This annotated bibliography provides bibliographic information and non-evaluative annotations of about 46 publications based on research with families of children with disabilities and authored by staff members of the Beach Center on Families and Disability in Lawrence, Kansas. Citations are organized into sections on book chapters, hearings and testimonies, journal articles, and monographs. Within each section citations are listed alphabetically by author. Publications date from 1985 through 1989. (DB)
Publications of Beach Center Researchers

Report AB-3

Julie Sergeant and Harriet Shaffer (Eds.)

1989

This annotated bibliography is among a number of bibliographies to be produced by the Beach Center at The University of Kansas.

Beach Center on Families and Disability

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The Beach Center on Families and Disability, a rehabilitation research and training center at The University of Kansas, is funded by the National Institute of Disability and Rehabilitation Research, United States Department of Education, and the University to conduct research on families with members who have disabilities. A major focus of the Center's research is the families of children who are supported by technology.
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INTRODUCTION

This listing describes publications based on research with families of children with disabilities. In these listings, one or more authors are staff members of The Beach Center on Families and Disability, a rehabilitation research and training center supported in part by the National Institute on Disability and Rehabilitation Research. Research projects span the life cycle and concentrate on families of persons with developmental disabilities, emotional disabilities, and technology support.

At this point in time, we are unable to provide copies of these book chapters, monographs, and journal articles due to existing copyright laws. These resources should be available at libraries associated with institutions of higher learning, or through interlibrary loan. In the future, we hope to have these documents available through the Beach Center.

The Beach Center is a research and training center with six fundamental beliefs about families related to positive contributions, great expectations, full citizenship, choices, strengths, and relationships. These beliefs are translated into a wide range of research, dissemination and training projects addressing family well-being across the lifespan. Newsletters and a publication catalog are available upon request. The Beach Center is unable to provide case management or direct services.

From a family systems perspective, this chapter addresses the reciprocal nature of the relationship between young children with exceptionalities and their families. The four components of the family systems framework provide the outline for the content, and vignettes and "fact or fable" statements illustrate the authors' points.


This chapter emphasizes the concept of individualization for families. The historical roles of parents are reviewed, and family systems theory is presented as a means of individualizing services. In conclusion, implications for service delivery and research are discussed.


Beginning with the requirements and implications of parental rights and responsibilities under P.L. 94-142, this chapter offers a broad-based look at family-professional interactions. Issues concerning parental involvement are reviewed, and family systems theory is outlined and described.


Addressing the issues surrounding the process of transition to adulthood, this chapter examines: (1) what transition means to the young adult and his or her family, and the need for future planning; (2) emerging adult needs and ways that families can plan to meet those needs; and (3) strategies for mobilizing a support system for families or young adults with a disability.

This chapter focuses on issues concerning fathers of children with a disability. Stress, personal and professional growth, self-esteem, and marital relations are all discussed. The authors include practical suggestions for professionals, including ideas for increasing the involvement of fathers, and professional resources such as books, organizations, and programs.


This chapter examines the increased role of decision-making in the lives of young adults. The authors argue that independence should be defined as one's personal choice of lifestyle, based on one's capacity and means to support that mode of living and one's personal values and preferences. Families and professionals are encouraged to allow young adults with mental retardation to make their own decisions to the greatest extent possible.


Guidelines for the assessment of family strengths, needs, and outcomes for IFSP development are presented in this chapter. Citations of instruments to measure family's strengths and needs, an example worksheet to help determine family needs, and a case study are included.


This book chapter describes the historical perspectives of viewing families with a disability as villains, victims, or service providers, and examines the impact these assumptions have had upon research and the design of service programs. Methodological problems are discussed, and future directions for family research are suggested.

This chapter describes families who are said to have made a positive adaptation to their family member with a disability. Ways in which the experience of having a child with a disability may strengthen families, some cognitive coping strategies, and implications of these contributions and strategies for family support services are discussed.


Descriptions of the impact of a child with a disability on families provide professionals a solid foundation on which to base family-school partnerships in this book chapter. The authors utilize family systems theory to explore that impact and include a brief list of resources for parents or professionals.


This chapter in an introductory textbook for special education emphasizes the need for professionals to broaden their perspectives to include the family system of which the child with an exceptionality is a member. Each of the four components of the family systems framework is described.


This chapter analyzes the values inherent in family research and intervention as a means for examining the ethical dimensions of professional practice. Varying perspectives from parents, persons with disabilities, and professional organizations are presented to encourage the reader to confront his/her own values.

Issues surrounding deinstitutionalization in the context of a family systems framework are examined in this chapter. The authors state that the components of the framework must be taken into consideration when determining the appropriate residential option for a family member with a disability. Suggestions are given for future research and policy considerations.


This chapter suggests a philosophical change in the orientation of service programs for children and youth with disabilities and their families. Family systems theory is used to support the shift from the professional's view of parents as the cause of their children's problems and as needing change to one of a service delivery system which changes and adapts to meet the varying needs of the diverse families in today's society.


This chapter presents the family systems conceptual framework with a focus on the life cycle component of the system, reviews theoretical and empirical literature on the life cycle needs of families with members who have mental retardation, and suggests future research, intervention and policy directions aimed at strengthening family adaptation over the full life cycle.


This chapter raises questions for professionals who work with people with mental retardation. Why these professionals provide certain interventions or services for people with mental retardation is examined, and the argument is presented that interventions often are self-serving for the professional rather than primarily beneficial to the person with a disability.

This chapter summarizes the contributions of several lawyers and one policy specialist to a conference on mental illness in people with mental retardation.


This chapter sets out the principal legal, human service, and political ideologies that have justified the movement toward community-based services. The author issues certain warnings about the nature of these ideologies and their meaning for people with mental retardation.


This chapter discusses the legal theories underlying the right to community services. The author argues that there is a trade-off between the values of freedom (liberty), equality, and community as law and policy seek to provide more community-based services.


This chapter argues that the political philosophy tied to quality of life considerations that guides families, professionals, and people with mental retardation should be one based on the "community." The author seeks to show how "creating community" is a philosophically grounded principle that should result in a higher quality of life for people with mental retardation.

This chapter develops an approach for analyzing the moral aspects of special education and behavioral interventions with children and adults who have mental retardation or other developmental disabilities. The authors' purpose is to highlight the moral dimensions of some interventions, point out the shortcomings of existing professional discussions on the subject, propose a model for analyzing the moral aspects of those interventions, and provide an illustration of that model.

This testimony discusses policy issues and programs which reject the pathology model of families. The focus on how to help families be successful includes four premises: (1) Families need help in attending to the extraordinary needs of their child on a day-in and day-out basis; (2) Families are infinitely diverse; (3) Balance is a key to successful family life; and (4) Families change over the life cycle.


This statement addresses three topics regarding the right to medical treatment for newborns with disabilities. The author asserts that federal action is needed to legislate against certain nontreatment practices brought about by discriminatory attitudes of some medical professionals; to monitor the role of Human Rights Committees and Infant Care Review Committees in hospitals; and to expand support for alternatives to nontreatment, such as adoption, foster-care placement, and even interim institutionalization.

This study examined aspects of parental planning for adult needs and the relationship of that planning to family functioning. The greatest needs identified by parents were residential, socialization, and employment. The paper discusses the results in terms of implications for professionals who work with families and future research directions.


This article reviews a number of issues related to family assessment as part of their involvement in early intervention programs. The authors recommend the inclusion of family needs assessment as a first step in developing family-focused interventions. Suggestions for the design, selection, and use of needs assessment are made.


The authors discuss the problem of establishing a code of ethics in interdisciplinary fields. They ask whether or not professionals in the field of mental retardation should have a code of ethics.


This paper describes two Transition Planners which were developed to assist parents in planning their child's transition to elementary school. Parents completed rating scales and answered open-ended questions to identify family and child transition-related needs, levels of family involvement in transition planning, and areas of both family and school responsibility.

This paper briefly discusses the federal regulations for the Early Intervention Program for Handicapped Infants, Toddlers and Their Families, and the Preschool Incentives Grant Program. The focus is on the transition of children between these two programs and possible effects on state administration of the Preschool program and local agency administration. Recommendations for facilitating the family and child's transition are provided.


This interview of nineteen parents whose children attended three preschools and were presently attending public school was conducted face-to-face to find out what parents perceived as major issues during their child's school transition. Parents expressed both concern and satisfaction regarding their child's school transition, their role as decision-makers, and the effects of the transition on their family.


This article discusses a survey conducted to ascertain the potential effect of recent federal protection and advocacy legislation on the lives of children with mental illness. The findings indicate a strong potential, especially regarding efforts to improve community-based services.


This article examines the issues of institutionalization versus family life, relationships between social work professionals and clients, and current practices in light of the three following assertions: (1) institutions are the least advantageous response for most children; (2) community-based services provide opportunities for social workers to assist their clients; and (3) broad-based advocacy is needed to improve current services to children.
This study utilized focus groups to research opinions about the expected outcomes for families from early intervention programs and their preferences for the methods to be used in gathering information for the IFSP. Demonstrating sensitivity to families, acknowledging the family as the ultimate decision-maker, and respecting the diversity and individuality of families emerged as important considerations to the study participants.


At age ten, Amy Turnbull wrote this article describing a study of second graders' attitudes toward people with mental retardation before and after the presentation of a lesson on mental retardation. Results as measured by the Wilcoxon Sign Test for Related Samples showed significant differences in the attitudes of the children.


A follow-up to Turnbull & Bronicki, 1986, this study tested three hypotheses: (1) Positive changes in attitudes toward people with mental retardation will remain the same over a period of time, (2) Teaching kids about mental retardation will improve their attitudes toward people with mental retardation, and (3) Any kid with a positive attitude and with a good understanding of mental retardation can teach other kids. The results of the study support these hypotheses.


This paper focuses on P.L. 99-457, Part H - Handicapped Infants and Toddlers. It briefly outlines the Part H goals and expectations for family support, suggests some possible outcomes for a comprehensive family support program, describes how these outcomes might be translated into assessment and service options, and concludes with a challenge for change in the future.

This article contrasts definitions and models of independence and autonomy, then discusses two prerequisites for independence: (1) access to the same opportunities of life as are available to people without disabilities, and (2) the capacity to participate in those activities. Finally, the authors examine issues in consent and decision-making.


This article examines three issues in the field of early intervention from an ethical perspective: (1) The use of the "fix-it" approach found in some applications of the developmental model, (2) The negative or pathological focus on the impact of a child with a disability on the family, and (3) The treatment and non-treatment of newborns with disabilities and the associated use of amniocentesis to identify birth defects during fetal development.


This article reviews the literature on parental attitudes towards supported employment and raises issues for the research community. The authors also note the role of expectations in service delivery and research.


Through an analysis of the court's decision on aversive interventions in the case of BRI vs. Leonard, the author explains why the case is a "victory" for those who oppose such interventions.


This positive book review of a work by David Braddock focuses on federal policy options in the area of mental retardation and developmental disabilities. Turnbull cautions, however, that state, local, and private expenditures as well as federal influences need to be considered when looking at mental retardation and developmental disability issues as a whole.

Through an analysis of written responses to the U.S. Department of Health and Human Services regarding federal funding to hospitals that discriminate against newborns with a disability, this study found that responses almost unanimously supported the proposed "Baby Doe" regulations. The content analysis and additional information related to the perceived need for early intervention and adoption services are reported and discussed.


This article describes the experiences of the principal author, a third grader, as she taught classmates about her friend Kevin, who has severe mental retardation and needs dialysis five times a day. She tested the hypothesis that teaching will help children know more about what to do with and be more comfortable around someone with a severe disability.


This study surveyed parents of children with and without disabilities who attended mainstreamed public school kindergarten classrooms. Results indicated group differences between parental expectation of and degree of satisfaction with their child's program, and similarities in views on parent involvement.

This report discusses barriers to adulthood and adult status that face people with disabilities. Methods of overcoming these barriers as implemented in the Scandinavian countries, Great Britain, and the United States are discussed. Responses of families to the adulthood of their children with disabilities, and some steps that policy makers and families can take to ensure adult status for people are examined.


A World Rehabilitation Fund (WRF) Grant funded this study and report on the Latin American family and its adaptations, coping strategies, and use of informal support in families with a member who has a disability. The Latin American family and its traditions, attitudes, and behaviors with respect to the transition of the member with a disability from adolescence to adulthood is also addressed.


This literature review utilizes Hill's (1949) ABC-X model of stress and coping to analyze sources of stress in families who have a member with a developmental disability, as well as family resources and perceptions that may mitigate the effects of those stressors. Implications and recommendations for future research are discussed.