Four issues raised by the 
Child and Adolescent Service System Program (CASSP) initiative

What is the nature of emotional disturbances in children?

The nature of what we customarily have referred to as "emotional disturbance" or "mental illness" in children is not signified adequately by those phrases. It appears on the basis of accumulated practice experience and research (especially longitudinal research) that what we refer to as "emotional disturbance" or "mental illness" in children is more accurately described as behavior that is disturbing to those who have to live with it.

Case examples, when viewed in the context of the more recent advances in understanding and treating children considered emotionally disturbed, have led us here at the Portland State University Research and Training Center to change our own terminology regarding children considered emotionally disturbed. We prefer the phrase "emotionally handicapped" because we believe it helps us shift our focus from the child-as-problem to the context-as-solution. It emphasizes that emotionally handicapped children are special children with special needs requiring special environments - specifically, ones that can accommodate, adjust to, or compensate for their disability.

This, it turns out, is consistent with the World Health Organization's perspective on disabilities as impairments that are defined in terms of their functional consequences in specific settings. Since we are concerned with improving services for emotionally handicapped children and their families, we are concentrating on research and training activities designed to help parents, teachers, employers and the helping professions find ways of modifying living, learning and working environments to accommodate, adjust to and compensate for children with emotional disabilities.

The CASSP initiative still refers to its target population as seriously emotionally disturbed children and adolescents. This is a questionable practice that should not be encouraged to continue under federal auspices. Continued use of this terminology will allow the CASSP initiative to be considered only as a "mental health" program in a very narrow sense, namely, one that funds and facilitates the application of intrapsychic treatment techniques to children and adolescents. All of CASSP's efforts at systems change will founder at the service delivery level unless new thinking emerges to guide the creation of new forms of intervention that focus on ways of modifying environments so that children are no longer handicapped by their emotional disabilities in those contexts. New thinking and new forms of intervention will not develop if we all continue to use the old words and phrases. And this brings us to the second issue.

continued on page 8
This is the first issue of a bulletin published by the Portland State University Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families. The center is funded by the National Institute for Handicapped Research (NIHR) and the National Institute of Mental Health (NIMH).

The primary activities of the center are:

1. to conduct research on ways of improving services to help emotionally handicapped children and youth to live at home, learn in school, and succeed at paid employment;
2. to develop training materials and programs for professionals, parents and employers; and
3. to serve as a resource center for other individuals and organizations working on behalf of emotionally handicapped children and their families.

The specific thrust of this initial publication is to introduce you to the center and its primary activities. There are three major center projects: Families as Allies, Youth in Transition and Therapeutic Case Advocacy. Each of these projects is described in separate articles in this issue of the newsletter. In addition, we have a lead article by Tom Young titled "Re-Thinking Emotional Disturbances in Children." This article should be thought provoking and we hope that it will elicit thoughtful responses to the issues raised by Dr. Young.

It is our intent to publish the bulletin on a quarterly basis. Each issue will revolve around a specific subject area. We plan to elicit guest articles related to the primary subject area of the newsletter. For example, the next bulletin will address issues of parent-professional collaboration in providing services to seriously emotionally handicapped children and youth. More detail is provided on page 5. We are excited about the progress of the Research and Training Center and its activities. We invite your comments and criticisms regarding the issues and concerns raised in this publication.
The Therapeutic Case Advocacy (TCA) Project is in its second year and has been warmly received by a variety of agencies, organizations, and institutions that serve many of Oregon's seriously emotionally handicapped youth and their families. The project is developing a model for delivering services to this population which combines three integral components:

1. Case management;
2. Case advocacy; and
3. Interpersonal therapeutic skills.

The goal of the service delivery model is to provide a "system of care" for each case that comprehensively addresses the needs of emotionally handicapped youth and their families.

It became apparent quite early in the project that a model would need to be applicable in more than one context. Hence, a model of therapeutic case advocacy, while utilizing the aforementioned components, must have the flexibility to make its appeal fairly widespread.

Two separate contexts were established for developing such a model: one approach involves structuring the model for use within a given agency (e.g., child welfare, juvenile justice, public school, or a mental health facility); and a second approach involves a model that can operate among a variety of agencies which serve a given client.

Both approaches of the model are being developed in conjunction with individuals and agencies who have had extensive experience in serving this troubled population. This will help facilitate the transition of therapeutic case advocacy from a conceptual or theoretical perspective to a practical or applicable set of procedures.

The model and its development will also benefit by receiving input from a national, as well as a local, advisory panel—each group possessing a broad range of expertise in serving emotionally handicapped youth. Included among local advisors are an attorney, an advocate, a state hospital outreach coordinator, a mental health facility executive director, an administrator from the county juvenile court, a county mental health program specialist, and a unit manager from the local branch of the state Children's Services Division. This range of representation will help in the formation and utilization of therapeutic case advocacy locally.

In any form of therapeutic case advocacy the idea of restructuring the youth's environment and related role players is of key importance. This does not imply forsaking the search for a medical or psychological cure; however, it presents the system of care approach as the primary focus of treating the emotional handicap.

The individuals and agencies with whom we are working have graciously welcomed the project. Collaboration will allow the development of a viable model of therapeutic case advocacy which utilizes techniques and practice skills already mastered by professionals. Therefore, collaboration will permit an easy transition from the drawing board to actual service delivery. Moreover, working collaboratively enhances the project's potential to identify and access resources, to identify systemic barriers to good practice, to expand networks and working relationships, and to provide technical assistance to local service providers. This has created an enthusiasm among administrators, managers, and line staff in youth and family serving agencies.

Currently several projects are in the works. Our model of therapeutic case advocacy is being tested in a child welfare
agency and will be tested in two mental health facilities in the near future. Drafts of the TCA Worker's Handbook, the TCA Workbook and the TCA Manual are available. These materials will undergo a year of field testing and will be revised to reflect our experiences in the field. An outline of the TCA Parent's Guide has been developed and the first draft of this guide is available as well. An annotated bibliography of advocacy has been published and is available through our Resource Service; addendums will be available as the bibliography is expanded. The project staff is making plans for a TCA Training Videotape that could be used by workers across disciplines and fields of practice. This videotape may prove valuable to parents and families of seriously emotionally handicapped children and will be available in mid-1987.

The future of the project will involve evaluation of the model of therapeutic case advocacy and the efficacy of the training materials produced. This evaluation of the model and training materials will not be restricted to the Oregon community. Indeed, to insure that the model will have widespread appeal, test sites are currently being considered outside Oregon. Conceptually the approach appears both viable and cost effective; however, generalizing the results must occur to determine reliability, validity and overall credibility of the model.

YOUTH IN TRANSITION PROJECT

The Youth in Transition (YIT) Project is a relatively new undertaking of the Research and Training Center. The project was initiated during the 1985-86 funding year. The original intent of the project was to employ a psychological rehabilitation model developed by Dr. William Anthony and his associates at Boston University's Center for Rehabilitation Research and Training in Mental Health. While designed for use with adults, we wanted to explore the model's applicability to adolescents who are emotionally handicapped and in the process of moving from youth serving systems to adult roles in the community. As the YIT project has evolved during the past year and our awareness of the transition issues faced by emotionally handicapped adolescents and their families has increased, our conceptualization of transition programming and intervention strategies which have an impact on the service needs of this population has broadened.

The psychiatric rehabilitation model continues to serve as a guide for the YIT Project. However, a literature review of alternative models of service delivery revealed that the psychiatric rehabilitation model was only one of many approaches available which may be employed with emotionally handicapped adolescents in transition.

In addition, important issues have emerged which will influence the nature of our work and the eventual products of the project. These issues include:

1. an increased awareness of the variety of transition programs and approaches currently being used by professionals in special education, mental health and vocational settings with the developmentally disabled;
2. the need for an articulated transition philosophy to be used by state and program planners as a guide for transition services;
3. the need for an initial assessment of exemplary transition programs in order to refine the concept of transition oriented services for emotionally handicapped adolescents; and
4. the lack of literature oriented to the transition needs of emotionally handicapped adolescents.

Programming and intervention strategies for emotionally handicapped adolescents moving from youth serving systems to adult roles
The concept of transition is complex and must be addressed from a variety of perspectives. We are defining transition as a progressive, developmental process towards the assumption of adult role responsibilities. Inherent in this definition are the accomplishment of adolescent developmental tasks and the acquisition of functional skills for role assumption in three primary environmental dimensions. These dimensions include:

1. the social and interpersonal environment;
2. the employment and/or educational setting; and
3. the daily living environment

(Halpern, 1979).

We view these three environmental dimensions as interrelated and inseparable when designing and implementing transition oriented programs. Transition programs must address all three dimensions in the services which are provided, and must be anchored in terms of teaching and skill building towards the next progressive step in the transition process. In essence, transition programs must be outcome oriented rather than cure or symptom oriented. In addition, many adolescents who are emotionally handicapped face a second transition: from institutional settings to community alternatives.

The professional literature is beginning to indicate that in order to minimize re-institutionalization, the most normalized community options must be used. This information directs us to the need for a transition oriented philosophy throughout the system of care for children, adolescents and their families, which has implications for both professionals providing services to this vulnerable population and planners designing service delivery programs.

Our proposed activities for the 1986-1987 project year will address areas of advocacy, information dissemination, and an intervention based philosophy and conceptualization of transition oriented service delivery. Specifically, next year's project goals are:

1. to advocate for the incorporation of transition oriented services at both the planning and program levels of service delivery;
2. to continue refinement and begin evaluation of a transition oriented philosophy and intervention model that address the transition needs of emotionally handicapped adolescents and their families; and
3. to provide state and treatment program consultation in order to coordinate a transition oriented approach between special education, vocational rehabilitation, mental health, child welfare, and juvenile justice agencies on behalf of emotionally handicapped adolescents.

An annotated bibliography describing treatment programs, curriculum strategies and intervention approaches to impact the transition needs of adolescents is now available. Program planners will find this information helpful in designing transition programs. A transition oriented philosophy guided by a principal based approach to service delivery will be implemented in a residential program in the Portland area this fall. An evaluation mechanism will be part of this project in order to assess the initial viability of the approach. This information will be helpful to further articulate the concept of transition as it applies to the emotionally handicapped adolescent.

Reference


FAMILIES AS ALLIES PROJECT

The Families as Allies Project reflects a particular set of beliefs about what the relationship between professionals and families of seriously emotionally handicapped children should be. The project is designed with the idea that the interests of these children will be best served if their parents and the service providers with whom they are involved work together as partners on their behalf. This collaboration should focus on developing the very best educational and treatment program for each child within the best possible service delivery system that can be put together.
Background

Relationships between parents and service-providing professionals have taken many forms over the years. Since the first recognition that emotional disturbance can and does exist among children, ideas about the causes and proper treatment of emotional disorders have influenced the relationships between professionals and family members.

Different theories about the etiology of emotional handicaps cast parents in a variety of roles, both as perceived by helping professionals and in their own eyes. For example, explanations of cause that emphasize the importance of early childhood experiences tend to portray parents as (usually unwitting) villains. In other words, parents have somehow, out of ignorance or even malice, either failed to create the conditions necessary for the optimum growth of their child, or have allowed damaging events to be a part of the child's experience. From this point of view it may be difficult for professionals, who have chosen to dedicate their lives to other people's children, to see parents as other than sick or, at best, inadequate. Interventions developed from this perspective range from family therapy strategies designed to change pathological family patterns to actions such as removing children from their (presumably pathogenic) homes. Parents as well as their children may be seen as "patients" in need of treatment. Whatever steps are taken, a result of this perspective for many families may be a sense of guilt and shame associated with the belief that they have somehow caused their child's problems. Additionally, parents may feel misunderstood, alienated, and, at times, resentful of professionals' attitudes and actions.

In contrast, theories featuring an organic explanation for childhood emotional disorders often cast the parents, along with their children, as unfortunate victims of poorly understood biological malfunctions. In this scenario, parents are likely to be seen as potential "clients" in need of service and support. The link between theories of causation, models of treatment and the way parents and professionals relate to each other may not be as direct as is suggested here, and it is certainly not as simple. The main point, however, cannot be denied: the relationship between parents of seriously emotionally handicapped children and representatives of the helping professions has often been uneasy. Parents have looked to experts for answers and solutions and have been disappointed. Professionals have often been frustrated by what appears to them to be a lack of motivation, resistance to treatment, or other uncooperative behavior on the part of family members.

The Families as Allies Project is aimed at achieving a more balanced and productive relationship between family members and service providing professionals. The project is designed to study the parent-professional relationship and to develop and teach ways that professionals and family members can join forces to promote positive change for children.

With regard to the etiology of emotional handicaps, the Families as Allies Project does not embrace a particular perspective or theoretical orientation. The evidence to support any theory is far from overwhelming. In addition, knowledge about causation is often irrelevant to the development of ways to promote the growth and rehabilitation of handicapped children and adolescents. The project does, however, operate from an assumption with regard to theories that may cause professionals to blame parents or parents to blame themselves for a child's misfortune: even if they are true, they are not useful.

Parent-professional collaboration toward improving services for seriously emotionally handicapped children and their families
Project Activities

Survey of Parent Organizations. We have completed a nationwide survey of self-help, support and advocacy groups that include parents of seriously emotionally handicapped children among their members. We conducted telephone interviews with over 200 groups across the country. A preliminary report of these research findings is available through our Resource Service.

Parent Organization Directory. Using information gathered from the survey, a national directory of parent organizations has been published and is also available through the Resource Service. Addendums to the directory will be published regularly as we receive information on more organizations. We think the directory will be useful to parents and professionals alike.

Annotated Bibliography. We have compiled an extensive annotated bibliography of the literature addressing the relationship between professionals and families of handicapped children. The bibliography also contains literature pertaining to parent self-help, support and advocacy groups. We found a wide variety of groups described in the published literature. Some of them were organized by professionals; others were initiated solely by parents. Copies of this bibliography may be obtained through the Resource Service.

Finding Kindred Programs. Through the parent organization survey and other avenues, we have discovered a number of innovative and exciting programs with goals that complement those of our project. Many parent organizations conduct training designed to help professionals understand the needs and feelings of parents of handicapped children. Some of this training is conducted jointly by parent-professional teams that model the collaboration they advocate. We plan to feature some of these programs in future issues of this bulletin.

Networking. Although not included as a formal goal in the original plan for the Families as Allies Project, linking people with common interests and needs has turned out to be an important project function. In particular, our activities related to the parent organization survey have stimulated a number of requests for referrals from people who want to start parent support groups.

Curriculum Development. We recently funded two curriculum development projects. The Parents, Let's Unite for Kids (PLUK) project of the Montana Center for Handicapped Children, in Billings, is developing a curriculum designed to promote collaboration between professionals and parents and to promote systems change on behalf of seriously emotionally handicapped children and youth. A second curriculum is being developed by the Parent Advocacy Coalition for Educational Rights (PACER) Center, Inc., in Minneapolis. They are producing a videotape which is also aimed at promoting collaboration between parents and professionals. Both curricula are expected to be in place in early 1987.

Parent-Professional Conference. In April, 1986, the Research and Training Center hosted a conference in Portland, Oregon. Its purpose was to promote collaboration between parents and professionals. The conference was attended by delegations of parents and professionals from each of thirteen western states. These delegations engaged in a process of developing collaborative strategies which they have begun to share with others and use in their home states.

The conference format was designed to serve as a prototype for similar meetings in other parts of the country. Such conferences are being planned for the southeast region for the winter of 1986-87, the north central region for the spring of 1987, and other regions for late 1987 and early 1988.

Complete proceedings of the western conference are available through our Resource Service. A summary of the conference will be featured in the next issue of this publication.
Rethinking Emotional Disturbances
continued from page 1

Where are the children considered "seriously emotionally disturbed"?

This is a serious political problem. Most of the CASSP target population is already in the care of other systems (education, child welfare, juvenile justice) with their own legal mandates that typically do not include the provision of mental health services—meaning typically, individual, group or family counseling/therapy by an accredited or certified mental health professional. Unless the CASSP initiative (at both federal and state levels of government) redefines what constitute mental health services, we can expect that all CASSP will produce is a more efficient method of referring or transferring responsibility for seriously emotionally handicapped children and adolescents to existing community mental health centers and state hospital units for children.

If, on the other hand, the mental health system (through CASSP) can redefine what constitute "mental health services" for seriously emotionally handicapped children and adolescents, then substantial collaboration with other child caring systems may be possible. But first CASSP will need a new mental framework or paradigm to replace the traditional conception of mental health services for this population. This brings us to the third question or issue that CASSP must address.

What constitutes "rehabilitation" for children considered "seriously emotionally disturbed"?

CASSP has not addressed this issue explicitly, only indirectly through its goal of improving services for children and adolescents with serious emotional handicaps. But even in that context, CASSP is attempting "systems change" through its grants to individual states. Their objectives are admirable, but their strategies may only re-shuffle existing arrangements.

We think services can be improved to the extent that they have the goal of creating and sustaining systems of care that are environmentally based, functionally specific, advocacy oriented and family centered. This perspective is one that views the nature of rehabilitation as one of care rather than cure. It also shifts the locus of anticipated change from the intrapsychic arena to the child's environment.

While the goal of creating and sustaining a system of care for the emotionally handicapped child is a logical extension of more recent understandings regarding the nature of emotional disturbances in children as discussed above, it has practical consequences as well. A system of care approach organizes services around the child rather than vice-versa. It encompasses but does not require traditional notions of cure. And perhaps most importantly, it combines the resources of both natural and formal support networks.

The system of care approach, then, redefines mental health services by shifting the focus of intervention from the child's internal emotional state to the various behavior settings—home, school, work and play. In each setting, the "treatment issue" is the extent to which those in the setting understand and adjust to the child's disability by providing individualized instruction, support and reward. But as we have noted, for most seriously emotionally handicapped children, these various behavior settings are under the control of other systems of care.

What this means in practice will vary, of course, but the central issue is that it is the interactions between the child and each of the living, learning, play and work settings that bring mental health. Rehabilitation is the modification of each behavior setting to the point where the child can function at some level that is no longer perceived as disruptive. In concert these modified settings constitute a system of care in which the components may involve caseworkers, case managers, foster parents and family therapists from the child welfare system; probation officers, correctional counselors, recreational or occupational therapists and youth advocates from the juvenile justice system; teachers, guidance counselors and special education instructors from the educational system; and relatives, friends, neighbors and clergy from the child's natural sup-
port system. This brings us to the last issue for re-thinking.

What is the role of parents and professionals in programs of rehabilitation?

Historically, mental health professionals and other service providers have viewed parents as contributing to the cause of emotional disturbances in their children. That perspective viewed successful treatment as requiring either removal of the child from the parents' control and influence or treating them simultaneously, or both. More recent awareness of the iatrogenic effects of removing children from their parents for treatment, combined with the changes practitioners have seen families capable of making in response to various family therapy/training/education approaches, have led to a re-examination of our understanding of parents' roles in the origin and evolution of emotional disabilities in their children and of our assumptions regarding their proper role in programs of rehabilitation. Specifically, practitioners have noted that parents of children with special needs rarely receive the information they require to understand their children soon enough, but that when they do, they are frequently the most effective advocates for their children.

There is a growing awareness that most parents of emotionally handicapped children would be more willing to act as "case advocates" for their children, if only they could get the help they need being parents. The question is whether they can look to professionals for that help and get it.

The CASSP initiative is actively promoting the involvement of parents of emotionally handicapped children in states' efforts to plan improvements in services for emotionally handicapped children. But ultimately it would seem necessary to promote professionals' involvement in helping the parents as parents. It seems doubly unfair to expect parents to struggle first with parenting their own handicapped child and then to advocate for improvements in services for other parents' children. It seems both more fair and more reasonable for professionals to collaborate with parents in both roles and their respective tasks. The system of care approach put forth here would provide a natural opportunity for both parents and professionals to work with and learn from each other. Both could share the burden of parenting and creating a system of care that combines formal and natural support networks on the individual "case" level. And perhaps both could share the burden of attempting advocacy at the "systems" level and sustain each other during the inevitable frustrations and disappointments these efforts entail.

Beyond the issues of advocacy and parent/professional collaboration, the system of care approach views family-oriented efforts as essential to improving services for this population. Every child deserves to have a viable family and this is no less true for emotionally handicapped children. In the system of care approach, since children with special needs require special environments, the child's natural family may not have the special resources to accommodate the child's disability. A specialized or therapeutic foster family home may be the special home environment needed. But this does not mean that the child's natural family should be excluded from the system of care. On the contrary, the system of care approach implies that while "home" and "family" need not be synonymous, both are desirable for sustaining an ongoing system of care.

In summary, for the CASSP initiative to succeed, it must de-mystify "emotional disturbances" in children by defining impaired emotional functioning in terms of specific living, learning, working and playing contexts; initiate collaboration with other child caring systems in the creation and maintenance of systems of care for each child; and reform professionals' attitudes and behaviors regarding parents of emotionally handicapped children.

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THE NEW YORK LONGITUDINAL STUDY

The following is a review of the New York Longitudinal Study, a study of behavior disorders in children. The results of the study were authored by Stella Chess, M.D., and Alexander Thomas, M.D., first in "Genesis and Evolution of Behavioral Disorders: From Infancy to Early Adult Life," and subsequently in Origins and Evolution of Behavior Disorders: From Infancy to Early Adult Life.

The Study

The study, begun in 1956, followed 133 subjects from early childhood to early adulthood. The focus of the study was to identify and characterize temperamental characteristics and to study their influence on normal and deviant psychological development. Data sources included parent and teacher interviews, school and behavioral observations, clinical evaluations, and direct interviews with the subjects in adolescence and early adulthood.

Temperament was measured in nine categories in terms of the child’s activity level, regularity in biological functions, response to new stimuli, adaptability, threshold of response, intensity of reaction, quality of mood, distractability and attention span.

Within these categories three "temperamental constellations" were defined: the "easy" child, the "difficult" child and the "slow-to-warm-up" child. The easy child was characterized by regularity, positive approaches to new stimuli, high adaptability to change, and mild to moderate mood intensity which is generally positive. The difficult child is characterized by irregularity, negative withdrawal responses to new stimuli, non- or slow adaptability to change, and intense mood expressions which are frequently negative. The slow-to-warm-up child is characterized by negative responses of mild intensity to new stimuli, to which the child would slowly adapt given repeated contact, less tendency toward

irregularity, and mild intensity of reactions.

The following are some of the results of the study:

1. significant correlations were found between:
   • easy-difficult temperament at age three and temperament in early adult life
   • easy-difficult temperament at age three and adjustment in early adult life
   • parental conflict at age three and early adult adjustment in a negative direction
   • adjustment at ages three and five and adjustment in early adult life
   • clinical case status in childhood (e.g., adjustment disorder) and in early adult life
   • clinical case status in childhood and early adult adjustment in a negative direction

2. separation, divorce or death of a parent was not predictive of early adult status

3. there were no consistent correlations based on sex of the child

4. childhood factors which correlated with a high risk for relatively poor overall adjustment and/or presence of a psychiatric disorder in early adult life included: difficult temperament, parental conflict and presence of a behavior disorder.

These conclusions account for 34% of the subjects. The authors explain that the differences in outcome for the remaining 66% may lie in either variables not rated in the study or in differences in the sequences in which individual subjects developed psychologically.

Theoretical Implications

In cases where behavior disorders developed in later childhood and adolescence, a review of early childhood data did not show symptoms of conflict and stress that may have led to the disorder. In view of

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☐ Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families
Held in April 1986 and attended by delegations from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketches, recommendations, worksheets, and evaluations.

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this, the authors question Freud's theory that neuroses are acquired only during early childhood.

The data do not support the theory that anxiety plays a primary role in the development of behavior disorders. Anxiety appeared to be a consequence rather than a cause of behavior disorders.

The concepts of goodness/poorness of fit and consonance and dissonance were useful in tracing individual developmental sequences. The authors conclude that "excessive stress resulting from poorness of fit between environmental expectations and demands and the capacities of the child at a particular level of development...leads to disturbed behavioral functioning" (Thomas, 1984a).

**Practical Implications**

"Parent guidance" was used to improve the goodness of fit for childhood clinical cases. The emphasis of parent guidance is to effect a change in the behaviors and overtly expressed attitudes of the parents as well as altering other unfavorable environmental influences. This technique generally required only a few sessions and was found to be quite effective in the majority of cases. With few exceptions, the recovery lasted throughout adolescence and early adult life.

The study offers a hopeful view of human development. Emotionally handicapped children can be helped. Family patterns and behavior can be refashioned and preventive and therapeutic interventions can produce change among all age groups.

**References**