1970).

[3]Ethel Roskies, Abnormality and Normality: The Mothering of Thalidomide Children, (Ithaca, N.Y.: Cornell University Press, 1972).

[4]Margaret Voysey, A Constant Burden: The Reconstitution of Family Life, (London: Routledge and Keegan Paul, 1975).

The Family and the Learning Disabled Child:

Studies of the learning disabled child and the family have come from observations of therapists. These therapists have suggested that the learning disability provides a symptom which gives the parents "vicarious satisfactions". Miller and Westman[1] reported on eighteen families of out-patients seen in a children's psychiatric hospital, all of whom had severe reading problems. These authors suggested that the reading problem provided "the ballast necessary to keep the marital enterprise on an even keel".[2] Bruce Peck[3] also viewed reading disability as part of family pathology and suggested that the condition was reinforced by "collusive arrangements" among family members. Family reactions to the diagnosis of Minimal Brain Dysfunction have been described by Gardner.[4] He observed that parents may slip into a chronic maladaptive pattern of managing their child. Either they become overprotective and gain satisfactions from the child's helplessness, or they may become martyred

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[1]Daniel R. Miller and Jack C. Westman, "Reading Disability as a Condition of Family Stability," Family Process, Vol. 3, (March, 1964) pp. 66-76.

[2]Ibid., p. 69.

[3]Bruce P. Peck, "Reading Disorders: Have We Overlooked Something?" in A Family Therapy Notebook, ed. Bruce P. Peck (Roslyn Heights, N.Y.: Libra Publishers, 1974).

[4]Richard A. Gardner, MBD: The Family Book About Minimal Brain Dysfunction (New York: Jason Aronson, Inc., 1973).

and withdraw from social participation. Kelman[1] has criticised the studies which attempt to describe the effect of the minimally brain damaged child upon the family because it has been all but impossible to isolate the effect of one occurrence upon an entire family. Barsch[2] inquired into the child raising practices of 177 families of cerebral palsied, brain damaged, mongoloid, blind and deaf children and noted that in none of these families did he find parents who buried themselves into social isolation as a result of having a handicapped child. To Barsch a more logical explanation was that some families socialize more than others.

The impressions of a therapist such as Gardner are not systematized in the same way as those of a researcher, but his sensitive observations illustrate the ways families reinforce the deviant self-concept. Overprotection communicates to the child that he is not considered capable of coping. A youngster is quite vulnerable to these definitions expressed in these subtle ways, and by emphasizing the child's deficits, the family encourages secondary deviation.

However, the family is not the only agent of control

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[1]H. Kelman, "The Impact on Families of Children with Cerebral Damage", in H.G. Birch, (ed.), Brain Damage in Children, (Baltimore, Md., Williams and Wilkins), pp. 77-99.

[2]Ray H. Barsch, The Parent of the Handicapped Child, (Springfield, Ill.: Charles C. Thomas, 1968).

in the process of labeling the handicapped child. Parents are dependent upon competent diagnostitians to examine the child and give concerned guidance and recommendations for remediation to both themselves and the youngster. They are dependent upon good programs in the community for educating the child and helping him find an appropriate job placement. They need a concerned community willing to find some place for this odd child in the scout troop, teen-aged interest group, or young adult group.

Agencies who identify, diagnose, and treat the handicapped child have been accused by labeling theorists of reinforcing deviance through the reification of diagnostic labels and subsequent treatment. The agents of control who process the learning disabled child in Winnipeg are described in Chapter III. Most of the agencies have been sensitive (perhaps too sensitive) to the use of diagnostic categories and have attempted to avoid "labeling" children by not using diagnostic categories. However, the parents' group (MACLD) has used the term learning disability for the purpose of diagnosis and as a basis of demanding service for this special group of children.

CHAPTER III

AGENTS OF CONTROL: THE LABELERS

Labeling theorists and researchers have stressed the culpability of the "agents of control"--those specialists who discover and treat individuals, thereby encouraging deviance in the people they seek to "help". Stoll[1] has suggested a classification of agents from which a model of a social control network for describing the labeling process of physically handicapped and the learning disabled can be constructed. She suggests a classification based upon 1) agents of detection and identification, 2) agents of diagnosis and categorization, and 3) agents of rehabilitation. Friedson[2] has pointed out that in many instances there are a number of agents each with a competing claim or philosophy to which the individual may be assigned or may assign himself with important consequences.

Agents of detection and identification are usually quite informal--the neighbor, a grandmother, or the leader

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[1]Clarice S. Stoll, "Images of Man and Social Control", in Frank R. Scarpitti and Paul T. McFarlane (eds.) Deviance: Action, Reaction, Interaction (Don Mills, Ont.: Addison-Wesley Publishing Co., 1975) pp. 253.

[2]Elliott Friedson, "Disability as Deviance" in Marvin Sussman (ed.) Sociology and Rehabilitation (American Sociological Association, 1965) pp. 71-99.

of the Brownie troop. The parents usually gather up and synthesize information gained from these people and may begin to have a vague feeling that "something is wrong" with this child. The parents may select a doctor, a psychologist, or an agency such as the Child Guidance Clinic to provide a diagnosis.

The agent of diagnosis or categorization is expected to simplify the information presented to him by the client and assign the person to a category. However, categories are at best general and loosely defined, and at worst stigmatizing.

Friedson[1] has suggested that rehabilitation agents servicing handicapped persons engage in four activities:

1. They specify what personal attributes shall be called handicaps.

2. They seek to identify who conforms to their specifications (categories).

3. They attempt to gain access to those whom they identify as handicapped.

4. They try to get those to whom they gain access to change their behavior so as to conform more closely to what the organizations believe are their potentialities.

Control agents usually work in large, bureaucratic organizations where efficiency is an important criteria in evaluating the effectiveness of the agency. Efficiency, manifest in a quest for order, control, predictability, objectivity, and rationality is developed through

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[1] Ibid.

organizational procedures which have been routinized and standardized. Flexibility and individuation becomes limited when workers are assigned large work loads and as these workers learn to deal with the emotional drain which occurs when human service workers become intensely involved with their client's problems.[1] No less routinized is the modern doctor's office where efficiency is essential in modern practice. The individual child is examined in an assembly line fashion and referred to another specialist if he doesn't meet standards in some aspect. Parents regret not the quality of the consultation with the doctor but its brevity.[2]

The studies consulted in the research of physically handicapped children described the parents' search for diagnosis and treatment from doctors and related professionals. The parents of learning disabled children, on the other hand, sought help from a variety of other sources with varying results. If initially they sought help from a doctor, his services were diagnostic only--and he referred the child to a specialist if remediation was indicated. The Child

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[1]Christana Maslach, "Burned-Out", Human Behavior, Vol. 5, (Oct. 1976) pp. 16-22. Social service professionals intimately involved with troubled human beings tend to lose concern for their clients when they are unable to cope with the emotional stress of repeated, intense interaction with these people. One of the signs of "burn-out" is the transformation of a concerned, creative person into a bureaucrat.

[2]Ray H. Barsch, The Parent of the Handicapped Child (Springfield, Ill.: Charles C. Thomas, 1968) pp. 84-86.

Development Clinic provided further diagnostic and remediation services for the pre-school child; the Child Guidance Clinic provided similar services to school aged children. A parents group, the Manitoba Association for Children with Learning Disabilities (MACLD) was formed out of a conflict with these agencies and the schools.

Agencies who service the handicapped have been accused of organizing and stabilizing deviant behavior into special roles by bringing a number of people together and labeling them in the same way. Erikson points out:

> Such institutions gather marginal people into segregated groups, give them the opportunity to teach one another the skills and attitudes of a deviant career, and often provoke them into employing those skills by reinforcing their sense of alienation from the rest of society.[1]

The School as Agent of Control: Schools have been accused of reinforcing the deviance of handicapped children by placing them in special classrooms and isolating them from interaction with normal children. Parents of these children have had to deal with youngsters who did not make friends in the neighborhood because they were bussed to other parts of the city. At school these youngsters were not on the playground with normal children, and at home they lived lonely, isolated lives. However, the school program

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[1]Kai T. Erikson quoted in Eliot Freidson, "Disability as Deviance" in Marvin Sussman (ed.) Sociology and Rehabilitation (American Sociological Association, n.d.) p. 87.

which stressed their "differentness" also protected them from the inevitable failures in the regular classroom and attempted to educate these children within the limitations of their handicap.

A compromise between the special education class and the regular class is the use of the resource teacher. This specialist is available to help children who are having difficulties. However, at the present time there is a controversy about the use of these teachers. The schools, now very sensitive to labeling, are beginning to question the effect of taking a child out of class for tutorial work with the resource teacher. The removal of the child acknowledges his "difference" and may be stigmatizing. One approach suggests that the resource teacher remain in the regular classroom and assist the regular classroom teacher with a particular child.

In Winnipeg there have been no special classrooms set aside specifically for the learning disabled child. The special education classrooms are for children with some degree of retardation or physical handicaps. A decision to assign a child to a special class is based on a diagnostic evaluation from the Child Development Clinic or the Child Guidance Clinic.

Child Development Clinic: Some learning disabled children are recognized during their pre-school years because of slow development or severe behavior problems.

The alert parent and physician may cooperate to refer the youngster to the Child Development Clinic for assessment. The Clinic is located in the Children's Centre at the Health Sciences Centre and is staffed by three pediatricians trained in child development, two social workers, two speech therapists, four psychologists, and an audiologist. These specialists use a team approach to evaluate and categorize the child. They may refer the youngster to pre-school programs at the Society for Crippled Children and Adults where special pre-school classes are available to the mentally retarded, the deaf, the cerebral palsied, and the language delayed child, or they may provide a speech therapy or a special pre-school program for him in the clinic. Each year approximately one hundred children are assessed for special school placement by the Clinic, and a special liaison has been established with the Child Guidance Clinic so that these youngsters can be given follow-up services when the child enters school.

The Child Guidance Clinic: services 10,000 students each year with a staff of 154 clinicians from twenty inter-disciplinary district teams. The Clinic was established in 1951 to treat students with learning and emotional problems, and the processing of learning disabled school aged children has become one of its tasks. Clinicians of the Child Guidance Clinic have avoided the use of the term "learning disabled" because of vagueness of the category and have often

treated these children within the framework of emotional disturbance rather than that of a neurologically-based handicap. They have had to rely on school personnel, some of whom are antagonistic to Child Guidance "interference", to cooperate in providing flexible and individual services to difficult children. Many families of learning disabled children, and thus consumers of the Child Guidance Clinic services, have been disappointed by the limited reading and speech therapy services available through this agency and by the mental health approach to their child's problem. As a result, parents have sought services elsewhere through diagnostic services out of the province.

MACLD, A Consumer Organization: Scurfield and Ryant[1] have noted that if social welfare organizations are classed as non-market organizations and are contrasted with market organizations, they differ in a number of important aspects. First, social welfare organizations do not seek profits. In contrast, the private market enterprise exists to produce a profit. Secondly, most social welfare organizations occupy a monopoly position with respect to the consumers of their service. The private organization, on the other hand, operates within a competitive market. A producer is able to judge the popularity and effectiveness

[1]P.J. Scurfield and J.C. Ryant, "Service Creation by Fiat: A Case Example," The Social Worker, Vol. 43, (Summer 1975) pp. 105-109.

of his product by the sales of his, in comparison with his competitor's products. Third, the social welfare organization is normally under community control rather than the control of owners and/or managers and is usually funded at least in part by governmental bodies. The results of these conditions are that "the market organization is better able to make rational policy decisions on the basis of valuable information and data derived from comparative market performance of their products."[1] The social service organization, by contrast, must make decisions based upon entirely different data.

Using the consumer frame of analysis, MACLD has emerged as a consumer organization which has been dissatisfied with the services offered for learning disabled children and has sought to initiate alternative services for them. This zealot volunteer organization has sought change within the schools through petitions to government and through establishing its own programs. MACLD has developed in conflict with the educational bureaucracies, and many of its members have felt thwarted by teachers and agency clinicians who have career investments in the *status quo* and have resisted recognizing learning disability as a neurological handicap.

MACLD parents are not reluctant to use the term,

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[1] Ibid.

"learning disabled". They are convinced that their child's learning problems are not due to retardation, lack of motivation, or emotional disturbances, and they have labeled their child learning disabled in order to demand services.

MACLD was organized in 1966 by three sets of parents whose children were in special education classes. Though bright and responsive, these youngsters were not achieving at school, and the parents resisted their placement in special education classes. This group of parents organized a chapter of the Canadian Association for Children with Learning Disabilities in order to work to obtain adequate diagnostic facilities and treatment for these children and to collect and diseminate information about learning disability. MACLD members have embarked upon an ambitious program in behalf of these children and their families. They have held annual conferences at which a number of outstanding people in the field of learning disabilities were invited to address parents and educators. They have submitted briefs to government calling for the hiring of resource teachers, and, they are presently involved working toward the promulgation of Bill 58, a bill which was passed by the Manitoba Legislature in June 1975 and calls for "mainstreaming" (integrating) handicapped children into regular classrooms. More recently they have succeeded in establishing a Learning Centre for children with learning disabilities. Many professionals have criticized their "superman planning",

a term used by Downs[1] to characterize planning "unfettered by reality--more daring, original, sweeping, and internally consistent than available in the disenchanting welter of conflicting interests in the real world." But as Downs admits, superman planners attempt to be supermen in action, and sometimes they succeed. MACLD's success rate has been impressive!

According to Perrow, the public school system is virtually insulated from parental preference by the professionalism of educators, and, therefore, the responsibility for effective teaching and student welfare has become principally a matter of internal organizational accountability.[2] Becker found (as many parents have found) that protocal within the educational system demands that the principal always support the teacher when a parent questions a teacher's ability.[3] However, the MACLD experience has shown that, though the educational bureaucracy may absorb innumerable complaints from individual, irate parents, it is quite vulnerable to pressure from a group of organized, demanding parents.

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[1]Anthony Downs, Inside Bureaucracy (Boston: Little, Brown and Company, 1967) pp. 216-218.

[2]Charles Perrow, "Members as Resources in Voluntary Organizations" in W.R. Rosengren and M.A. Lefton (eds.) Organizations and Clients: Essays in Sociology of Service (Columbus, Ohio: Chas. E. Merril) 1970, pp. 52-53.

[3]Howard Becker, "The Teacher in the Authority System of the Public School," Journal of Educational Psychology, Vol. 27, pp. 128-141.

Because the term "learning disability" is not commonly used by professionals in the Winnipeg area, it is very probable a child with learning problems will not be categorized as learning disabled by any of the legitimate agents of diagnosis unless the youngster is referred to the MACLD Learning Centre. The diagnostitian usually attempts to designate the areas in which he is deficient and describe him as "difficult to teach", a term which throws a challenge to the teacher. The parents may hear about MACLD from a friend or a newspaper advertisement and may contact the organization to help "make sense" of their child's failure. MACLD maintains a telephone counseling service which is staffed by parents of learning disabled children and is willing to mail literature on learning disability to any parent requesting it. These leaflets contain a description of learning disability which provides parents with a practical check list of symptoms against which they can compare their child's performance. If the parents feel after studying this information that their child is, indeed, learning disabled, they may join the MACLD organization and define the child within this framework. Nicholas Hobbs[1] has pointed out the advantages of labeling a child learning disabled:

> It implies a specific neurological condition for which no one can be held particularly responsible, and yet it escapes the

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[1]Nicholas Hobbs, The Futures of Children (San Francisco: Jossey-Bass Publishers, 1975), pp. 79-82.

> stigma of mental retardation, there is no implication of neglect, emotional disturbance, or improper training or education nor does it imply a lack of motivation on the part of the child. For these cosmetic reasons, it is a rather nice term to have around.

However, the term carries with it the implication that the child cannot be held responsible for certain tasks and behaviors as included in this list of characteristics of learning-disabled children issued by the United States Department of Health and Social Development:[1]

1 Hyperactivity
2 Perceptual-motor impairments
3 Emotional lability
4 General coordination deficits
5 Disorders of attention (short attention span, distractibility, perseveration)
6 Impulsivity
7 Disorders of memory and thinking
8 Specific learning disabilities
   a) Reading
   b) Arithmetic
   c) Writing
   d) Spelling
9 Disorders of speech and hearing
10 Equivocal neurological signs and electroencephalographic irregularities.

The parent who familiarizes himself with this list may develop the expectation that the child will have these deficiencies and may encourage the child to conform to them by excusing him from more normal performance--thus reinforcing the labeling process. The child who withdraws from normal school activities, both social and academic, because of the

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[1]Quoted in Bert Smith, Your Nonlearning Child. (Boston: Beacon Press, 1968) p. 24.

label, learning disability, is probably well on his way to secondary deviance--a rather high price to pay for any special services which might be obtained from the use of the label.

Summary: The parents of the handicapped child synthesize the information given to them by other people associated with him and decide whether to ask for additional assistance. In Winnipeg the pre-school child who is slow in developing, may be referred to the Child Development Clinic for assessment. This clinic offers diagnostic services and some remediation in speech therapy and a pre-school program for emotionally disturbed children. Other youngsters may be referred by this clinic to a pre-school class at the Society for Crippled Children and Adults. The school aged child may be referred to the Child Guidance Clinic which provides diagnostic services and remediation in the areas of speech, reading, and emotional problems. The Child Guidance Clinic professional may make specific recommendations and the school may implement these recommendations through assignments to a special education classroom or resource teacher help. These agents of control offer primarily diagnostic and short term remediation. They rely on pre-schools and schools for long term remediation. The special education class typifies the remediation system attacked with such vigor by labelling theorists because the failures in the school system are brought together in these

classes and isolated from normal children. The educator defends these special classes because, without them, many children might have to remain at home, and attendance in a special education class is "more normal" than remaining at home.

The referral process has many pitfalls where parents are easily lost if they are not wise to bureaucratic procedures. Discontinuities between recommendation and remediation are difficult to detect and even more difficult to correct. Parent organizations have emerged to help parents with the very difficult job of parenting the handicapped child. The Manitoba Association for Children with Learning Disabilities has developed in conflict with the established agencies of diagnosis and remediation, and members of this organization have used the term, learning disabled, to "make sense" of their child's behavior and to demand appropriate services. In so doing they risk "labeling" their child by describing his incapacities so that he uses these definitions to avoid mastering stages of maturation and growth.

CHAPTER IV

METHODOLOGY

Previous studies of the labeling process have generally focused upon the deviant--who he is and how he came to consider himself as such. In contrast, this study has focused on the agents of control and the family, specifically, as an agent of control. The literature of the parenting of the handicapped child was reviewed in order to identify the process the family experiences in the diagnosis and treatment of the physically disabled child. Fourteen interviews were conducted with twenty-seven parents whose learning disabled teenager belonged to the MACLD Teen Group. From these data a sequential model of the labeling of the handicapped child emerged. Additional insights on the agents of control were obtained by participant observation as a member of MACLD and as a member of the Minister of Education's Implementation Review Committee for the Provision of Alternatives for Children with Special Needs, and from interviews conducted with key agency personnel.

The information gained from parent interviews and from library research of the literature of the family and the handicapped child was analysed by the constant

comparative method of qualitative analysis described by Glaser and Strauss.[1] This method was selected because it was designed to "result in the creation of developmental theories of process, sequences, and change pertaining to organizations, positions, and social interaction." It was not intended that this study test hypotheses but, rather, to explore the general notions about the impact of the family on the labeling process. Therefore, the comparative, qualitative method was the most appropriate method for investigation.

Studies From the Literature

Davis[2] studied the social-psychological impact of polio on the families of fourteen polio victims aged four through twelve. In order to analyse the case histories of these families, he used four stages leading from the identification of "something's wrong" through treatment and adjustment to a permanent crippled condition. These overlapping stages of "passage through crisis" were:

> Prelude Stage: Parents recognized that something was wrong but did not consider the possibility of an extraordinary illness. They resorted to very common remedies such as aspirin and rest.

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[1]Barney G. Glaser and Anselm L. Strauss, The Discovery of Grounded Theory: Strategies for Qualitative Research, (Chicago: Aldine Publishing Co., 1967), p. 114.

[2]Fred Davis, Passage Through Crisis: Polio Victims and Their Families, (New York: The Bobbs-Merrill Co., Ltd., 1963).

Warning Stage: Parents became aware that the condition was more serious than first thought. All new information was usually met with rationalization, vacilation, or denial until the diagnosis established the condition as Polio.

Impact Stage: Diagnosis and the immediate reaction to diagnosis. The search for a "reason why".

Inventory Stage: In which a realistic prognosis was sought. The family began to assess the long-term effects of the illness.

Meadow[1] studied the process of identification of deafness in a state residential school for children. She identified three stages similar to those described by Davis.

Stage One: The Diagnostic Funnel: during which the number of alternative diagnoses are narrowed.

Stage Two: The Diagnostic Trauma: during which parents are given a diagnosis of deafness.

Stage Three: Alliance for Treatment: when the various professionals make recommendations for such special treatments as speech therapy.

Hewett[2] undertook the study of 180 families of cerebral palsied children who were known to the Spastic Society's Family Help Unit in Nottingham, England. The purpose of the study was the evaluation of services available to these children and the comparison of family life in these families with that of "normal" families. This study of families of children aged one through nine was not primarily a process study, but some of the material gathered was of a process nature--particularly that pertaining to

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[1]Kathryn P. Meadow, "Parental Response to the Medical Ambiguities of Congenital Deafness", Journal of Health and Social Behavior, Vol. 9, pp. 299-309.

[2]Hewett, The Family.

identification and diagnosis, and considerable case history material was quoted. Hewett was more interested in the practical day-to-day aspects of caring for the young handicapped child, but she summarized the experiences of the mothers in her sample which were comparable with mothers of other handicapped children:

> Most of the mothers in this sample had come to a gradual realization that there was something wrong with their babies over a period of months. However, these mothers, too, eventually had to face the fact that this 'something' could not be cured but would affect the child all his life. This realization probably has to be complete before the mother can take the next step, that is, adjusting her expectations of the child and her handling of him to the realities of his disability.[1]

Voysey[2] conducted a series of four interviews during a period of a year with each of the mothers of twenty-two children who had serious handicaps. The interviews explored 1) the onset of the disability, a stage comparable to Meadow's Funneling or Davis' Prelude and Warning Stages, 2) the encounters with the medical agency (diagnosis), and 3) family life with the handicapped child. Roskies[3] interviewed twenty mothers of children enrolled in habilitation programs

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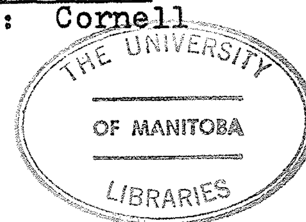
[1]Ibid., p. 201.

[2]Margaret Voysey, A Constant Burden: The Reconstitution of Family Life, (London: Routledge and Keegan Paul, 1975).

[3]Ethel Roskies, Abnormality and Normality: The Mothering of Thalidomide Children, (Ithaca, N.Y.: Cornell University Press, 1972).



for Thalidomide deformed children. Using semi-structured interviews, she probed 1) socioeconomic status, 2) the birth, 3) the baby's arrival at home, 4) the present and 5) the future.

These studies from the literature were used as comparison groups[1] for the purpose of delineating a sequence of three stages which families of physically handicapped children pass through in adjusting to the crisis of making sense of a child's handicap. These crisis stages, common to all of these studies, coincided with Stoll's categories of agents of control,[2] (See Figure 1), and were stages during which the family gathered and processed information. Hamburg and Adams[3] have suggested that after the first stunned response to crisis, people seek first information related to blame and responsibility, then information about treatment, and finally information concerned with prospective loss and change of function. The individual family synthesizes the information as it is made available and presents it to the child in such a way that the child is able to define expectations for himself.

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[1]Glaser and Strauss, The Discovery of Grounded Theory, pp. 79-100.

[2]Clarice S. Stoll, "Images of Man and Social Control" in Frank R. Scarpitti and Paul T. McFarlane (eds.) Deviance: Action, Reaction, Interaction, (Don Mills, Ont.: Addison Wesley Publishing Co., 1975).

[3]David A. Hamburg and John E. Adams,"A Perspective on Coping Behavior Seeking and Utilizing Information in Major Transitions", Archives of General Psychiatry, Vol. 17 (Sept. 1967), pp. 277-284.

Figure 1

Crisis Stage and Correspondent Control Agent for Processing the Handicapped Child

Crisis Stage	Control Agent
Identification Cues perceived but may be rationalized, reinterpreted or met with vacilation	Agents of Detection and Surveillance
Diagnosis Involves a series of definitions and redefinitions as more information becomes available.	Agents of Diagnosis or Categorization Agents of Remediation
Remediation Hope for "cure" is given up and limitations of the handicap are acknowledged	Agents of Remediation

Parent Interviews

The parents selected for this study were a group of parents who had enrolled a child in the MACLD Teen Group. In the fall of 1975 these youngsters were organized into a recreational group under the auspices of MACLD. A coordinator, funded through a Local Initiative Projects grant, contacted members of the organization who had teenaged children and invited the parents to enroll their child in the group. There was no screening. Any teenager who wished to join the group was presumed to be learning disabled and was invited to participate in the activities. The parents met at the end of the school year to help the coordinator to evaluate

the program and to discuss summer plans. The researcher attended this meeting and addressed the group to ask their cooperation with the research. All but one parent agreed to an interview.

The twenty-seven parents were interviewed in their home as a maritial pair except one single parent who was interviewed individually. The Interview Format (Appendix A) used was constructed in two parts. Part I was designed to elicit the social characteristics of the family--occupation and education of the mother and father, age of children in the household, etc. Part II contained open ended questions about the child and his career as a student. The format was pretested on two sets of parents who had learning disabled children and were members of MACLD. These parents discussed children who were the same age as those in the research sample but did not belong to the Teen Group. The research interviews were taped, after the informants had given their permission. Informants usually answered the factual questions in the first part of the interview and moved on to the second part which probed more sensitive areas without hesitating. Most parents seemed genuinely interested in providing the researcher with a picture of the problems of raising a learning disabled child, and in some instances, the parents wanted to expand upon the interview into areas not included in the Format. One parent in particular thought it was important for the interviewer to be

aware of the sexual problems of the adolescent learning disabled boy and directed a part of the interview to a discussion of this topic.

The parental interviews, recorded and transcribed on to typescripts were coded by negotiation unit. This unit was designed to conform to the criteria of Becker and Greer[1] which specifies that coding should be 1) inclusive so that any incident is assigned to a category if there is any reason to believe that it might be considered relevant, 2) individualized by the recording of either complete verbal expressions of an attitude or complete acts, and 3) complete, that is, recorded in all relevant details including the ideas expressed, the actions taken, the people present, the date, and the setting. This negotiation unit was synthesized from Martin's conceptual framework of negotiation utilizing his categories of extent and outcome.[2]

Two or more actors may engage in a negotiation when there is ambiguity or disagreement concerning guidelines, and when one of the actors hopes to achieve a goal in the situation. (See Negotiations, p. 8 & 9) Parents who are

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[1] Howard S. Becker and Blanche Greer, "The Analysis of Qualitative Field Data", in Richard N. Adams and Jack J. Preiss (eds.) Human Organization Research, (Homewood, Ill.: Dorsey Press, Inc., 1965) p. 280.

[2] B.W. Martin, The Negotiated Order of the School, (Toronto: MacMillan of Canada, 1976) pp. 10-12.

concerned about a child's inability to achieve in the classroom may contact a number of professionals in an attempt to negotiate guidelines for understanding the child's deficits and to obtain remediation which "makes sense" to them. The negotiation unit was constructed for the purpose of coding individual parental negotiations with various agents of control. Each time a parent reported a contact with a professional agent of control, the ensuing interaction was recorded on a Negotiation Worksheet. (See example in Appendix B). The elements of the individual negotiation unit which were coded were: 1) subject of the negotiation, 2) direction -- who initiated the negotiation for whom, and 3) outcome. Possible outcomes were: a) agent of control's point of view accepted in its entirety, b) all of the actor's compromised, c) nobody really compromised, d) family's point of view accepted in its entirety, and e) other. These Negotiation Worksheets were compared by crisis stage: Identification, Diagnosis, and Remediation to Being Handicapped.

Commonalities at each stage were remarkable in many instances. The library researched groups were all physically disabled and were processed similarly by agents of control from medical settings. The learning disabled children, however, were seen not only by physicians, but also by diagnosticians from the school and social service agencies. Because these children received services from a number of

types of organizations, the process of diagnosis and referral, and therefore of labeling, varied in several ways both within the category of learning disabled and between the learning disabled and the physically handicapped children.

Exploratory Participation

Cicourel[1] has noted that in carrying out investigations in the modern community, it is expedient to establish intimate contacts with the people who have controlling voices in the community. The organizations serving learning disabled children form a type of community-of-interest, and the researcher has much to gain from informal observation and interviews with the people who are involved in this area. Of central interest has been the MACLD organization because one can explore with parents informally their concerns and interests. The researcher has attended parent groups, conferences, and monthly meetings and has sat on the Executive Board as a Social Action Chairman, and in this way, has come to recognize the issues that are important to this group. Members have been most cooperative in providing copies of documents pertaining to the organizational development of the group and have talked at length about their individual experiences within the organization.

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[1]Aaron V. Cicourel, Method and Measurement in Sociology, (New York: The Free Press, 1964), p. 41.

Agency Personnel Interviews

The information gained from MACLD members was invaluable, but as Cicourel[1] cautions, informants may be frustrated or naive and may not be reliable sources of information about some aspects of a substantive area. Therefore information was solicited from key people in agencies processing learning disabled children. Individual interviews were conducted with a psychiatrist from the Child Guidance Clinic, the Director of the Child Development Clinic, the Director of the Child Guidance Clinic, the Area Service Director of the Child Guidance Clinic, and the Director of Student Services from a school district. These individuals clarified the procedures of their particular agencies *vis a vis* the learning disabled child. Each interview was specially focused about the specific knowledge the particular administrator could provide. A few spoke from personal conviction; the others interpreted agency policy. Each interview added a new perspective and helped to verify hunches and impressions gained from other sources. Committee participation focused upon current problems in the field of special education and supplemented the information gained from library sources, from parents, and from interviews with professionals from the agencies.

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[1]Cicourel, p. 54.

Summary

This research into the analysis of the family as agent of control in the labeling of the handicapped child has been qualitative and comparative. A three-step sequence of stages leading from 1) identification, 2) diagnosis, and 3) remediation and adjustment to the handicap was delineated through the comparison of five studies from the literature of the family and the physically handicapped child. Fourteen interviews were conducted with twenty-seven parents of learning disabled children, and the information from these semi-structured interviews was coded by negotiation unit and classified according to the three stages of identification established for the families of the physically handicapped children. The results of this comparative study are presented in Chapter V.

CHAPTER V

THE LABELING PROCESS AND THE HANDICAPPED CHILD

The process which leads from recognition that a child is "different" to a specific diagnosis creates a crisis in the family. During the initial stage of the process, the stage of identification, when ambiguity concerning the child's condition as "normal" or "not-normal" persists, the parents must evaluate cues from their own observations and from those such as teachers, grandparents, and neighbors who are in close contact with the child. The parents become important agents of identification by evaluating the information about the child and by deciding whether or not to consult an agent of diagnosis. If the child is found handicapped in some respect, a rehabilitative program may be recommended, and the parent will be asked to cooperate in following the recommendations of the agent of rehabilitation. Thus the parents become the key control agents for the child and negotiate not only the category of diagnosis but the treatment of the child.

The duration of the period of identification may be brief as in the case of the thalidomide child born without arms. On the other hand, this period of ambiguity may be prolonged and enigmatic in conditions such as mental retardation or

learning disability when the child has no physical deformity but fails to keep up with his peers at developmental stages. The child's condition may be detected during the first year or may exist undetected until the child enters school. The parents and others concerned with the child's differentness will seek help from a diagnostition, a control agent, who uses his specialized knowledge and the lingo of his trade to assert his right to make decisions for the child.[1] The parents may accept the professional's definition in total, question parts of it, or terminate the relationship and seek help elsewhere. Some parents feel that they may question the professional further; others do not. Some professionals take the time to be sure that the parents understand thoroughly; others do not. The synthesis of professional information with family information (professional recommendations with family willingness to comply with such recommendations) requires an ability to negotiate on the part of all the agents of control--the family, the diagnostitions, and the rehabilitation staff.

A description of the process of the diagnosis and treatment of the handicapped child, generally, and the learning disabled child, specifically, is developed in this chapter through an examination of the stages of 1) identification

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[1]Julius A. Roth, "The Treatment of Tuberculosis as a Bargaining Process," in Arnold Rose (ed.) Human Behavior and Social Processes (Boston: Houghton Mifflin, 1962).

2) diagnosis or categorization, and 3) remediation, and also the agents in control of each of these stages. Five process studies[1] of physically handicapped children and their families have been analysed in order to provide a composit description of the stages the family follows in attempting to "make sense" of their child's condition. The data gained from the interviewing of the parents of learning disabled children has been analysed and integrated in accordance with these sequential stages. All handicapped children manifest a primary deviance or condition which limits their ability to perform some tasks. Acknowledgement of the primary deviance through diagnosis or categorization excuses the youngster from performing specific tasks. Remediation and treatment offer correction of the condition or, failing correction, alternate systems which enable the child to achieve successes within his limitations. Secondary deviation in the physically handicapped person[2] occurs when the individual organizes his life about his incapacities rather

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[1] Fred Davis, Passage through Crisis: Polio Victims and Their Families (New York: The Bobbs-Merril Co., Inc., 1963). Sheila Hewett, The Family and the Handicapped Child: A Study of Cerebral Palsied Children in Their Homes, (Chicago: Aldine Publishing Company, 1970). Kathryn P. Meadow, "Parental Response to the Medical Ambiguities of Congenital Deafness", Journal of Health and Social Behavior, Vol. 9, pp. 299-309. Ethel Roskies, Abnormality and Normality: The Mothering of Thalidomide Children, (Ithaca, New York: Cornell University Press, 1972). Margaret Voysey, A Constant Burden: The Reconstitution of Family Life, (London: Routledge and Keegan Paul, 1975). These studies are briefly discussed on p. 40-43.

[2] See Page 17.

than his capacities. His adaptions to disability are greater than that required by the impairment, and he becomes secondarily deviant, a "victim" of labeling.

Diagnostic Search

Stage One: Identification: Concerned parents seek to evaluate their abilities in parenting by comparing the development of their children with those of relatives and friends. Depending upon the age of the child, they will use different bases for comparison. Thus the newborn is measured in inches and pounds whereas the ten year old boy may be measured by hockey-playing skills, grades in school, or physical stature. Some parents supplement this information with material on normal development and are knowledgeable about the "Terrible Two's" and "Trusting Three's". When a child's development is different, the parents may not recognize this difference, or they may dismiss it as unimportant. On the other hand, they may recognize that "something's wrong" and seek professional opinion about the child.

The success of diagnosis as a negotiated process may depend upon the direction of the initiation of detection as presented in Figure 2. Whether the expression of concern is first made by parent or professional may have important consequences for the negotiation process. If the parent recognizes a problem and consults a professional agent of diagnosis, the parent is likely to be cooperative with suggestions

for remediation. If the professional substantiates the suspicion of the parent that, indeed, there is something wrong, the parent can be expected to negotiate a treatment plan with the agent in charge of remediation. If the condition is first identified by a professional such as a teacher, the parent's cooperation first must be enlisted before further diagnostic testing can be implemented. The parent who consults a professional diagnostic agent because she is uncertain about the child and is reassured by the control agent that the child's condition is normal, risks being called "over-protective" (not cautious). The professional who identifies a condition which is later unsubstantiated risks upsetting the parents in order to rule out doubts, but on the other hand, he may be considered "cautious" or "thorough".

Figure 2

Expectations for Parent-Professional Negotiation Based Upon Source and Direction Of Referral

	Parent Initiated	Professional Initiated
Pathology Labeled	Negotiation and co-operation in identification and treatment likely	Cooperation of parents must be enlisted before diagnosis and/or referral can be pursued.
No Pathology Identified	Parents risk being called "over protective"	Professional risks upsetting parents. May be considered cautious and thorough.

Families of physically handicapped children became aware of something amiss in various ways. Mothers of cerebral palsied children worried when their child was not sitting up at the time of their first birthday or had failed to keep up at some other developmental stage.[1] The mother of a deaf child noticed at the time the girl was four months old that she did not respond to her when she tried to talk to her and soothe her.[2] A mother of a polio victim recognized that when the doctor checked the child's neck for stiffness that he was considering the possibility of polio.[3] In most instances the first cues are explained away by common, everyday terms--the lazy baby, a child with the flu etc. Later, sometimes after a number of less everyday attempts at solution, a more serious explanation is considered. Meadow has termed this progressive narrowing of a number of alternatives for explaining the child's set of symptoms as the <u>diagnostic funnel</u>.

<u>Stage Two</u>: <u>Diagnosis or Categorization</u>: The professional diagnostitions are the "legitimate labelers", the agents of control who validate the observations of the agents of identification that the child is, indeed, deviant in some

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[1]Hewett, pp. 38-46.

[2]Meadow, pp. 300-302.

[3]Davis, pp. 23-29.

aspect.[1] These same agents may serve also as agents of rehabilitation, or they may refer the child to a selected agent of rehabilitation. When a child is brought to a diagnostitian, the parents bring a list of presenting problems for the professional to evaluate. The professional must interpret these conditions, gather further information through testing or inquiry, and arrive at a name for the condition. Balint[2] has suggested that the diagnostic process is a "devious path" by which the client and the professional arrive at a compromise". He has suggested that the process involves propositions, counterpropositions, offers, acceptances, and rejections until an "acceptable illness" is agreed upon. Thus the services of the professional should involve more than technical diagnostic skills; the professional must use negotiating abilities in order to arrive at an agreement with the parents about a diagnostic category for the child. The diagnosis once agreed upon is then interpreted to the child by the parents, and the child learns what sorts of behaviors and activities are "excused" because of his handicap.

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[1] Clarice S. Stoll, "Images of Man and Social Control", in Frank R. Scarpitti and Paul T. McFarlane (eds.) Deviance: Action, Reaction, Interaction (Don Mills, Ontario: Addison-Wesley Publishing Company, 1975) pp. 250-258.

[2] Michael Balint, The Doctor, His Patient, and the Illness (New York: International Universities Press, 1975).

Friedson has pointed out that it is often "sheer accident" which agent is selected by the parent to help the family deal with the uncertainty surrounding a child's condition.[1] It may be the police, the minister, or the child's doctor. The parents depend upon this diagnostitian to "make sense" of their child's condition, but researchers have found physicians, in particular, evasive and unwilling to discuss candidly the diagnosis for the child. A similar situation existed in this study of the learning disabled child when children were transferred to special education classes without the family fully understanding the reasons for the change. Principals seemed reluctant to discuss the child fully with the parents.[2]

Voysey[3] studied parents of children with a variety of handicaps, and reported that parents in many cases were never provided with clear definitions of the child's condition. She recognized that the doctor had to be cautious in predicting the future for the child lest the parents become overwhelmed by despair and defeatism. Meadow[4] in studying deaf children reported that sixty percent of the

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[1]Eliot Freidson, "Disability as Deviance", in Marvin B. Sussman (ed.) Sociology and Rehabilitation (American Sociological Association, n.d.), pp. 71-99.

[2]See pages 63-64.

[3]Voysey, p. 100.

[4]Meadow, pp. 300-302.

parents she interviewed in her research experienced four or more medical consultations before arriving at a diagnosis of deafness. One-third of the parents had been told by the first doctor consulted that the child was not deaf. She attributed the physician's inability or unwillingness to consider the mother's suggestion of deafness to the stereotype of the over-anxious mother--"the nervous, cloying, inquisitive, overprotective, neurotic woman--in short, the typical American mother."[1] Davis[2] reported that in the instance of children who became ill with polio, the doctor usually gradually "broke the bad news" to the parents. In many instances the child was sent to the hospital for "tests", and the parents were informed by a member of the hospital staff about the diagnosis. Davis suggested that this strategem relieved the physician of the necessity of performing the "dirty work" of facing the parents with such devastating news. Roskies[3] studying families of children deformed because the mother had been taking thalidomide during pregnancy, found that there was confusion and contradiction about when the mother was told, how much she was told, and when she was allowed to see the baby. Typically the mother might wake up in a delivery room and see that there were tears in the nurses' eyes and the doctor strangely silent.

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[1]Ibid.,

[2]Davis, pp. 29-33.

[3]Roskies, pp. 56-68.

For the next day or so she would be refused permission to see the baby (hospital regulations, baby weak, or another reason). The nurse would avoid eye-contact when she brought in her tray, and finally the doctor, or the doctor and the husband, or priest would arrive, and a curtain would be drawn around her bed and then she would be told.

Hewett[1] writing about spastic children and their parents found that doctors were reluctant to discuss a diagnosis of the child's condition. Of a group of twenty-one children, six of the parents found it difficult to convince the doctor that there was anything wrong with the child; three had become aware of the diagnosis by chance--one overheard the word "spastic" when the doctor was talking with a consultant, and the other two were able to make out the word "spastic" written on their doctor's referral notes. Hewett commented:[2]

> It is probably difficult for the doctor to decide how and when to tell the mother that her child has a condition for which he can offer no cure. But when parents are already suspicious or anxious, it is a mistaken kindness to keep them in suspense any longer--it is clear that someone should be available to give repeated explanations...it may be unrealistic to wait for questions from the parent before initiating such discussion.

In the instance of the learning disabled children

[1]Hewett, pp. 44-87.

[2]Ibid., p. 41.

studied in this research, ambiguity and uncertainty might emerge prior to the time the child entered school, and in most of the fourteen cases studied, it had not been resolved at the time of the research interview. It was not unusual after the interview was completed for a parent to ask for assistance in finding some professional help with problems currently presented by the child. The first hint that "something's wrong" varied. It was immediate for two families whose child was born with a serious heart condition which necessitated surgery while the child was still an infant. These youngsters were under careful observation during their pre-school years and performed at a borderline level when they entered school. Five of the fourteen children were identified as "different" after entering school. One of these five survived in school for four years without learning to read, and it was not until the family moved from Winnipeg that the child's reading disability was recognized. Two other youngsters in the sample were recognized in their pre-school years, but they were living out of the province at the time. One child was examined by a private psychologist and referred to a special school for learning disabled children; the other was diagnosed and treated as emotionally disturbed but was later found to be hard of hearing.

Slow speech development accounted for all six of the children who were referred to the Child Development Clinic

prior to the time the children entered school. These mothers took their children to the pediatrician for regular examinations at ages two and a half and three and called the attention of the doctor to their concern about retarded speech development. Typically the physician brushed off the parent's concern and refused to negotiate a definition of "not-normal" for the child. Mrs. 7 reported:

> He went through a period of very garbled speech, and I realize now that he thought he was responding to what we said. Every time we went to the pediatrician I said, 'Ronald isn't talking. I think he has a speech problem.' I think doctors are so used to over anxious parents. I didn't say anything until he was three because I knew children who didn't speak until they were three. I would mention it everytime, and finally, when he was four and a half I said to the doctor, 'I really want you to listen.' Usually he was quiet. The doctor asked him a few questions such as his name, and you could not make out what he was trying to say. The doctor was startled, and he said he would have to refer to the Child Development Clinic at Childrens.

Another mother recalled:

> When Kathy was about four I took her to our doctor because she was not talking. He held a piece of gum in front of her and asked her what it was. She said, 'um', and the doctor was satisfied. I had to work to convince him that she was not talking. He referred her to the Child Development Clinic, and Dr. Mc. said that she was definitely slow. He recommended a slow learners class. When she was seven I thought there was something wrong with her eyes. I took her to my doctor, and he said I was an over protective mother. Then I took her

> to Dr. B. and I told him I wanted her eyes tested. They discovered she had congenital cataracts. There is no danger of them getting worse, but she looks through dirty window panes all the time.

One of the children was visibly physically different from the others, and one might expect that he would have been identified earlier, but his diagnosis did not deviate from the process experienced by other parents of language impaired pre-school children in the study. This child has some paralysis of the facial muscles, but this condition went unnoticed. Like other youngsters in the sample, he was not talking at the age of three. He could understand language, but he could not talk. His doctor "eventually" referred him to the Child Development Clinic. He was given speech therapy and treated for emotional disturbance. Four years later his doctor apologised to the parents because it was finally established that the child's tongue was partially paralysed; fifteen years later a speech therapist with neurological training diagnosed a condition of pseudo-bulbar disarthria, a manifestation of brain damage which his parents understood inhibited his ability to speak clearly.

The physicians who delayed in referring these children for speech therapy were not avoiding giving these parents "bad news" as in the instances reported in other studies of the physically handicapped children. Rather the physicians refused to negotiate the possibility of abnormality

and discounted the mother as "overprotective". Hewett[1] and Davis[2] have both attacked the use of this term which therapists seem to use so glibly but which no one has succeeded in defining with any precision. Wright[3] has compiled a list from the unpublished dissertation of Shere which lists twelve behaviors ascribed to children of overprotective parents. Perhaps, if agents of diagnosis used more objective criteria rather than responding to personal feelings in assessing the concerns expressed by mothers, the diagnosis would be more immediate.

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[1]Hewett

[2]Davis

[3]Beatrice A. Wright, Physical Disability--A Psychological Approach (New York: Harper & Row, 1960) p. 306.

1. He is overdesirous of petting and cuddling. He likes to sleep in the same room with his parents or even in the same bed with one of them. He is afraid to sleep alone.
2. With younger children he is bossy and aggressive but with older children or adults he is oversubmissive and docile. He is usually very well behaved at school.
3. He is cheerful when he is with his parents or anyone with whom he feels secure but is inclined to cry or be unhappy when he is separated from them.
4. He is overconforming; he obeys implicitly.
5. He is usually apathetic, but in the presence of strong stimuli he may become highly emotional. He may have temper tantrums.
6. He has little or no curiosity. He is interested only in matters of which his parents approve. He shows behavior indicative of insecurity when he is with children his own age who are more mature than he is.
7. He is shy and unfriendly to strangers. He does not know how to play with other children, yet does not like to play alone; he may prefer to be with his parents; he may like to read rather than to play.
8. He is jealous of anyone who appears to threaten his position with loved ones.

Five of the six children who were treated during their pre-school years at the Child Development Clinic were not identified as learning disabled nor minimally brain damaged. Early signs are not as clear as later ones. The nuances of perceptual disturbances, difficulties in concept formation, distractibility etc. may have been noted, but their significance was not communicated to the parents. The sixth child was sent to pre-school for retarded children at the Kinsman Centre and from there into special education classes. He was autistic-like in his responses, and he remained in special education classes for several years until it was established that his intelligence was normal.

Upon entering school all but one of the fourteen youngsters in the research sample were unable to function as normal students and were immediately identified as "problems". One youngster was placed in a class for the hard of hearing, and one, who showed autistic responses was placed in special education classes when he entered school. Two were withdrawn from public school and sent to private

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9. He is afraid in many situations, even where there is no real danger.
10. He is pleased by flattery and depressed by adverse criticism. He constantly asks for assurance of parental favor; he often asks for approval of what he is doing.
11. He prefers to have help in all his activities and is inclined to reject responsibility. He does not dress himself or get to school on time without help.
12. His feeling of insecurity is manifested by nervous habits, which may serve as emotional releases or as attention-getting devices.

schools where they could have more individualized attention. Six were placed in special education classrooms eventually. One remained in a regular classroom without any resource support until Grade Six, and two were diagnosed minimally brain damaged and remained in regular classrooms with the aid of drugs and resource teacher help.

Five children who had not previously been recognized as "different" were identified by school officials when the child began school. Parents seemed willing to have their child retained in grade and complied with requests that the child be referred to the Child Guidance Clinic. In two instances the parents reported that the child was seen several times at the Child Guidance Clinic, but the parents were unable to understand the reason for these visits. Seemingly when recognition that "something is wrong" with the child originated with the school, the parents initially were less demanding of an explanation of either diagnosis or remediation. They seemed to trust the wisdom of the school agencies to provide the proper handling of the child's education.

The diagnosis of learning disability for the fourteen children in this sample was imposed by parents rather than clinicians. In some instances the diagnosis of learning disability was substantiated by professionals, but in most instances the parents selected this diagnosis themselves--thus becoming diagnostic agents for their child. The

Winnipeg Schools and the Child Guidance Clinic have avoided the use of the term "learning disability" because of the ambiguity of the term and the concern with the negative effects of "labeling" a child. MACLD operates a large public information program and counsels parents whose children are having school problems. The organization refers parents to other associations if a more appropriate one exists, but it does not screen out any parent who wishes to join the MACLD organization. The decision to participate in MACLD and to treat their child as learning disabled is an individual decision for each parent to make.

The MACLD group of teenagers which comprised the sample for this study represented a grab bag of handicaps. Only three of them had been able to remain in regular school classes. Of the youngsters from special education programs, eight exhibited some retardation; one was hearing impaired; one autistic; one hyperkinetic, and one whose parents declined to participate in the study, was unknown to the researcher. Within any handicap there is usually a wide range of manifestations of disability ranging from minimal to severe. These children were all described by their parents as social isolates, but there was a wide range of other incapacities described. Some were quite capable and moving toward independence and employment. Others were more severely handicapped by retardation, and in some instances, emotional disturbance.

The line between retardation and learning disability is a very thin one. Clinically the line is drawn between the child who is uniformly deficient and the child who shows some inconsistent strengths or descrepancies between capacity and achievement. Either may appear "stupid" in a classroom situation when exposed to unfavorable comparison with his normal peers. The learning disabled child, however, will have areas of competence. Many of the youngsters in this study sample were "borderline" in their capacities. The question then posed is whether retardation or learning disability should be the master status for remediation. The learning disability status offers hope to parents that through the "right" program of remediation, whether it is exercises to improve perception or tutoring to improve reading, the child will improve and become normal. Birenbaum[1] suggests that the parents of the retarded child bear a courtesy stigma by sharing "a web of affiliation with the stigmatized" and utilize a number of strategies in managing this courtesy stigma of parenting the mentally retarded child. One of the strategies identified from this study is the use of the learning disability status rather than that of mental retardation as a means of handling this courtesy stigma.

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[1]Arnold Birenbaum, "On Managing a Courtesy Stigma", Journal of Health and Social Behavior, Vol. 11 (Sept. 1970) pp. 196-206.

Search for Remediation

Stage Three: Impact and Rehabilitation: Hamburg and Adams[1] have suggested a series of information gathering steps through which people move after the first stunned response to becoming caught up in a crisis:

1) Information gathered in relation to blame and responsibility
2) Information gathered about treatment
3) Information gathered concerning prospective loss and change of function.

During this period of information gathering, people attempt to maintain satisfactory internal conditions for both processing the information as it comes to them and for initiating action. If successful with integrating the information obtained and with maintaining an ongoing stability within the family, the family will be able to move on to the stage of mastering the new situation which implies an ability to act flexibly and to keep some degree of autonomy for each of the members. Davis[2] found that parents who were trying to understand their child's hospitalization with polio, sought very early to evaluate their own responsibility. They wondered whether they might have limited the child's activities and thus avoided his exposure to the virus, or they interpreted the illness as being punishment by God for

[1]David A. Hamburg and John E. Adams, "A Perspective on Coping Behavior", Archives of General Psychiatry, Vol. 17, pp. 277-284.

[2]Davis, pp. 36-44.

their own transgressions. Meadows[1] recognized that parents of deaf children were concerned about the etiology of the hearing loss. She attributed these strong feelings to an underlying concern that the condition might be hereditary but recognized that there might be a number of reasons for these feelings. Zuk in reference to parents of mentally retarded children noted:[2]

> The great parental concern over isolating the cause of the handicap can also be viewed as an attempt to shift anger and guilt. Guilt is reduced when a specific cause of the child's condition can be given.

According to Roskies,[3] the majority of mothers of thalidomide deformed children were relieved to learn that their child's handicap was due to the medication because it established the cause as external rather than hereditary. Fewer mothers were centrally concerned with the fact that the deformity could have been prevented.

Parents of learning disabled children looked for a physical basis to the child's handicap and in some instances were able to pinpoint one. One child had become autistic-like after a severe fever; one child was born after the mother had had measles while pregnant, and one mother had

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[1]Meadow, p. 303.

[2]Gerald Zuk in Meadows, p. 263.

[3]Roskies, p. 96.

taken heavy doses of tranquilizers during pregnancy. Heredity was suspected in some instances. One child's father had been learning disabled, and the hard of hearing child's only sibling was also hard of hearing. Very often more basic than etiology was the ambiguous concern over "whose fault" was the child's inability to succeed at school. Parents often blamed the schools.

Heavy criticism of the special education system was expressed, and only four of the children in the learning disability sample had not been in a special education class at some time during their elementary school years. Socially the children were isolated in these classes and had no opportunity to interact with "normal" children. At the time these children were in elementary school these classes were in basements or other remote parts of the school, and the children were not allowed on the playground at the same time as the "normal" children. Parents complained that many of the teachers had very low expectations for the children and provided little or no stimulation.[1] One very perceptive mother analysed:

> Mrs. 12: Segregated that is what they were! The teacher had literally an apple box to sit on in that dingy basement! You know that Mr. D.

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[1]The topic of teacher expectations has been a controversial one. See Robert Rosenthal and Lenore Jacobson, Pygmalion in the Classroom (New York: Holt, Rinehart and Winston, Inc., 1968) and Janet D. Elashoff and Richard E. Snow, Pygmalion Reconsidered (Worthington, Ohio: Charles A. Jones Publishing Co., 1971).

> He was the first to break through this. He had one youngster, Sam, who was terribly talented, and he asked the art teacher if he would give him some lessons. She said that she would give him all the equipment if Mr. D. would take it to his room. He said, 'I don't mean that. I want them to go to you!
>
> He got these kids to graduation that year. We were at graduation--my husband, myself, and my mother. There was a reception afterwards. We were wondering since Sandy had been a good student if he might not have gotten some honorary mention or something. At the reception Mr. D. came and said that he didn't know what went wrong. Sandy was to get an award, but his name wasn't read. I can still remember the anger.

Some children had been assigned to special education classes without anyone in the family understanding the reasons for placement. Mrs. 2 noted that the teacher was very careful about what she said about Betty and remarked, "I guess a lot of people flare up. I can understand that." Betty's early career was hard to trace:

> Interviewer: With Betty, what happened after she started public school?
>
> Mrs. 2: They told me to get an eye test and an ear test, and then they put her in F. School.
>
> Interviewer: In a special education class?
>
> Mr. 2: Yes.
>
> Interviewer: Did you assume she was retarded?
>
> Mr. 2: No! No! But then we didn't know much about special classes. She never said anything, but I think the kids used to tease her because she went to a dummy school.
>
> Interviewer: When did you become aware that

> she might be learning disabled?
>
> Mrs. 2: When she started in at R. School. I felt that there was no hope until I met this group (MACLD). Then I found out they could live with other people. Just make them behave and live like normal.
>
> Interviewer: Was she ever seen by someone at the Child Guidance Clinic?
>
> Mrs. 2: Well, this is what I mean. We have never had her at any clinic.

Mrs. 4 talked about her experience with Kathy. Kathy spent two years in kindergarten on the advice from a doctor at the Child Development Clinic, then:

> Mrs. 4: When she entered grade one she had a teacher who had no patience for the slow child although she was excellent with the bright ones. She was the one who had her transferred to special ed. At that time it was good because I will tell you she (Kathy) was physically ill. The doctor diagnosed it as "flu". The principal called to say that he was transferring her to another class and she would be transported by bus and would need a lunch. That was my introduction to special education. I was glad to tell Kathy she didn't have to go back to her class.
>
> Mr. 4: She was frustrated. She couldn't do the work and she felt so bad that she was physically ill.

One child was not given the protective shelter of a special education class nor a category which might shield him from the humiliation of not keeping up with the rest of the class. Mrs. 11 described her first contact with Gene's grade one teacher who threw her book on the floor and announced that, "There is no way he can get through grade

one!" In the years which followed Mrs. 11 visited the principal on numerous occasions to discuss her boy who was becoming a chronic truant. The child was promoted each year, and the principal assured the family that everything possible was being done for Gene. At the time the child entered grade six, he was working at a grade three level, and the teacher had called the mother over to the school to discuss Gene's cheating. The parents took their problems with Gene to the doctor who referred him to Children's Hospital. The doctor to whom he was referred took the initiative of meeting with the school board and asking for a modified program for the boy.

Adjustment to the Handicap: Upon initially discovering that their child was physically handicapped, most parents seemed to have tremendous faith in the professionals to cure the child. Only later, as their high expectations were crushed, did the parents seek an outcome which was less than total recovery. During this inventory stage, the family became more aware of the limits of the professionals and lost their great faith in the healing power of the doctor. A similar period of reevaluation took place in the families of the learning disabled children and has continued to occur and reoccur as the child moved through adolescence. Some families of physically handicapped children accepted rehabilitation and remediation in the place of cure; some never did. Some families of learning disabled children looked to new programs, new tutors, more individualized teaching to

"cure" the learning disability. Some recognized the limitations of their child and tried to help them adjust within the realities of the facilities available. The drama of the early crisis phase receded, and the family began to see professionals on a routine service basis. A phenomenon described by Balint, the "collusion of anonimity" was inevitable as a number of professionals--social workers, teachers, doctors etc. drifted by--all doing their job to "service" the client but none of them taking ongoing responsibility for that child and his family. "Vital decisions were taken without anybody feeling fully responsible for them."[1] Knowledgeable parents could offset this situation by becoming advocates for their child and by seeking for and demanding services for their child. Many families lack the persuasive skills or the knowledge of bureaucratic processes necessary for interceding in behalf of their child.

The family arrived at a homeostasis, a stability which allowed them to accomplish family business despite the added burden of a handicapped child. Hewett[2] found that families of cerebral palsied children met the day-to-day problems the handicap created with patterns of behavior very similar to families of normal children. Voysey[3]

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[1]Balint, p. 76.

[2]Hewett, pp. 194-207.

[3]Voysey, pp. 128-131.

spoke of the normalization process as "the presentation of normal parenthood" in which the parents did not deny the differences between their family and normal families but did only "what a normal parent would do under the circumstances in question." Davis[1] noted that almost invariably parents were unaware of any changes which had occurred within the family even if chance remarks indicated considerable change. Evidentally the change-producing experiences were muted by a sense of sameness and steadfast continuity of identity to the family.

As noted before, the library studies of families with physically handicapped children were short termed studies of younger families, However, as the handicapped child moves toward adulthood, the developmental crisis of adolescence disturbs the family balance. The parents no longer may be able to aspire to conventional parenthood because the handicapped child may have only limited access to adult roles (job and marriage). Some parents begin to realize that they are facing the long-time care of a semi-dependent child, and they recognize that the family cycle may never be completed through this child establishing himself in the adult work world and having his own family. The families of the learning disabled children in this study were involved in this very serious reality.

Only one of the youngsters surveyed in this study

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[1]Davis, p. 133, 175-178.

could hope to use education as a step upward to a career. The rest could use the education system for vocational training. Six of the children in this study had either dropped out of high school or had graduated from R.B. Russell. Three had not found employment, and three were employed in unskilled jobs. These youngsters had been through the special education classes when resources were minimal and special education teacher training very limited. The children were social isolates with no friends other than those in the MACLD group. They had very limited outlooks for employment.

Erikson[1] has described the task before the young adult as the establishment of an ego identity from the "inner capital accrued from all those experiences when successful identification led to a successful alignment of the individual's basic drives and his endowment and his opportunities." For the handicapped teenager this implies the "competence to manage incompetence". He may be triply disadvantaged.[2] First he must contend with the identity imputed to him by others i.e. stigmatization. Secondly his disability may isolate him from attaining inter-personal skills, and, as a result, he may come to regard himself as

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[1]Erik H. Erikson, Childhood and Society, 2nd ed. (New York: W.W. Norton & Co., Inc., 1963) pp. 261-269.

[2]Voysey, p. 155.

incompetent and begin to organize his life about his disabilities rather than his abilities. In the language of the labeling theorist, his deviance develops into a secondary deviance. Hewett observes:[1]

> The parents, and later the child himself, must walk a tight-rope between acceptance of the fact that he is different from other children and insistence that he should be like them in as many ways as possible. If they emphasize his differences, continually, 'making allowances' for his disability and learn a habit of helping and shielding they may be branded 'overprotective'; if they minimize his handicap, treat him as an ordinary member of the family and speak with optimism of his mental attainments or physical prospects, they may be judged to have 'failed' (sic) to accept the situation.

Still handicapped teenagers are as sexually aware as any other teenagers. Two of the youngsters in the learning disabled group had become involved in a serious relationship. They had purchased engagement rings and announced their engagement. The boy worked as a warehouseman, but the girl's mother found him grossly unattractive, and his impulsive behavior frightened her. She sought to sever the relationship between her daughter and the boy by taking the girl on a three month trip. Two boys were of great concern to their families because they had been caught window peeking. Another had been enticed into performing homosexual acts with older teenagers.

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[1]Hewett, p. 202.

Davis[1] found that some families stressed normalization for polio-crippled children while others stressed dissociation, although all families alternated between strategies occasionally. The degree of handicap was not always the most important variable in determining whether the family adopted a normalization approach, and some families with more seriously handicapped children were most successful in normalizing the child's adjustment. However, in instances where the handicap was profound rather than moderate, the child had less access to normalizing situations such as regular school classes and friendship groups. Under these circumstances, even where a predisposition toward normalization existed, the social environment induced dis-associative tendancies.

Adolescence for the normal child is a time of growth during which the child moves from being almost entirely dependent upon the family to developing his own identity through looking elsewhere for emotional support and values. If, as in the case with handicapped children, the child remains dependent upon the family for a prolonged period of time because of a lack of access to friendships and/or experiences of success, the role of the parents at this stage becomes doubly precarious. Three families of learning disabled children were having serious trouble with near psychotic or suicidal young adults. Three were concerned

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[1]Davis, pp. 148-162.

with withdrawn, overly dependent graduates of R.B. Russell who did not have the resources to establish themselves in the adult employment world. These youngsters were rapidly joining Farber's[1] "surplus population"--those people unable to "fill the slots" in modern society despite all the parental push toward normalization. Seemingly the families which offered comfort, concern and protection, were faced with children whose dependence was reinforced by the lack of opportunity in the work world.

Cummings, Bayley, and Rie have suggested four factors involved in the successful parenting of the handicapped child:

> 1) Characteristics of child's state: its implications for independence of function, its salience of visibility and associated stigma-value, its demands upon parental caretaking.
>
> 2) Parental personality features such as their caretaking competences prior to the onset of child's deficiency state.
>
> 3) Family resources: for diversifying and sharing caretaking roles, for compensatory approximation of family's goals through alternate members, for flexibly varying approaches to solutions of problems created by the existence of the deficient child.
>
> 4) Community resources for treating and rehabilitating deficient children and for

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[1]Bernard Farber, Mental Retardation: It's Social Context and Social Consequences (Boston: Houghton Mifflin, Co., 1968).

> integrating them into its economic and social life.[1]

The parents who either do not have a clear understanding of the child's limitations or because of personal need, misinterpret the diagnosis, may contribute to a misdiagnosis--a very confusing situation for the child. Two major types of misdiagnosis have been observed in this study of labeling the learning disabled children. Type I errors in which the agents of control have refused to categorize when the child apparently _is_ learning disabled, and Type II errors in which the child has been categorized learning disabled when it is doubtful that this is the primary reason for his school-related problems.

When a Type I error occurs, the child may be denied the services he needs. In the case of Ronald, the youngster had a history of busy hyperactivity, speech problems, severe reading problems, and tremendous difficulty in recalling the sequences of letters which constitute words. He was removed from kindergarten because of his hyperactive behavior and finally sent to a private school where the classes were small. He returned to public school in grade six and experienced a happy and productive year with help from an excellent teacher and resource teacher team. The following year

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[1]S. Thomas Cummings, Helen C. Bayley, and Herbert E. Rie, "Effects of the Child's Deficiency on the Mother: A Study of Mothers of Mentally Retarded, Chronically Ill, and Neurotic Children", _American Journal of Orthopsychiatry_ Vol. 36, (July 1966) pp. 595-608.

he went to a junior high school where the academic standards were high, and his mother went to the school to explain Ronald's chequered school career up to that point. The principal was unimpressed with her description of his learning disability and gave Mrs. 7 a talk about "the evils of labeling".

Mr. 7 Suggested:

> I had the feeling at R School, they did not want to recognize the problem because they weren't able to deal with it, and they wanted it put off on someone or something else.

Mrs. 7 added:

> The most difficult thing was the attitude on the part of the staff that he could do a lot better if he tried. This may have been true, but they didn't seem to get the picture of why he was not trying.

The child's year in school was disasterous. The parents felt the change from the supportive environment of the elementary school to a demanding one in junior high school served to disillusion the boy and contribute to his eventual failure that year. The following year Ronald attended another school where the attitude was significantly different. He was allowed to do some of his lessons on a tape recorder and was referred to the MACLD Lions Learning Centre where he made excellent progress.

The 13's could never remember the terms brain damage, learning disability, or retardation being used to describe Harry, but all were applicable to him. At the age of fifteen he came to the attention of Children's Aid because of

angry exchanges with his father. Henry had repeated grade one and been referred to the Child Guidance Clinic where his mother had taken him for several appointments. Finally he was placed in a special education class because he was "slow". Unfortunately he perseverated and had severe temper tantrums. The parents were unable to "make sense" of his behavior and overprotected him--not allowing him to leave the house unaccompanied. Seemingly every effort had been made _not_ to "label" Henry, but his present patterns of withdrawal have become alarming. The parents have only recently been given a more realistic understanding of his deficiencies and capacities.

A type II error in which the child is categorized learning disabled when he is _not_ may also be detrimental. The youngster may be excluded from programs which are more appropriate to his condition. This is particularly evident in the case of the retarded child who is nearing completion of high school and is ready to look for employment. The retarded adolescent is eligible to provincial programs ranging from sheltered workshops to vocational counseling and federal social security. Parents may prefer to use the term learning disabled, but in so doing they may cut him off from the services designed to help him find a normalized adult role.

These errors seem to occur as a result of the present policy of not "labeling" handicapped children. The

underlying philosophy, growing out of labeling theory, confuses refusal to categorize or diagnosis with repudiation of labeling. Actually practitioners using this strategy are avoiding only a part of the labeling process. As described by Lemert,[1] labeling is a series of interactions in which the deviant individual is identified, categorized, and treated within the dimensions of a "label". The schools by identifying and providing remediation are using two stages of the labeling process without using the categorization stage. They may provide the parents with enigmatic assessments in many instances rather than a clear diagnoses--thus hoping to bypass the labeling process. However, they are leaving parents bewildered and questioning.

Parents, on the other hand, have been quite willing to use the label "learning disabled" as a basis for understanding their child's inability to function in the classroom. They have adopted the term with or without legitimation from an official agent of diagnosis. In the absence of a clearcut diagnosis or a diagnosis which is acceptable to the family, parents have sought to "label" their child "learning disabled" by defining him as learning disabled, by attending meetings and conferences at which they can gather information to form a basis for expectations about the performance of learning disabled children, and by enrolling him in a special group for learning disabled children.

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[1]See p. 17

Labeling the Learning Disabled

Among these learning disabled children the labeling process varied depending upon the manifestations of the disability. Most youngsters with more severe conditions would remain handicapped; others able to compensate for their deficiencies were in regular school programs and could expect to have access to regular employment channels and adult roles. A sequence of stages was generalized from the study of the experiences of these youngsters leading from the early stage of identification through secondary deviance. The labeling process outlined here was generalized from the study of this unique group of socially isolated youngsters and may not be characteristic of other learning disabled children -- either within or outside of the MACLD organization.

Pre-school Identification

Stage 1: Child during pre-school years identified as "different". Parent consults physician about developmental problems such as slow speech.

Stage 2: Child referred to the Child Development Clinic. Given remediation such as speech therapy or special pre-school program.

School Identification

Stage 3: Child enters school. Is identified "a problem".

Stage 4: Child referred to the Child Guidance Clinic.

Remediation

Stage 5: Child assigned resource teacher help.

Stage 6: Child placed in Special Education Class.

Diagnosis

Stage 7: Parent becomes aware of MACLD and contacts the organization.

Stage 8: Parent decides that the child is learning disabled, with or without verification from some professional assessment, and joins MACLD.

Labeling

Stage 9: Child accepts the definition offered by the parent and begins to use this "label" to escape difficult situations.

Summary

Parents studied in this research, attempted to negotiate with a number of professionals in order to gain some understanding of their child's handicap and to develop some strategies of remediation. The parents of the physically disabled children described in the literature studies were all given services in a three stage sequence of identification, diagnosis and remediation. The process was very different for the parents of the learning disabled children. Many professionals sought to avoid "labeling" the child through eliminating the diagnosis stage of the sequence. The parents themselves, assigned the category "learning disabled" to their child by joining the Manitoba Association for Children with Learning Disabilities (MACLD) thereby

developing expectations for "learning disability" types of performance from the child.

The handicapped child first learns the meaning of his disability within the family setting, and the parents, in turn, depend upon the information provided by various professionals. Whether or not the child becomes trapped into secondary deviance as manifest in using his handicap as a means of withdrawing from mastering the developmental stages of maturation may be dependent upon the family's definition of his capabilities - a definition which is usually negotiated between the parent and professional.

CHAPTER VI

DEVIANCE, DIAGNOSIS, AND DISABILITY: SUMMARY AND IMPLICATIONS FOR FURTHER RESEARCH

This research has sought to add to existing knowledge about the labeling of children and specifically the family's experience in the labeling process. Most studies of labeling children have focused upon the bureaucratic agencies such as those of the juvenile justice system or the special education system, and only in the studies of physically deviant children has the family experience been examined. This study has attempted to utilize the literature of the family and the physically deficient child as a basis for analysing the labeling process of another category of handicapped child--the learning disabled child. Using the qualitative techniques delineated by Glaser and Strauss,[1] the researcher has compared the labeling process described in five studies in the literature of the family and the handicapped child with the experiences described by twenty-seven parents of learning disabled children. The parent interviews were non-randomly selected, and in no way could they be

[1]Barney G. Glaser and Anselm L. Strauss, The Discovery of Grounded Theory: Strategies for Qualitative Research (New York: Aldine Press, 1967).

Human Policy Press, P.O. Box 127, University Station, Syracuse, N.Y. 13210

Figure 3

Poster Used by Agencies Servicing Handicapped Children

P.O. Box 127 / University Station / Syracuse, N.Y. 13210

considered representative of the universe of learning disabled children or their families. However, the findings reported in this study describe the process by which these families recognized and defined a disability. In so doing this research extends the understanding of labeling theory into an area where it has previously not been applied.

The Family as Labeler

The human infant begins life with potentials for social development. His behavior is interpreted and given meaning by the family which surrounds him and monitors his progress.[1] He comes to define himself through the family's responses to him which are categorized as "bright", "cute", "nasty", "pathetic", "bad", or a number of other epithets. Each verbal statement is accompanied by gestures such as a smile, a hug, or perhaps a frown and a tone of voice quickly interpreted by the child as pride, disapproval, fury, or some other emotional reaction. As long as the child's social contacts are limited to his family, there is no escape from its judgement. The child who is constantly belabored for being stupid or generally inferior to other children has no choice but to accept this appraisal of himself and to behave

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[1]Sheldon Stryker, "Symbolic Interaction as an Approach to Family Research." Symbolic Interaction: A Reader in Social Psychology, Jerome G. Manis and Bernard N. Meltzer, (eds.) (Boston: Allyn and Bacon, 1967). "Symbolic interaction Theory: A Review and Some Suggestions for Comparative Family Research," Journal of Comparative Family Studies, III (Spring 1972) pp. 17-32.

accordingly. The self concept he develops within the family will form the basis of his definition of himself as he ventures into the non-family world.

When the child enrolls in school he begins a long struggle within himself and within his family for independence. He needs to be secure enough and free enough to enter into peer groups and school activities where he can develop aspects of his identity apart from his family. This entrance into the non-family world becomes particularly stressfull for the handicapped child and his family since the handicapped child is often banished from the society of his normal age-mates, and the normal personal growth which usually takes place at this time may be arrested not only by the child's specific limitations but also by the lack of opportunities society makes available to him for participation.[1]

The presence of a deviant child creates a problem in the management of family identity. Children are expected to reflect with credit the values held important to the family--athletic prowess, toughness, piety, popularity, or whatever attributes are deemed important by the family. The child who is "different", poses a problem to the family which must handle the stigma associated with presenting such

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[1] Constantina Safilios-Rothschild, The Sociology and Social Psychology of Disability and Rehabilitation (New York: Random House, 1970). This author deals with the prejudices against the handicapped.

a child. The families in this study sought a diagnosis which would explain the child's condition. They sought a diagnosis which would present the child most favorably--not stupid, not emotionally disturbed, but learning disabled.

Smith[1] has observed that the labeling perspective differs in the case of the physically deviant individual from the behaviorally deviant individual. The deviant is commonly perceived by labeling theorists as a victim or under-dog. However Smith noted that the physically deviant individual, instead of being a passive recipient of a "label", often actively sought the "label" and with it the resources available to those assigned this specific category. This research supports Smith's observations. Families of these learning disabled children sought this diagnosis and services through joining MACLD and through labeling their child learning disabled.

The negotiations recorded concerning diagnosis and remediation in this research were reported by parents retrospectively and not by an observer skilled in noting interaction processes. They reflect only parent's selective memories of events which took place over a period of usually ten years. They contain no insights from doctors or school personnel who were present at these interviews. However,

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[1]Richard T. Smith, "Societal Reaction and Physical Disability", Walter R. Gove (ed.) The Labelling of Deviance: Evaluating a Perspective (New York: John Wiley & Sons, 1975).

the informants reported a series of one-sided, closed negotiations between themselves as parents and the professionals. The professional is expected to dominate the interview, and he assumes his opinion will be accepted. However, parents, particularly working-class parents, had very little understanding of their child's disability. Either the information given these parents was minimal and obscure, presented in much to brief and abrupt a fashion, or the parents did not feel free to ask for more information or clarification. Information is a resource to the family, but as Coelho and Hamburg[1] have suggested, during crisis periods it is absorbed and processed in specific sequences, and painful information is assimilated in very small doses.

Information is also expensive. MACLD was founded by middle class parents--many from professional backgrounds who spent hours scouring out material in libraries about learning disabilities. They took their children to clinics in the United States for diagnosis. They had the time, the financial resources (even if borrowed), and the knowledge of formal organizations necessary to pursue this diagnosis for their child. The children from professional families in the research population had all been given assessments and services in addition to those provided through the Winnipeg

[1] George V. Coelho, David A. Adams, and John E. Adams, Coping and Adaption (New York: Basic Books, Inc., 1974).

Child Guidance Clinic and the Child Development Clinic. The children from working-class families, on the other hand, had been routed into special education classes, and in special education classes they remained without further reassessment.

The parents studied in this research became the primary agents of control in the labeling process. They were the identifiers, the monitors, the coordinators, the record keepers, the advocates, and the negotiators in behalf of the child. They "muddled through" attempting to negotiate with systems which were closed to negotiation, and finally they decided upon the diagnosis of learning disability themselves. The diagnosis provided an acceptable explanation of the child's enigmatic behavior and also directions and hope for remediation.

A handicap is a primary deviance for which the individual is not responsible. The handicapped child, assumes a role similar to the sick role described by Parsons and Fox.[1] Sickness allows the individual to withdraw from normal activities and responsibilities. For the child who is being pushed and pulled along a "tension-ridden" path towards adulthood, illness can provide a method of escape from obligations. Through an indulgent attitude toward the ill child, the family may invite the youngster to perpetuate

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[1]Talcott Parsons and Renee C. Fox, "Illness, Therapy, and the Modern Urban American Family", in Norman W. Bell and Ezra F. Vogel (eds.) A Modern Introduction to the Family (Englewood Cliffs, N.J.: Prentice-Hall, 1967).

his illness. Like the sick child, the handicapped child may be excused from some types of obligations and not held responsible for his inability to perform them. However, the handicapped child is not expected to "get well". The danger of becoming "labeled" is that of drifting into secondary deviance in which the child responds to his "label" and the societal reaction to the label by organizing his social roles and self-regarding attitudes around his deviance. Thus the handicapped child might use his physical disability as a basis for escaping from using his residual capacities productively.[1] For some of the learning disabled children studied in this research, secondary deviance was <u>not</u> eliminated by agency attempts to avoid "labeling" through ruling out the stage of diagnosis. These youngsters were experiencing secondary deviation manifest in psychosis, suicidal episodes, and passivity. Too capable for sheltered workshops, too inadequate to find and keep conventional employment, these young adults were retreating from establishing themselves as autonomous individuals. The true malingerer is a rarity.[2] Therefore withdrawal into apathy and emotional disturbance provided an alternative to a

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[1]Edwin Lemert, "The Concept of Secondary Deviation" Edwin Lemert (ed.) <u>Human Deviance, Social Problems, and Social Control</u> (Englewood Cliffs, N.J.: Prentice-Hall, 1967).

[2]Judith Lorber, "Deviance as Performance: The Case of Illness", <u>Social Problems</u>, Vol. 14 (1967) pp. 302-310.

conscious decision to become dependent. Parents of these children were reexploring the implications of their child's handicap--his social isolation and inability to find employment. As the hopes for remediation seemed to fade, they were beginning to consider the possibilities of long term dependency upon the family.

Diagnosis as One Stage in the Labeling Process

The logic of labeling theory is deceptively clear and uncomplicated, and many policy makers and practitioners have accepted it uncritically. "Labeling" has become a term of disparagement, and many practitioners have sought to eliminate "labeling" and the effects of "labeling" by deleting one stage (diagnosis) in a three stage process. (See Figure 3.) Although the learning disabled children studied in this research were _identified_ as "different", and _treated_ in the school system as "different", they were assigned no diagnostic category lest they be "labeled". This suggests a very simplistic application and understanding of labeling theory!

Labeling is inescapable for the handicapped child. His disability constitutes a primary deviance and prohibits him from performing certain activities. The handicap may be visible as in the instance of the crippled child or only identifiable through behavior such as the retarded child's slow school performance or the learning disabled child's

hyperactivity. Still the child <u>is</u> different and will be identified as different by family, peers, and professionals. As such he may be given remediation whether it is resource teacher help twice a week, placement in a special education class, or three Ritilan tablets each day. To eliminate "labeling", it would be necessary to eliminate <u>all three stages</u> in the labeling process i.e. identification, diagnosis, and remediation. Once the child is identified (which is inevitable with the handicapped child) it would be reprehensible to deny services to him in an attempt to avoid the allegedly deleterious effects of "labeling". It would seem equally fatuous to deny a diagnosis to a family trying to understand their child.

Labeling theorists seem to argue that it is the term itself and the hostile reaction that accompanies it which brings forth disastrous results. These categories are, of course, symbols--very imprecise symbols; they have meaning in that they produce definitions of the situation and some expectations for performance. The terms designating physical deviance are generally neither degrading nor humiliating as are the terms used to describe behavioral deviance. They are statements of a physical condition--a basis for clarification. These terms lack precision, and the same term may be used to describe a very severe handicap or a very minimal one. Expectations are physically and socially determined. Parents gather information from a number of resources both

professional and casual in attempting to negotiate the meaning of a particular diagnostic term for their particular child. Thus it is the family and not the bureaucratic agency which eventually "labels" the handicapped child.

Implications for Further Research:

This research has been comparative and exploratory, and as such, it has opened new areas for further investigation and research:

1) Previous process research into families of handicapped children has been limited to short term studies of the young handicapped child. As this research indicates, the meaning of the handicap for the family changes as the child enters adolescence which demands peer group participation and adulthood with its demands for entering an occupation and finding a mate. Longitudinal studies would be less vulnerable to retrospective interpretation on the part of the parents and would provide more complete developmental information on the handicapped child, his family, and his non-family interaction.

2) Negotiations between parent and professional provide the basis of the family's and thus the child's understanding of the child's limitations and abilities. Such negotiations might be more completely and objectively recorded if the transactions were observed by a person trained in a form of interaction process analysis. Such a system of analysis would provide a more objective basis for

examining the types of negotiations professionals use in attempting to handle parents' concerns about handicapping conditions--both during the crisis of discovery and diagnosis and the ensuing periods of adjustment to the limitations of the handicap. These analyses would also add to the literature on crisis and the processing of information in crisis situations.

3) The sample used in this research was unique and not representative of all families of learning disabled children. Notably lacking from this study were families whose children made a satisfactory adjustment to their handicap or "grew out" of the condition as they matured. A study of families with such children, both from the MACLD organization and from families who have handled this handicap without using the services of this organization, would provide information about alternate ways in which the problems associated with the identification, diagnosis, and remediation of the learning disabled child have been handled.

4) Finally we need to question the impact of the diagnosis stage on the labeling process. As this research revealed, disregarding the diagnosis did not ipso facto eliminate secondary deviance. In fact, the ambiguity of not understanding "what's wrong" created a severe problem in itself. Sampson et al[1] found that persons who were

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[1]Harold Sampson, Sheldon L. Messenger and Robert W. Towne, "Family Processes and Becoming a Mental Patient", Earl Rubington and Martin S. Weinberg (eds.) Deviance, the Interactionis Perspective (New York: The MacMillan Co., 1968).

grossly disturbed and overtly psychotic often remained in the family without being categorized as mentally ill. The absence of a diagnosis did not stem the ongoing deterioration, and eventually the individuals had to be hospitalized. In these instances the lack of diagnosis did not seem to delay, detour, or ameliorate the individual's condition.

Labeling theory, then is useful in investigating the field of disability and rehabilitation. However the concepts developed within the context of behavioral deviance are not always directly transferrable to the field of physical disability without study and modification. These recommendations suggest areas for research which should prove fruitful in further exploration of the labeling of handicapped individuals.

APPENDIX A

INTERVIEW FORMAT

PART A

Age of Child__________

Other Children in the Family by age and grade__________

____

____

Education Father________________

Occupation Father________________

Education Mother________________

Occupation Mother________________

Religion

Protestant________

Catholic__________

Jewish____________

Ethnicity________________

Member of MACLD____________How did you hear of MACLD?___

If so, do you attend meetings regularly_________; Participate on committees__________

Specifically, what are the problems presented by your child?

____

____

____

____

Which of these concerns you most?________________

Complications of pregnancy or birth______________

Does he have any physical handicaps?_____________

If so, explain________________________________

____

Has he ever received medication for hyperactivity?_______

Was his developmental progress normal for such accomplishments as crawling, walking, speaking, dressing himself?

____

____

____

PART B

How did you first become aware of your child's problem?

With whom did you discuss this problem -- neighbors, relatives, friends, etc.?

Who have you contacted (agencies or professionals) for help with your child? What recommendations did they make? Were they helpful? In what way? Did you feel free to call back? Did you?

Which teachers and/or principals have been helpful?

Have you ever contacted your school superintendant or school board concerning your child?

How have you explained your child's handicap to others?

Has your child's behavior caused any disruptions in your social activities?

Does he have friends, or is he a loner?

What are his interests?

Does your child have troubles with other children bullying him? How has he handled it?

In what ways has your spouse helped with your child?

What effect has the presence of your learning disabled child had on other children in the family?

APPENDIX B

NEGOTIATION WORKSHEET AND CODING INSTRUCTIONS

Coding Instructions

1) Identify negotiation units in the typescripts and assign a number from 1 to n to each unit. A negotiation occurs when a parent and professional confer about the identification, diagnosis, or remediation of a child's handicap. The numbers are assigned consecutively with the first negotiation in Interview 1 assigned the number 1 and continuing throughout the entire set of interviews. (Do not start each interview with number 1). Write the number of the negotiation unit in the margin of the typescript next to the text of the negotiation.

2) Transfer the identifying number for each negotiation unit on to the Negotiation Worksheet. List the number of the negotiation in the space alloted by Negotiation Number and the number of the interview in which the negotiation occurs in the space marked Interview Number.

3) Briefly describe the content of each negotiation. Examples:

"My child is not talking."
"We are transferring your child to a special class."
"Mrs. 6, I am afraid your child is mentally retarded."

4) Identify direction of negotiation in terms of who initiated the negotiation. (The professional may control the negotiation without initiating the consultation.) If the parent initiated the negotiation, indicate this situation by listing the word, parent, an arrow, and the type of professional consulted:

Parent ⟶ Doctor

If the professional contacted the parent, list the type of professional, an arrow, and the word, parent:

Teacher ⟶ Parent

In the event the parent was referred to the professional by another professional, list the referring professional, an arrow, the word, parent, and the type of professional to whom the parent was referred:

Principal ⟶ Parent ⟶ Psychologist

5) Describe briefly the outcome of the negotiation. Examples:

Doctor recommended drugs to control Jane's hyperactivity.

Psychologist diagnosed mental deficiency; parents refused to accept the diagnosis.

Mother asked for speech therapy for child; principal agreed to refer child to Child Guidance Clinic for speech therapy.

6) Circle the number below outcome which most closely described the outcome of the negotiation.

NEGOTIATION WORKSHEET

Negotiation Number ______ Interview Number ________

Content: ____

____

Direction: ____

Outcome: ____

1) Agent of control's point of view accepted in its entirety.
2) All of the actors compromised.
3) Nobody really compromised.
4) Partents point of view accepted in its entirety
5) Other ____

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