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ABSTRACT

A curriculum for preservice maternal health and public health professionals on children with special health care needs (disabilities and chronic illnesses) and their families is presented. Principles underlying the curriculum are considered, along with guidelines for developing partnerships with families for field placements. The eight core modules cover: beliefs and values; issues in epidemiology; service use, costs, and financing; laws, legislation, and policies; issues of culture, collaboration, and coordination regarding community-based systems of care; how cultures, societies, and families adapt to children with special needs; child development in the context of a chronic illness or disability; and empowerment. Additional modules concern: health care reform, young adults with special health care needs, pediatric acquired immune deficiency syndrome (AIDS), needs assessment, program evaluation, risk factors in mental health, nutrition issues, and international issues. For each module, information is provided on content and rationale, instructional objectives, definitions of key concepts, instructor guidelines, core readings, and additional readings. Supplemental resources are also identified, including texts, bibliographies, workbooks, videotapes, a list of laws and legislation, and descriptions of national resource centers and networks. A field placement evaluation questionnaire is included, along with a curriculum evaluation form. (SW)

Curriculum on

Children with Special Health Care Needs and Their Families

First Edition

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INTRODUCTION

This document describes a comprehensive curriculum related to children with special health care needs and their families. Recent changes in federal health and education law have dramatically altered public policies for these children and their families. During the next several years, new initiatives for health care reform, greater precision in estimating the number of children with special needs, and continued advances in biomedical technology will bring further changes to this field. As a result, the next generation of child health professionals, particularly those who will assume leadership positions in state and federal public health programs, will need an extraordinarily broad knowledge base to develop effective programs responsive to new concerns in an increasingly complex world. The curriculum described in this document begins to identify and outline that knowledge base.

The curriculum begins with a specification of eight core modules. For each core module, we:

1) describe its content,

2) provide a rationale for why it was included in the curriculum,

3) identify specific instructional objectives,

4) define the key concepts related to module's content,

5) provide a sampling of instructor guidelines (i.e., relevant didactic techniques or resources),

6) identify two to four core readings that are directly related to the instructional objectives, and

7) include a longer, supplementary list of readings.

This material should allow instructors to select portions of or adapt the curriculum to their particular training goals and institutional constraints.

We designed the curriculum to address the educational needs of students who would benefit from a public health perspective on this group of children and their families. Thus, it is relevant to students in maternal and child health, pediatrics, nursing, early intervention, nutrition, physical and occupational therapy, psychology, social work, special education, speech and language pathology, and audiology. The modular design of the curriculum allows for flexible implementation to meet different educational purposes and training needs.

A deliberate selection of ideas, concepts, and values provides the foundation for this curriculum. In Section I, we specify these underlying principles. The second section presents the curriculum's core modules. Additional modules are in Section III; these are provided for students who are pursuing further study on selected topics. Section IV addresses critical issues in evaluating instructional efforts based on this curriculum. The final section includes lists of instructional resources.

We hope that the curriculum reflects dominant issues in the field and provides a foundation for current and future teaching efforts. Like ideas themselves, however, curricula live and change. They do so in response to new developments in the field; to the goals and personalities of the educators and students who struggle with them; and to the social, economic, and professional forces that exist in the institutions that house them. Moreover, new work is constantly appearing in print, so that any published curriculum becomes less comprehensive as time goes by. In this period of impending health care reform, new issues and challenges are emerging quickly. This document, therefore, reflects issues relevant to the mid-1990s -- one moment in an ongoing history of ideas and programs related to children with special health care needs and their families. (See Wallace et al. (1971) for a description of a curriculum implemented in the 1960s.)

One of our primary assumptions in developing this curriculum was that the modules will serve as points of departure for persons interested in developing a particular class, a seminar series, a semester-long course, or a comprehensive multi-year curriculum. Like any categorization scheme, this one imposes somewhat artificial boundaries on an evolving field of knowledge. Furthermore, some topics are embedded within a module (e.g., cultural issues) because, from our perspective, they have not been sufficiently developed in the literature to warrant separate treatment. As the field expands, these topics are likely to attract enough attention to deserve a separate module. In general, we assume that an instructor will select, arrange, sequence, or expand the core modules in a manner that fits a given educational program or setting.

In keeping with current trends, we use the term children with special health care needs to refer to children with all types of serious ongoing physical health conditions, disabilities, and chronic illnesses. These terms are used interchangeably.

Two advisory groups provided substantial assistance in the development of this curriculum. The first, the National Advisory Group, included individuals who have developed similar programs. Members of this group, listed in Appendix A, contributed substantially to both the on-going process of curriculum development as well as its content. Anita Farel provided guidance with special wisdom, based on her teaching experience in the School of Public Health at the University of North Carolina. Nancy Johns DiVenere was an extremely valued reviewer of many drafts, showing us how family participation and family-oriented material will improve the goals of any instructional effort.

Overall, the members of the National Advisory Group generously shared course material they had developed in their own sites, as did other colleagues across the nation. Particularly useful documents included the following:

1. Parent to Parent of Vermont and The Center for Developmental Disabilities, University Affiliated Programs of Vermont (Winter, 1992). Family-centered Institutes: Implementing a model for the preparation of family-centered practitioners. Further information may be obtained from Nancy Johns DiVenere. (See Appendix A for address.)

2. Schwab, William (1989). Diagnosing Doctors. Madison, Wisconsin: Physician Education Project on Developmental Disabilities. Further information and related materials may be obtained from the author. (See Appendix A for address.)

3. Eaton, Antoinette (ongoing). Workbooks developed for the Continuing Education Institutes for Children with Special Needs at the Columbus Children's Hospital in Columbus, Ohio.

4. Association for the Care of Children's Health (1990). Physician Education Forum Report. Bethesda, Maryland: ACCH.

5. Farel, Anita (1992). Federal Register Workbook, a compendium of pertinent laws and regulations.

6. Blasco, P. (1991). Parents-as-Teachers Program. Further information may be obtained from Dr. Peter Blasco, Box 721 UMHC, Harvard Street at East River Road, Minneapolis, MN, 55455.

Our community advisory group (also listed in Appendix A) included parents of children with special needs, professionals involved in community-based programs, and faculty representing diverse health professions. The group met several times during the years in which the curriculum was developed and continues to meet periodically to review progress in implementing the curriculum. Group members provided comments on the curriculum itself, identified opportunities for community or family-based field experiences, and considered how individuals from the community might selectively and strategically be involved in direct educational efforts.

Information from 16 other MCH programs in Schools of Public Health was also gathered through a survey in mid 1992. A report of that survey may be found elsewhere (Ireys & Farel, 1994). As part of that survey, faculty in these programs were asked to send a copy of the outline or reading list for courses specifically related to children with special health needs. Faculty from five programs reported that their department had such a course and sent syllabi from these courses. We also reviewed published descriptions of related curricula (Bishop, 1993; Coury, 1990; Desquin, 1986; Tomaszewski, 1992).

Finally, many colleagues gave their time to read early drafts of the curriculum and to write us with suggestions about general concepts or specific references that should be included. Readers were Robert Biehl, Gil Buchanan, Martha Coulter, Dena Goldberg, Holly Grason, Bernard Guyer, Sarah Horowitz, Henry Ichiho, Kenneth Jaros, Naomi Morris, Martha O'Grady, Roz Parrish, Joan Patterson, Donna Peterson, Debbie Walker, Helen Wallace, and several other persons who returned our comment sheet unsigned. Members of the Committee on CSHCN of the Association of Maternal and Child Health Programs read and discussed an early draft. Rochelle Mayer and Carol Suitor of the National Center for Education in Maternal and Child Health, and Scott Katz (a doctoral student in the MCH Department) were extraordinarily helpful in the final stages of the project.

Overall, comments from many parents and professionals have contributed to this document. We thank them all and absolve them from any of our remaining oversights. Despite their efforts, we have probably overlooked key concepts or left out important citations. We trust that our friends and colleagues will point out these omissions, and we will address them in subsequent editions.

Limitations in resources forced us to draw some boundaries around the effort and, as a result, certain areas have not been included. For example, we have not included a module on genetics and issues in gene-based treatments because time ran short. Issues related to injury prevention in the population of children with special needs have also been neglected because of the extremely scant literature in this area. Both of these topics are extremely important and we hope to include them in a subsequent edition. Also, in most modules we have paid little attention to historical issues. Again, limitations in time and energy prevented us from developing historical perspectives. There are no modules on specific diagnostic conditions or on intervention techniques, such as providing family-centered service coordination or family-centered nursing services. Because of the number of childhood chronic conditions and the variety of professions involved, incorporating this type of material was impractical. We did, however, include in the compendium of texts (Section V) books that are directly relevant to particular disciplines. In addition, we elected not to address topics in prenatal care (despite their relevance to primary prevention of chronic conditions) because this topic is sufficiently complex to warrant separate treatment.

Fiscal support for the development of this curriculum was provided through a supplement to the Maternal and Child Health Training Grant provided to The Johns Hopkins School of Hygiene and Public Health (Program Director: Dr. Bernard Guyer) by the Maternal and Child Health Bureau of the Public Health Service, United States Department of Health and Human Services. Merle McPherson and Elizabeth Brannon of the MCH Bureau played an extraordinarily supportive role and provided substantive guidance at key points along the way. The value orientation and specific objectives embedded in the curriculum reflect our beliefs about the key issues and questions within the field of children with special needs. They are informed by, but do not necessarily represent, the perspective of the Maternal and Child Health Bureau or our advisory groups.

Comments from our Advisory Boards and experience in implementing courses based on this curriculum will inform and expand the current version, especially in respect to instructional methods. We welcome comments from those who use portions of this curriculum and trust that this document and future editions will both contribute to and be informed by innovative instructional efforts in many sites. The last page provides a brief evaluation form to return to us with comments about the curriculum.

Finally, this effort to develop a curriculum has involved larger issues of instructional strategies for graduate and professional students. Issues of general teaching methods are well beyond the scope of this work, but it is worth noting that the field of children with disabilities and chronic illnesses provides numerous opportunities for active and experiential learning. Recent publications related to active learning (e.g., Christensen, Garvin, & Sweet, 1991) have defined the exciting challenges of creating classroom environments where teachers and students are true partners in the pursuit of insight and knowledge. Requiring field experiences with families, inviting parents or youth with disabilities to be co-teachers, or reading testimonies written by parents of children with chronic illnesses and disabilities can energize and enliven teaching efforts by engaging students, families, and professionals in an ongoing dialogue. These activities invariably create bonds between students, families, and professionals in the field. These bonds are the foundation for partnerships that will serve an important educational purpose and reflect the spirit in which health services should be delivered. In our view, how instructors teach this curriculum will mirror their beliefs on how health services should be delivered. A teaching style that is based on and nurtures collaborative partnerships among students, faculty, families, and professionals in order to accomplish important educational objectives may also encourage students to establish such partnerships with families throughout their careers in the health services.

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SECTION I

UNDERLYING PRINCIPLES AND STRATEGIES

As most instructors know, teaching itself is a value-laden exercise. The process of selecting critical ideas to include in a curriculum, the way these ideas are organized and communicated within a specific course, and even what readings are assigned are all shaped by beliefs about what is important for students to learn. Teachers rarely specify the values and beliefs that inform their teaching. As a result, students inherit certain perspectives on the world that remain largely out of consciousness, unquestioned and unexamined. This is especially perilous in the field of children with disabilities and chronic illnesses where myths about these young persons and their families -- about their abilities, perspectives, and expectations -- have severely attenuated their opportunities. As a step toward specifying our beliefs and values, we present here several principles that have informed the design of the curriculum. These principles are summarized in Table 1.

The first and most critical organizing principle for this curriculum is the importance of clarifying the values and beliefs that underlie one's professional identity. Personal beliefs shape professional actions. In the field of services for children with chronic illnesses or disabilities and their families, this truism has critical implications because often these children and adolescents and their families have been victims of unwarranted myths about their competence and their value as individuals. It is essential, therefore, that students be given opportunities to articulate and examine their assumptions about children and adolescents with disabilities, and about the families in which they live. Hopefully, as students' beliefs and values are clarified, they will develop a professional identity based on respect, responsive listening, and truth-telling.

Second, because children live in families who are in turn part of a community, public health resources should assist communities in supporting their families and should bolster the role of families as primary caretakers of their children. In many training programs, an emphasis on professional development and the technical aspects of delivering services obscures the central importance of family and community in promoting the development of children. An organizing principle for this curriculum is that services must be responsive to the evolving structure of communities and to the needs of the many varieties of "family" that now exist in this country. In some instances, children with special needs will require care and assistance beyond what a family or community can provide. Special efforts on behalf of these children may be necessary to assure either that their families receive the support they need to maintain their primary caretaking responsibilities or that other appropriate arrangements are made for the child to live safely.

TABLE 1

CORE PRINCIPLES UNDERLYING THE CURRICULUM

1. Instructors and students should identify and clarify the values and beliefs that underlie their own professional identity.

2. Public health resources should assist communities in supporting families and should bolster the role of families as primary caretakers of their children.

3. Individuals with chronic illnesses and disabilities and their families progress through developmental stages that shape their needs; as a result, issues of development should be an important part of instructional efforts related to this population.

4. Each child and family has strengths that should be recognized and integrated into service planning and program development.

5. Students should be exposed to the broad range of perspectives that shape programs for children and youth with special needs and their families, including the viewpoints of families, program administrators, and service providers.

6. Regardless of their direct involvement in programs for youth with special health needs, all MCH students will encounter during their professional careers many children and adolescents with disabilities and chronic illnesses. They must be knowledgeable about this population and related public programs.

7. Government has a key role to play in supporting care of children and youth with special health care needs and their families.

8. Curricular objectives should be reinforced by integrating field and classroom work and by assuring that students are exposed to different sides of critical issues through invited guests and carefully planned field experiences.

9. Evaluation is critical to improving and up-dating educational efforts and should incorporate the viewpoints of all participants.

Third, children and adolescents with chronic illnesses and disabilities and their families move through developmental stages. Like most issues in the field of maternal and child health, issues related to children with special health needs must be understood in the overall context of child and family development. Moreover, different families may follow different developmental courses. Students should be exposed to a broad range of families who vary in terms of composition and cultural background.

Fourth, each child and family has strengths, and public programs must recognize and build on these strengths. A sole reliance on a deficit model ignores capacities within individuals and families and may undermine the ability of family members to address and solve problems for themselves. Acknowledging the importance of identifying family and child strengths is essential for public programs.

Fifth, no one discipline or perspective is sufficient to address the needs and concerns of families of children with special needs and their families. Therefore, students should be exposed to the broad range of perspectives that shape programs for children with special needs, including those of families, program administrators, and pertinent service providers. We believe it is essential for course instructors to incorporate these individuals actively in curriculum planning and as teachers, guest speakers, and resources for special field experiences or classroom projects. Ideally, diverse perspectives should be represented in all discussions in order to demonstrate 1) the different vantage points from which issues are viewed and 2) the importance of integrating these perspectives in the development, implementation, evaluation, and maintenance of community-based programs. Furthermore, incorporating adults who have had chronic illnesses or disabilities since childhood provides a long-term developmental perspective that can not easily be duplicated through other means. Supplemental resources and considerable creativity will be needed to assure that diverse perspectives are substantively represented in any particular educational effort. Of special importance is the need to compensate and support these participants in accordance with their responsibilities and effort. Families of children with special needs may require supplemental support to assure ongoing involvement and to acknowledge sufficiently their contributions.

Sixth, students in all facets of the child health field, including primary care practitioners and subspecialists should be exposed to a core set of issues related to children and adolescents with ongoing physical health problems. These youth are increasingly being integrated into community institutions. Moreover, from an economic and public health perspective, this group of children and adolescents, while comparatively few in number, claim a vastly disproportionate amount of health care resources; no comprehensive service or financing system can be created without accounting for this group of young persons. Regardless of their direct involvement in programs for youth with special health needs and their families, all MCH students will encounter in their professional careers many children and adolescents with disabilities and chronic illnesses and their families. They must be knowledgeable about this population and related public programs and must be able to distinguish the effective programs from the ineffective, the biased from the fair, and the feasible from the naive.

Seventh, government has a key role to play in supporting care of children with special needs and their families. We believe that this principle is incontestable. The nature of the government's role, however, is open to vigorous debate. An underlying question within many of the core modules concerns the extent to which government programs can or should be involved in solving identified problems.

Eighth, we have constructed this curriculum with the needs of students in mind and have suggested instructional approaches that are consistent with how students learn. As our previous principles suggest, we believe that students should bring away from this curriculum a deep appreciation of 1) the developmental needs of these children and their families and 2) the family-centered approach to the organization and delivery of services. Furthermore, students should be exposed to key debates within the field in order to appreciate emerging issues. Curricular objectives should be reinforced by integrating field and classroom work and by assuring that students are exposed to different sides of critical issues from invited guests, case study methods, and field experiences. General goals and strategies for field experiences are outlined below.

Finally, evaluation is critical to the curriculum in order to maintain high educational standards and to identify new training needs and opportunities as they arise. Two areas of evaluation are considered essential: 1) the effect of the curriculum on students' beliefs, knowledge, and behavior and 2) participants' (i.e, students, faculty, guest speakers, and involved families) assessments of the curriculum's strengths and weaknesses. Evaluation methodologies for these areas are discussed in Section IV.

Field Experiences: Goals, Strategies, and Issues

Personal contact with community-based professionals or families who have children with special needs provides an important opportunity to validate and expand upon classroom learning, and to integrate theory with direct observation. Integrating an experiential component, however, requires careful planning and collaboration with both parents and community-based professionals.

Field experiences with parents can take several forms but typically the family will serve as a host for a student, incorporating the student into family activities for a few hours at several points during a semester or term. Field experiences in community-based programs typically involve contributing to a special project or observing a particular activity (e.g., service coordination) across different settings.

The overall context and timing of field placements in relation to classroom experiences are also important. For example, field placements can be oriented in relation to issues of the family's adaptation to the condition; alternatively, they can be oriented around issues of how government programs have influenced family life. The field experiences can be provided at the beginning of a course, when students' may have little overall knowledge of the field; or they can be provided after students have been exposed to certain topics and have developed some conceptual orientation that can help them organize their observations. The critical task is to identify the rationale for a particular strategy in light of the specific goals of the training program.

Field experiences with families offer students many opportunities for creative projects. For example, in a course offered under the auspices of Parent-to-Parent of Vermont, a student developed a videotape of a child at home in order to demonstrate what the child could accomplish in a familiar setting. The video was shown to the child's teachers, who had expressed doubts about the child's functional abilities; as a result more appropriate educational goals were developed. In another setting, a student assisted a family in developing a loose leaf notebook that highlighted the key points in the child's medical history and described the child's current needs. The parents used the book whenever a new health care professional become involved with the child's care, and therefore avoided numerous repetitions of the child's history.

Field placements with families have great potential for providing students with important insights, but they also require special planning to assure that families are supported appropriately in their role as teachers and that they also benefit from (or at least are not burdened by) the experience. Issues of safety, privacy, legal liability, and financial burden must be addressed. If possible, parents should be reimbursed to some extent in recognition of their contributions to the students' educational experience.

We have identified guidelines for developing partnerships with families for the purposes of field placements. These are listed in Table 2.

TABLE 2

GUIDELINES FOR DEVELOPING PARTNERSHIPS WITH FAMILIES FOR FIELD EXPERIENCES

1. Involve parents in the planning of educational activities that will involve field experiences for students.

2. Ask these parents and key community-based practitioners to assist in identifying potential host families and in organizing the orientation meetings for families that wish to participate.

3. Develop written guidelines for both families and students that describe the mission and objectives of the visit and their expected roles.

4. Provide orientation and planning sessions for participating families to familiarize them with the purpose of the field placement and to discuss what kinds of activities they want the students to be involved in. Assure that the families can contact the program director at any point if issues or concerns arise.

5. Provide orientation sessions for the students to familiarize them with the purpose of the field placement and to identify strategies for organizing their observations in a written format in a journal or summary report. For example, students' observations can be recorded in a journal and then summarized in view of the principles of family-centered care.

6. Schedule a debriefing with participating families and students at the end of the field placements to evaluate the experience and to discuss collectively what worked well and what difficulties were encountered.

7. Assure that participating families and students have opportunities to evaluate in writing the different aspects of the field experience.

Relevance to the Year 2000 Objectives

This curriculum directly addresses several public health objectives for the Nation as defined by the Maternal and Child Health Bureau, in reference to the overall objectives specified in Healthy People 2000 (US Department of Health and Human Services, 1990). Relevant objectives include:

> Achieve for all low income children, including those with disabilities, access in the preschool years to appropriate and high quality early childhood development programs.
>
> All states will establish a statewide network of comprehensive, community-based health care systems that serve ... children with special health care needs; the systems will assure family-centered, culturally-competent, and coordinated services.
>
> All children from birth to age 21, including those with special physical and mental health care needs, will have a source of health care financing that includes comprehensive preventive, diagnostic, and therapeutic benefits.

Students participating in educational settings that cover the core curriculum modules outlined in this document will be exposed to the basic concepts related to these objectives.

Overview of Core Modules

Each module contains: 1) a description of the content of the module, 2) a rationale for why it was included in the curriculum, 3) specific instructional objectives, 4) definitions of the key concepts related to module's content, 5) instructor guidelines (i.e., relevant didactic techniques or resources), 6) two to four core readings that are directly related to the instructional objectives, and 7) a longer, supplementary list of readings.

The definitions of most key concepts are taken from specific references that are identified on the key concept page; full citations for these references are in the reading lists accompanying the module. Definitions of other key concepts have been adapted from multiple sources. Both the definitions and the suggested instructional techniques are provided to identify some of the central ideas in this field and methods for communicating the content of the module. Our intent is to be suggestive. Developing a comprehensive teacher's guide -- containing, for example, detailed outlines of specific lectures, well-tested strategies for group discussion, and actual handouts for varying types of educational settings -- was beyond the scope of available resources.

The core readings include two to four articles, chapters, or books that relate directly to the specific objectives. In many instances, several readings addressed a topic equally well; our final choices were based on judgements about "readability" to a comparatively uninformed audience. With two exceptions, we limited the number of selections to what would be reasonable homework for a single class of two hours. If additional time is available, the core readings can be expanded to include selections from the supplementary reading lists. One of the exceptions to this pattern is **Module D: Laws, Legislation, and Policies**; in this module we first list general overviews of policy development and trends in the field and then list readings pertaining to each piece of legislation. The other exception is **Module F: Development in the Context of a Chronic Illness or Disability**; here again, we first list general overviews and then readings pertaining to each developmental stage.

We have tried to be fairly expansive in developing the supplementary reading lists. In doing so, we want to suggest the scope of material available so that others may select the combination of readings suitable to their particular setting. In some areas, the literature is quite large and differentiated; even semester-long courses would only begin to cover the important material. In these instances, we have selected what we believe to be "classic" articles from early years and have included comparatively more citations from recent years. The modules may be used independently; hence, we have listed some articles in more than one module because they are particularly relevant to several topics or areas.

The ordering of the modules suggests a reasonable sequence of topics. We start with "real life stories" that can provoke discussions of students' beliefs and values. This material should be of inherent interest to most students and provide specific examples of concepts that will be discussed subsequently. The next pair of modules (**Module B: Issues in Epidemiology** and **Module C: Costs and Financing**) deal with core public health concerns, and provide the foundation for a public health perspective on this population of children and families. The next pair of modules (**Module D: Laws, Legislation, and Policies**; and **Module E: Community-Based Systems of Care**) deal with issues of policy and program development, implementation, and evaluation. These two modules can be seen as applied or practice-oriented modules. The next pair (**Module F: How Cultures, Service Systems, and Families Adapt to Children with Special Needs**; and **Module G: Development in the Context of a Chronic Illness**) raise issues related to basic topics such as child development, family functioning, cultural studies, and risk factor analysis. The final module (**Module H: Empowerment and Beyond**) brings students back to social and personal values. Any ordering of topics has benefits and drawbacks. The most important task is to specify one's logic for sequencing modules in relation to particular educational goals and to gather evidence for whether the selected sequence contributes to accomplishing those goals.

Overview of Additional Modules

In this section we identify areas that 1) are emerging new topics where the literature is changing rapidly, 2) have or are likely to attract considerable research or programmatic attention, or 3) can serve as topics for further study by advanced students. We assume that instructors or advanced students will use these modules as points of departure for developing lectures or projects beyond what would be appropriate for an introductory course. These modules could also serve as a focus for a continuing education program or a seminar series.

As we did with the Core Modules, we include a description of the content, a rationale, a list of specific objectives, and a reading list for each additional module. Because we assume that these modules will be used primarily for special studies or individual projects, we have not included instructor guidelines. Some Advance Modules are closely related to particular core modules; for example, Needs Assessment is closely related to Community-Based Systems of Care. In these instances, many of the items included in the reading lists of the core modules are also included in the reading lists of the additional modules.

The first module pertains to the major topic of the moment: health care reform. As of this date (April, 1994), the details of the plan that will be passed by Congress are unknown, and therefore the implications for children with special health needs are only speculative. Several reports and articles have been published to date, and this module lists them. The next two modules pertain to special groups within the larger population of children with special needs: older adolescents facing the transition to young adulthood, and children infected with HIV. The next two modules focus on concerns that arise frequently in relation to State Programs for Children with Special Health Care Needs: needs assessment and program evaluation. These modules assume that students have some knowledge of the larger literatures pertaining to needs assessment and program evaluation. Two modules address specific disciplinary foci: mental health and nutritional issues, largely because of the special interests of the authors. The final module deals with international concerns.

Overview of Supplemental Resources

Section V includes a list of supplemental resources that can be used for instructional purposes or to identify other avenues for further investigation of particular topics. Several available texts cover the field of policies and programs for children with chronic illnesses and disabilities, including:

Blum, R.W. (Ed.). (1984). Chronic illness and disability in childhood and adolescence. Orlando, FL: Grune and Stratton, Inc.

Hobbs, N. & Perrin, J. (Eds.). (1985). Issues of care of children with chronic illness: A sourcebook on problems, services, and policies. San Francisco: Jossey-Bass.

Stein, R. (Ed.). (1989). Caring for children with chronic illness: Issues and strategies. New York: Springer.

Wallace, H.M., MacQueen, J., Biehl, R., & Blackman, J. (Eds.) (1994). Children with Disabilities and Chronic Illnesses: Challenges and Solutions in Community Care. Oakland, California: Third Party Associates, Inc.

We list these and other, disciplinary-focused texts in Section V. In many instances, we reference selected chapters of these texts within particular modules. These texts should be consulted, however, during preparation of a course or specific instructional effort.

In addition, the National Center for Education in Maternal and Child Health (NCEMCH) published in 1993 Children with Special Health Needs: A Resource Guide. This document includes a descriptive overview of federal and state programs for children with special health needs, an annotated list of current publications, a list of organizations that can provide additional information, and a list of state directors of programs for children with special health needs. The Guide is an extremely useful reference document for identifying resources for projects on special topics. It can be obtained from:

The National Center for Education in Maternal and Child Health,
2000 15th Street North, Suite 701
Arlington, VA 22201-2617
TEL (703) 524-7802
FAX (703) 524-9335.

Technical Reference Notes

References conform generally to conventions set forth in the Publication Manual of the American Psychological Association, Third Edition (1983).

At the end of some references we note the following: [NCEMCH]. This indicates that the work can be obtained from the National Center for Education in Maternal and Child Health at the address listed above.

At the end of other references we note the following: [National Maternal and Child Health Clearinghouse]. This indicates that the work can be obtained from:

The National Maternal and Child Health Clearinghouse
8201 Greensboro Drive, Suite 600
McLean, Virginia 22102
TEL (703) 821-8955 x254 or x265
FAX (703) 821-2098

SECTION II

CORE MODULES

MODULE A

BELIEFS AND VALUES

CONTENT

This module offers an opportunity for students to examine their experiences, feelings and beliefs about children and adolescents with disabilities or chronic illnesses and their families. Ideally, the module provides direct contact with parents and siblings of children with disabilities or serious health problems, and with youth themselves. The educational setting should foster a discussion that identifies the special issues of relating to and interacting with children and adolescents with special needs and their families. The philosophy and practice of family-centered care should be introduced and discussed at this time. This module should enhance students' respect for the diversity of individuals with a chronic illness or disability and underscore the need for family-professional collaboration in service delivery.

RATIONALE

One's experiences and values will shape the way that one responds to individuals who may require certain accommodations to function effectively. As professionals, it is essential that we become aware of the beliefs and expectations that we hold about others, including those with disabilities. This module is necessary to the curriculum because it encourages health professionals to be vigilant for biases that prevent truly collaborative relationships with families. One way to address these biases is to become familiar with persons who have disabilities or chronic illnesses and their families -- to see the person beyond the disability -- and to understand how one's reactions or professional training may interfere with this process. Emphasis will be placed on: 1) how language communicates implicit values and the importance of using language that respects the person and the family (e.g., placing the person first, as in "a child with a disability"); and 2) the importance of including families in all aspects of program planning.

SPECIFIC OBJECTIVES

1. Students will articulate their beliefs and values concerning individuals with chronic illnesses or disabilities, and how these beliefs shape their actions.

2. Students will develop an appreciation for the perspectives of children with a chronic illness or disability and their families.

3. Students will be able to articulate their attitudes and beliefs about the role of the family within the health care system.

4. Students will participate in discussions with parents and siblings of children with chronic illnesses and disabilities and with youth themselves, if possible, as a means of addressing the following questions:

> Does interacting with a person who has a chronic illness or disability bring discomfort? If so, why? If not, why not?
>
> How do your beliefs influence your feelings about individuals with disabilities, and how might this affect your work?
>
> What attitudes and beliefs would best support families and assist them in meeting their needs, regardless of how you feel about any particular child or family?
>
> In what ways might a public health professional or a direct provider who had no direct personal experience be handicapped in responding to the needs of a child with a serious health condition or disability?

5. Students will be able to discuss issues related to the impact of defining persons by their health conditions or disabilities and to explain why, to many individuals, terms such as "handicapped child" and "case management" are inappropriate.

KEY CONCEPTS AND DEFINITIONS

Family centered care refers to a set of beliefs and values about how health care should be provided, as well as a set of health care practices and related skills.*

Family centered care is a philosophy that:

Recognizes and respects the pivotal role of families in the lives of their children;

Strives to support families in their caregiving roles by building on their strengths as individuals and as families;

Respects and supports the choices families make for their children;

Promotes typical patterns of living in the hospital at home and in the community; and

Views families and professionals as partners committed to excellence at all levels of health care.

Family centered care is a set of health care practices and skills including:

Involving families in decision making from the start;

Using families as consultants in planning programs;

Relationship-building skills;

Incorporation of a broad repertoire of communication skills;

Truthfulness and openness of communication; and

Involvement of families in all levels of policy-making.

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* Adapted from material made available by: Ms. Beverly Johnson, Institute for Family Centered Care, 5715 Bent Branch Road, Bethesda, Maryland, 20186.

INSTRUCTOR GUIDELINES

The key task for this module is to encourage students to reflect on and discuss their experiences with youth who have chronic illnesses or disabilities and their families -- and to identify the range of thoughts and feelings that these experiences might have generated.

It is helpful to have some shared experience to start off the class, such as watching a relevant videotape (see list in Section V) or having a parent talk about his or her child. This material can be used to raise questions such as:

What experience with disability or chronic illness have you had?

Did anything in the video or parent's comments remind you of anyone you have known personally?

What have your experiences been with young persons with serious chronic illnesses or disabilities and their families? What thoughts or feelings stand out from these experiences?

What disability or chronic illness is most challenging for you, and why?

Several strategies promote a positive, productive discussion, including the following:

Assure that each student describes at least one relevant experience and what it meant to him or her; the most reserved student may offer the most thoughtful or honest insight.

Acknowledge that many persons have feelings of embarrassment that they believe are inappropriate or socially unacceptable to admit.

Acknowledge some of your own personal challenges encountered in relating to a child with a chronic illness or disability.

Leave enough time for discussion because it may start slowly; premature termination may prevent some of the more thoughtful comments from emerging.

Complete reading of one of the books written by parents (see Section V) usually raises compelling questions for students and provides much material for discussion. We especially recommend the Dorris, Featherstone, and Massie & Massie works.

CORE READINGS

Hall, L.M. (1990). The effects of a disabled child upon the family: A singular testament. Copyrighted presentation at the Continuing Education Institute on Children with Special Health Needs, Columbus Children's Hospital, Columbus, Ohio.

Massie, P. (1985). The constant shadow: Reflections on the life of a chronically ill child. In N. Hobbs & J. Perrin (Eds.), Issues in the care of children with chronic illness: A sourcebook on problems, services, and policies. San Francisco: Jossey-Bass.

Shelton, T., Jeppson, I., & Johnson, B. (1987). Family-centered care for children with special health care needs. Bethesda, Maryland: Association for the Care of Children's Health.

SUPPLEMENTARY READINGS

Alexander, R. & Tompkins-McGill, P. (1987). Notes to the experts from a parent of a handicapped child. Social Work, 32(4), 361-362.

Anderson, B. (1985). Parents of children with disabilities as collaborators in health care. Coalition Quarterly, 4(2,3), 15-18.

Baker, B. (1983). Parents as teachers: Issues in training. In J. Mulick & S. Pueschel (Eds.) Parent-professional partnerships in developmental disability services. Cambridge, MA: Academic Guild.

Beckett, J. (1985). Comprehensive care for medically vulnerable infants and toddlers: A parent's perspective. In Equals in this partnership: Parents of disabled and at-risk infants and toddlers speak to professionals (pp. 6-13). Washington: National Center for Clinical Infant Programs.

Beckett, J. (1989). With a parent's eye. In R. Stein (Ed.) Caring for children with chronic illness: Issues and strategies. (pp. 101-116). New York: Springer.
Brewer, E.J., McPherson, M., Magrab, P.R., & Hutchins, V. (1989). Family-centered, community-based, coordinated care for children with special health care needs. Pediatrics, 83, 1055-1060.

Gray, H.B., McConnell, B. & Schrock, K.M. (1991). Plenary Session II: Family-centered care. making changes happen: Proceedings from Region V conference, University of Chicago, Chicago IL: pp. 31-46.

Harrison, H. (1993). The principles for family-centered neonatal care. Pediatrics, 92(5), 643-650.

Hostler, S.L. (1991). Family-centered care. Pediatric Clinics of North America, 38, 1545-1560.

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Leff, P.T. & Walizer, E.H. (1992). Building the healing partnership. Brookline Books.

SUPPLEMENTARY READINGS, CONTINUED

National Center for Clinical Infant Programs (1985). Equals in this partnership: Parents of disabled infants and toddlers speak to professionals. Washington, D.C.: National Center for Clinical Infant Programs.

Pizzo, R. (1983). Parent to parent. Boston: Beacon Press.

Robertson, L.W. (1991). The world of parents of children with disabilities. Exceptional Parent, April/May, 46-49.

Simons, R. (1987) After the Tears. San Diego, California: Harcourt, Brace, Jovanovich.

Turnbull, A. & Turnbull, R. (Eds.). (1987). Parents speak out: Then and now. Columbus, Ohio: Charles E. Merrill.

Vohs, J. (1989). Vision and empowerment. Infants and Young Children, 2, vii-x.

MODULE B

ISSUES IN EPIDEMIOLOGY

CONTENT

This module: 1) provides an overview of epidemiological issues, including incidence and prevalence rates for childhood chronic illnesses and disabilities within the nation as a whole and within racial and ethnic subgroups; 2) introduces key concepts related to the definition of the population; and 3) reviews estimates of the risks for mental health and family problems associated with chronic physical illnesses and disabilities in children.

RATIONALE

Estimates of the size of the population of children with special needs vary widely -- in part because no uniform definition of the population has been used. Students who plan careers in any aspect of maternal and child health must be aware of what is known regarding the size and distribution of this population and the critical gaps in knowledge. This module is included in the curriculum as a means for defining the size and scope of critical epidemiologic problems in the field.

SPECIFIC OBJECTIVES

1. Students will be able a) to estimate the size of the population depending on the study's assumptions, methodology, and definition of the population; b) describe the epidemiological methods used to make the estimates, c) be able to discuss the limits of their confidence in any particular estimate, and d) discuss the political and fiscal implications of applying different definitions.

2. Students will learn estimates of the risk for mental health problems associated with chronic illness or disability in childhood.

3. Students will learn how the following concepts have been defined in the field: pathology, impairment, functional limitation, and disability; the noncategorical perspective; and severity.

4. Students will be able to evaluate these concepts in terms of their historical significance, theoretical value, and implications for policy and research.

KEY CONCEPTS AND DEFINITIONS

The following definitions are taken from Report and Research Plan of the National Center for Medical Rehabilitation Research (1992):

Pathology:	Interruption or interference of normal physiological and developmental processes or structures
Impairment:	Loss or abnormality of cognitive, emotional, physiological or anatomical structure or function, including all losses or abnormalities, not just those attributable to the initial pathophysiology.
Functional: limitation	Restriction or lack of ability to perform an action in the manner or within the range consistent with the purpose of an organ or organ system.
Disability:	Inability or limitation in performing tasks, activities, and roles to levels expected within physical and social contexts.
Societal limitation:	Restriction, attributable to social policy or barriers (structural or attitudinal), which limits fulfillment of roles or denies access to services and opportunities that are associated with full participation in society.

The following is taken from citations listed in the supplementary reading list under the category **The Noncategorical Perspective**:

Noncategorical perspective:	Children with diverse diagnoses are viewed as members of a single class for programming and policy purposes, rather than as members of particular subgroups based on diagnostic classification. The basis for this approach comes from evidence that children with varying diagnoses are quite similar in the rehabilitative, social, and psychological aspects of their lives. Variation within diagnostic groups is as great as variation between diagnostic groups on most social, psychological, and family variables.

KEY CONCEPTS AND DEFINITIONS, CONTINUED

The following distinctions are taken from Stein and colleagues (1987), and indicate different approaches to defining severity:

Biological severity:	Refers to the underlying physiological processes and biomedical markers of disease state; some conditions have generally accepted indices of severity, such as hemophilia (where percentage of clotting factor can be used as an index of biological severity), but well-validated or generally accepted indices of biological severity do not exist for many chronic conditions.
Functional severity:	Refers to the impact of the disorder on an individual's ability to perform age-appropriate activities, and may be measured by indices of functional status.
Burden of condition:	Refers to the impact of the disorder on the family or society, and may be measured by extent of family disruption or service use.

INSTRUCTOR GUIDELINES

This module assumes that students have a basic understanding of epidemiology and principles of public health. The following are some suggested strategies for accomplishing the specific objectives in this module:

> Use the table on the following page as a handout to illustrate the range of estimates of the size of this population and the distribution among subgroups with differing levels of condition severity.
>
> Lead a discussion on the trends in the size of the population of children with special health needs, specifically targeting the dynamic relationship between prevalence and incidence.
>
> Discuss factors influencing the trends and estimates such as changing definitions and advances in technology.
>
> Use handouts to review and discuss the meanings of key concepts, the relationships among them, and how these have changed over time.
>
> Compare and contrast differences in prevalence estimates for different racial groups, and use these to discuss possible race and socioeconomic factors that influence rates.
>
> Compare different approaches to defining "severity" and the implications of these approaches for survey methods and accuracy in estimating prevalence.
>
> Break the class into small groups for a homework assignment. Assign each group a state and have them estimate the number of children with special health needs using material from the reading lists (e.g., HECCH, 1990). Bring class together for discussion of pros and cons of a given method.

Prevalence of Children with Chronic Health Conditions: Results from Selected Surveys

Source[*]	Total	Mild	Mod	Sev	Survey	N	Pop
1. Newacheck & Taylor, 1992	31%	66%	29%	5%	NHIS, 1988	17,110	<18
2. Newacheck et al., 1991	32%	67%	23%	10%	NHIS, 1988	7,465	10-17
3. Gortmaker et al., 1990	9%				NHIS, 1981	11,699	4-17
4. Newacheck, 1989	6%	30%	62%	8%	NHIS, 1988	15,181	10-17
5. Cadman et al., 1986	20%				OCHS, 1981	3,294	4-16

[*] Comments on the Sources:

1. Defined chronic condition as one of 19 conditions listed in the NHIS (the checklist method). Defined severity as extent of "bother" and degree of limitation in daily activities. Noted that Afro-Americans were 51% and Hispanics were 67% more likely than Whites to fall into the severe category.

2. Defined chronic conditions using the checklist method. Noted little difference in prevalence by poverty status. Levels of severity correspond to 1, 2, or >3 conditions.

3. Defined chronic conditions using checklist method. Noted higher prevalence among those with less income.

4. Defined population as limited in activities. Mild is limited in nonmajor activities; moderate is limited in kind or amount of major activity; severe is unable to conduct major activity.

5. Defined population as those with either or both a chronic illness/medical condition or limitation in normal functioning. Noted higher prevalence among those in poverty.

CORE READINGS

Incidence/Prevalence

Newacheck, P.W., Stoddard, J.J., & McManus, M. (1993). Ethnocultural variations in the prevalence and impact of childhood chronic conditions. Pediatrics, 91(5, Supplement), 1031-1039.

Newacheck, P.W. & Taylor, W.R. (1992). Childhood chronic illness: Prevalence, severity, and impact. American Journal of Public Health, 82, 364-371.

Yeargin-Allsopp, M., Murphy, C., Oakley, G., Sikes, R., et al. (1992). A multiple-sources method for studying the prevalence of developmental disabilities in children: The Metropolitan Atlanta Developmental Disabilities Study. Pediatrics, 89, 624-630.

Mental Health Epidemiology

Cadman, D., Boyle, M., Szatmari, D., & Offord, D.R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. Pediatrics, 79, 805-813.

Gortmaker, S.L., Walker, D.K., Weitzman, M., & Sobol, A.M. (1990). Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. Pediatrics, 85, 267-276.

Definitional Issues

Institute of Medicine. (1991). Disability in America: Toward a national agenda for prevention. Washington: National Academy Press. (pp. 76-95).

Stein, R., Coupey, S., Bauman, L., Westbrook, L., & Ireys, H. (1993). Framework for identifying children who have chronic conditions: The case for a new definition. Journal of Pediatrics, 122, 342-347.

CORE READINGS, CONTINUED

The Noncategorical Perspective

Stein, R.E.K. & Jessop, D.J. (1989). What the diagnosis does not tell: The case for a non-categorical approach to chronic illness in childhood. Social Science and Medicine, 29, 769.

Severity

Stein, R.E.K., Gortmaker, S.L., Perrin, E.C., Perrin, J.M, Pless, I.B., Walker, D.K., & Weitzman, M. (1987). Severity of illness: Concepts and measurements. Lancet, 1506-1510.

SUPPLEMENTARY READINGS

Incidence/Prevalence

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Health and Education Collaboration for Children with Handicaps (HECCH) (1990). *The incidence and prevalence of conditions in children: A sourcebook of rates and state-specific estimates for DHHS Region IV*. (Second Edition). Chapel Hill, NC: University of North Carolina at Chapel Hill.

Kiely, M. (1987). The prevalence of mental retardation. *Epidemiologic Reviews*, *9*, 194-218.

Martini, L., & MacTurk, R.H. (1985). Issues in the enumeration of handicapping conditions in the United States. *Mental Retardation*, *23*, 182-185.

Newacheck, P.W. (1989). Adolescents with special health needs: Prevalence, severity, and access to health services. *Pediatrics*, *84*, 872-8

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Newacheck, P.W., Budetti, P.P, & McManus, P. (1984). Trends in childhood disability. *American Journal of Public Health*, *74*, 232-236.

Newacheck, P.W., McManus, M.A., & Fox, H.B. (1991). Prevalence and impact of chronic illness among adolescents. *American Journal of Diseases of Children*, *145*, 1367-1373.

Newacheck, P. & Stoddard, J. (1994). Prevalence and impact of multiple childhood chronic illnesses. *Journal of Pediatrics*, *124*, 40-48.

Palfrey, J.S., Walker, D.K., Haynie, M., Singer, J.D., Porter, S., Bushey, B., & Cooperman, P. (1991). Technology's children: Report of a statewide census of children dependent on medical supports. *Pediatrics*, *87*, 611-618.

Pless, I.B., & Douglas, J.W.B. (1971). Chronic illness in childhood: Part I. Epidemiological and clinical characteristics. *Pediatrics*, *47*, 405-414.

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Pless, I.B., Satterwhite, M.A., & VanVechten, D. (1976). Chronic illness in childhood: A regional survey of care. *Pediatrics*, *58*, 37-46.

Mental Health Epidemiology

Cadman, D., Rosenbaum, P., Boyle, M., & Offord, D.R. (1991). Children with chronic illness: Family and parent demographic characteristics and psychosocial adjustment. *Pediatrics*, *87*, 884-889.

Weiland, S.K., Pless, I.B., & Roghmann, K.J. (1992). Chronic illness and mental health problems in pediatric practice: Results from a survey of primary care providers. *Pediatrics*, *89*, 445-449.

Definitional Issues

Copley, H., Cowan, A., Pickett, O. & Reiss, J. (1992). *Maternal and child health (MCH) thesaurus*. Gainesville, FL: National Center for Policy Coordination in Maternal and Child Health.

Hahn, H. (1985). Toward a politics of disability: Definitions, disciplines, and policies. *Social Science Journal*, *22*, 87-105.

Nagi, S.Z. (1965). Some conceptual issues in disability and rehabilitation. In M.B. Sussman (Ed.). *Sociology and rehabilitation* (pp. 100-113). Washington: American Sociological Association.

Nagi, S. Z. (1991). Disability concepts revisited: Implications for prevention. In Institute of Medicine. *Disability in America: Toward a national agenda for prevention*. Washington: National Academy Press. (pp. 307-350)

National Center for Medical Rehabilitation Research. (1992). *Report and Research Plan*. Washington, DC: NCMRR.

SUPPLEMENTARY READINGS, CONTINUED

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The Noncategorical Perspective

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Severity and Functional Status

Crewe, N.M. (1986). Assessment of physical functioning. In B. Bolton (Ed.). Handbook of measurement and evaluation in rehabilitation, 2nd ed. (pp. 235-247). Baltimore: Paul H. Brookes Publishing Company.

Damiano, A.M., Bergner, M., Draper, E.A., Knaus, W.A., & Wagner, D.P. (1992). Reliability of a measure of severity of illness - Acute physiology of chronic health evaluation. Journal of Clinical Epidemiology, 45, 93-101.

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Fleming, J. (1991). Overview of functional health status: Measures in nursing. In M.L. Grady (Ed.). Primary care research: Theory and methods Washington, DC: U.S. Department of Health and Human Services.

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Zaman, S.S., Khan, N.Z., Islam, S., Banu, S., Dixit, S., Shrout, P., & Durkin, M. (1990). Validity of the 'ten questions' for screening serious childhood disability: Results from urban Bangladesh. International Journal of Epidemiology, 19, 613-620.

MODULE C

SERVICE USE, COSTS, AND FINANCING

CONTENT

This module covers information about patterns of service use, the costs of services, and how services are paid for. It is necessary to distinguish 1) between medical interventions and nonmedical but equally needed services (e.g., social services, physical therapy); and 2) among the primary sources of payment for services (e.g., private insurance, public programs, families). There is a complex relationship between availability of coverage and service use, and many gaps exist between costs and coverage. Moreover, patterns of insurance coverage vary by region, the family's economic status, and type of condition. Different financing methods are reviewed and discussed in relation to this population of children and their families. Issues of risk adjustment are considered in relation to predicting future costs for insurance purposes.

RATIONALE

Children with disabilities and chronic illnesses represent the high-cost segment of the childhood population in terms of health services. No reasonable reform in the health care system can be implemented comprehensively or successfully without accounting for this population. To be effective as health care professionals, students must appreciate the complex financing arrangements that pay for services to this population and the effects of different financing schemes on service access and quality of life.

SPECIFIC OBJECTIVES

1. Students will be able to identify patterns of service use within the population of children with special needs, and the implications of these patterns for overall costs of care.

2. Students will be able to identify sources of health financing for services needed by these children (i.e., private insurance, public programs, philanthropic institutions, disease-oriented voluntary associations, research and demonstration programs, and family funds), to specify the strengths and weaknesses of these sources, to pinpoint where gaps in coverage exist, and to appreciate the enormous variability in coverage across state, communities, employers, and families.

3. Students will be able to identify how families may combine these funding sources to provide comprehensive coverage for their children.

4. Students will be able to discuss issues related to managed care for this population, and how insurance rates are determined in part by predictions of future costs.

KEY CONCEPTS AND DEFINITIONS*

Assisted living refers to individually-oriented services that combine housing, supportive interventions, personal care, and health services in a manner that support individual choice and decision-making.

Capitation refers to a method of payment for health services in which a physician, hospital, or other provider is paid a fixed amount for each person served or enrolled regardless of the actual number of services provided to that person.

Income spend-down refers to the method by which an individual or a family establishes Medicaid eligibility by reducing gross income through medical expenses until net income (after medical expenses) meets Medicaid financial arrangements.

Indemnity payments refer to predetermined payments made by insurance companies to policy holders to cover the cost of a particular service, regardless of the actual cost of that service.

Managed care refers to health care that is provided to a particular population under the auspices of a single institutional entity (such as a Health Maintenance Organization) that seeks actively to control services and avoid unnecessary or inappropriate use of services. Under managed care there are significant financial disincentives to use health services and providers not associated with the plan. The covered population can be defined as subscribers to a private HMO or Medicaid recipients within a particular geographic area.

Risk adjustment refers to the process of predicting costs for a subsequent year based on such variables as age, sex, use of services in the past year. Insurance companies and governments need to predict costs in order to establish estimates of total costs for a particular group. With these estimates, premiums can be altered to assure that sufficient funds are available to pay claims. There has been comparatively little work in establishing predictive formulas for children with serious ongoing physical health conditions.

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* Definitions adapted from Familiar Faces: A Chartbook on The Status of America's Vulnerable Populations, available from The Center for Vulnerable Populations, The National Academy for State Health Policy, 50 Monument Square, Portland, Maine 04101.

KEY CONCEPTS AND DEFINITIONS, CONTINUED

Strategies and mechanisms for limiting health services under either traditional fee-for-service or managed care arrangements include (adapted from Horowitz & Stein, 1990):

- Restricting eligibility for coverage to certain groups such as employers who have worked a certain length of time;
- Restrictive clauses that deny coverage completely or for certain periods of time to persons with any pre-existing condition or with certain pre-existing conditions;
- Requiring co-insurance, where coverage is limited to a percentage of health care costs;
- Requiring co-payments, where payment is required for a portion of the costs of services;
- Limiting coverage to only certain services;
- Limiting number of encounters or number of days for particular services;
- Limiting total dollars paid for a particular policy or person; and
- Limiting access to services by placing conditions such as prior authorization before services can be rendered.

INSTRUCTOR GUIDELINES

The following are some suggested strategies for accomplishing the specific objectives in this module:

> Use the following pages as handouts to review patterns of service use, associated costs, and sources of financing. Combining the lists of sources of cost and payment within a case study approach can aid in identifying common gaps in coverage.
>
> Use a case study method to identify sources of cost and financing for the range of services needed by a child with a serious ongoing health condition. Discuss issues regarding gaps in coverage, out-of-pocket expenditures, and lost opportunity costs.
>
> Break class into small groups and assign one model of health service delivery (e.g., fee-for service, HMO, single-payor) for children with special health needs to each group. Have each group discuss the model in respect to funding, utilization rates, and barriers and incentives for children with special health needs. Using the Georgetown workbook exercise on funding (Fox & Yoshbe, 1986), have groups estimate the costs and cost-benefits of their model. Bring groups together for a discussion and comparisons of the models.

Differential Patterns of Service Use

1. Children and adolescents with disabilities use more services than their healthy counterparts. The following table, abstracted from Newacheck (1989), illustrates this point for adolescents:

	Without Disability	With Disability
Average number of bed days:	3.7	12.2
Mean annual physician contacts:	2.7	8.0
Hospitalizations per 100 persons/year	3.8	18.1
Hospital days per 1000 persons/year	181.0	1646.0

2. Within the population of children with disabilities and chronic illnesses, a comparatively few children account for a disproportionate share of the costs. The figures below (adapted from Newacheck and Taylor, 1992) illustrate this point:

Of all children with a chronic condition in the sample:

65% had a mild condition

30% had a moderate condition

5% had a severe condition.

The 5% with a severe condition accounted for:

33% of all hospitalizations

27% of all bed days

24% of school absences

19% of physician contacts.

Sources of Cost

Children with special health care needs require both medical and non-medical services; some of these services result from their need for special accommodations beyond what is required strictly for medical treatment. The following list illustrates some of the services that children with disabilities and chronic illnesses need and provides a starting point for identifying sources of costs in caring for these children. Students can discuss what financing options are available for each type or category of service.

Medical Care	Primary health care
	Specialty services
	Hospitalization
	Home nursing services
Therapeutic Services	Physical therapy
	Occupational therapy
	Speech therapy
	Nutrition services
	Special educational services
Equipment And Supplies	Adaptive equipment (e.g., wheelchairs, walkers, braces)
	Durable medical equipment (e.g., ventilators, feeding pumps)
	Disposable medical supplies (e.g., syringes, ostomy bags)
Transportation	Routine transportation (e.g., wheelchair vans)
	Emergency medical transportation
	Long distance travel
Other Special Services	Personal attendant care
	Respite care
	Specialized daycare and babysitting services
Home Adaptation	Ramping
	Electrical and plumbing upgrades to accommodate child's needs
	Accessible bathrooms, sinks, etc.
Recreation	Accommodations to allow for family recreation
	Summer camps

Sources of Financing

From a population perspective, many financing mechanisms exist to pay the costs of services required by children with special needs and their families. For any particular family, however, only some of these sources of financing are available, and what is available typically covers only some of the costs. The eligibility criteria or coverage restrictions associated with each source of financing, together with the lack of coordination among programs, leads to many gaps in coverage. The following list of sources (only a partial list), combined with the previous list of needed services, provides a starting point for identifying potential gaps in coverage for a particular family or for the population as a whole.

Public Programs

Medicaid, including waiver programs and managed care programs

State Programs for Children with Special Needs

Supplemental Security Income

Special Categorical State Programs

Special Education or Early Intervention Programs under IDEA

Special research or demonstration projects

Medicare (for certain conditions)

Private Sources

Private insurance policies, including traditional fee-for-service policies and managed care policies such as HMOs

Disease oriented voluntary associations (e.g., March of Dimes, Hemophilia Foundation, etc.)

Family out-of-pocket monies

Community institutions such as churches or local philanthropic organizations

Special demonstration projects

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>
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>
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MODULE D

LAWS, LEGISLATION, AND POLICIES

CONTENT

This module provides a critical examination of pertinent health and education programs and policies for children with special needs and their families at state and federal levels. It covers the key goals and objectives of the following legislation: Title V (CSHCN Program), IDEA, SSI, Vocational Rehabilitation, and the Americans with Disabilities Act (ADA). Examples of condition-specific legislation (e.g., the Ryan White legislation) are also covered. Medicaid, Head Start, and EPSDT are reviewed insofar as they pertain to this population.

RATIONALE

Federal and state laws have established many of the financial and conceptual frameworks for efforts to assist children with special needs and their families. No professional will be effective without understanding the complex set of legislative actions that influence how health and educational services for children with special needs and their families are delivered, monitored, and financed. Moreover, public health professionals who practice in this field must understand how implementation of each of these programs within a particular state affects the functioning of the others.

SPECIFIC OBJECTIVES

1. Students will be able to identify the goals, objectives, target population, locus of administrative responsibility, and key concepts of the critical laws that shape the educational and health services for this population.

2. Students will be able to describe key milestones in the history, structure, and implementation of at least one piece of legislation.

3. Students will consider the implications of legislation including how a specific piece of legislation may affect individual children and their families.

KEY CONCEPTS AND DEFINITIONS

University Affiliated Facilities (UAFs) are centers originally established in the early 1960s through the leadership of the Kennedy family (and often named after the Kennedy family), and now supported through a variety of federal and state monies. These centers typically conduct basic biomedical research and provide assessment and treatment services to individuals with disabilities.

Medicaid waivers refer to special provisions within the Medicaid program that typically "waive" certain financial eligibility criteria for entry into the Medicaid program. There have been a series of Medicaid waivers, including Katie Beckett waivers (which no longer exist), home-and-community based waivers, and model waivers. These different waiver programs have somewhat different requirements in terms of the number of persons and/or geographic location covered, but they share the common goal of making Medicaid available to children with disabilities so they can live at home instead of living in an institution.

Medicaid's "Medically Needy Program" refers to the program that states can elect for individuals who meet the categorical eligibility criteria for Medicaid (i.e., they live in families with a single or an unemployed parent) but who do not meet the financial eligibility criteria. Under a Medically Needy Program, states may extend eligibility to individuals who will incur health expenses which, when deducted from income, bring their net income below a designated level.

Least restrictive environment refers to the educational setting that sets the fewest limits on an individual student's opportunities for participating in regular educational environments.

Reasonable accommodation, as used in the American's With Disabilities Act, is any modification or adjustment to a job or the work environment that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions. It also includes adjustments to assure that a qualified individual with a disability has rights and privileges in employment equal to those of employees without disabilities.

INSTRUCTOR GUIDELINES

Strategies for accomplishing the specific goals include:

Use the following handout to walk students through the maze of legislation pertaining to this population of children.

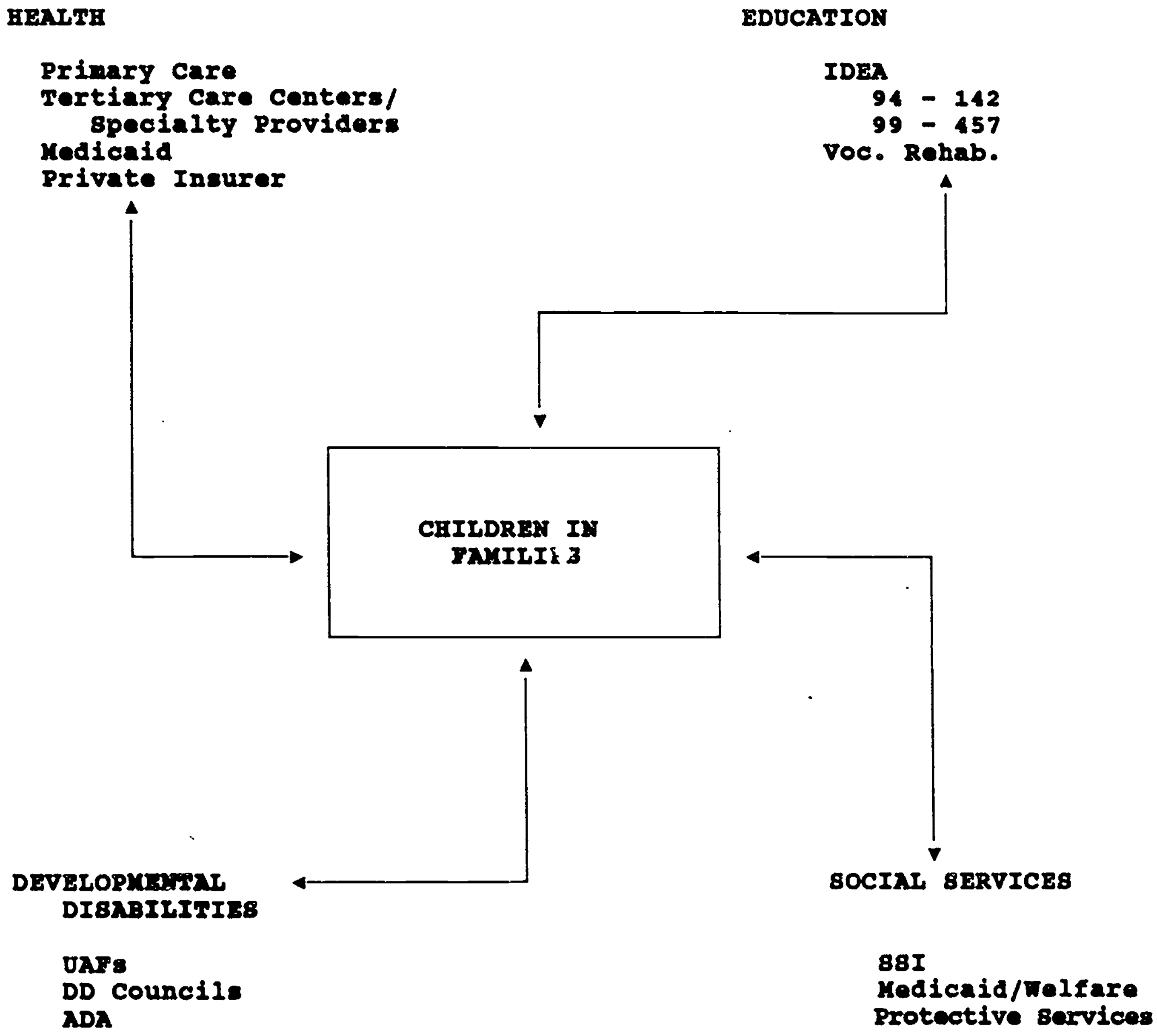
Examine the legislative history, the specific laws, and the regulations pertaining to a specific federal program; assist the students in becoming familiar with the Federal Register by examining it in relation to a particular law.

Compare and contrast two initiatives (e.g., IDEA and Title V) in terms of the detail and nature of the law and published regulations, raising questions about the implications and consequences of varying degrees of specificity for actual implementation.

Select a family with a child who has a chronic illness or disability and examine what federal or state laws, programs, or policies have affected its ability to care for the child. What programs might have been helpful but were not available and why not?

Use a chronology of legislation to identify and discuss key laws. See the brief list in this module; consult Ballard, Ramirez, & Weintraub (1982); or contact Dr. Anita Farel for a comprehensive workbook on this subject.

SERVICE SYSTEMS FOR CHILDREN WITH SPECIAL NEEDS



HEALTH

- Primary Care
- Tertiary Care Centers/
  Specialty Providers
- Medicaid
- Private Insurer

EDUCATION

- IDEA
  - 94 - 142
  - 99 - 457
- Voc. Rehab.

CHILDREN IN FAMILIES

DEVELOPMENTAL DISABILITIES

- UAFs
- DD Councils
- ADA

SOCIAL SERVICES

- SSI
- Medicaid/Welfare
- Protective Services

A CHRONOLOGY OF SELECTED LEGISLATION PERTAINING TO CHILDREN WITH SPECIAL NEEDS

1935 PL 74-271, The Social Security Act

Created the Crippled Children's Service: A national medical insurance plan to support specialty medical care for children who had crippling conditions or disorders that would lead to crippling conditions and "who could benefit from treatment;" funded by federal monies with state matching the federal dollars.

1958 PL 85-840, Amendments to the SSA

Increased appropriations under Title V for children with mental retardation (MR); created demonstration programs for children with MR; provided $1 million that would lead in 5 years to 77 special clinics (Lesser, 1985).

1962 President Kennedy's Panel publishes MR report

Linked MR to maternal health; suggested that to prevent MR, society must decrease complications associated with childbearing and increase quality and extent of prenatal care; recommended greatly enhanced research efforts.

1963 PL 88-156, Mental Retardation Facilities and Community Mental Health Centers Construction Act

Special project grants for clinical, training, and research programs for children with MR; established UAFs in medical institutions to provide training in care for children with MR and other disabilities; supported by the federal MCH Bureau; did not specify links to state MCH or CCS programs or pediatric departments.

1965 PL 89-97, Amended the SSA

Authorized Medicaid and created the Children and Youth Program.

1969 Executive Office Order

Responsibility for Title V transferred to PHS, MCH Bureau, from the Children's Bureau.

SELECTED LEGISLATIVE CHRONOLOGY, CONTINUED

1970 PL 91-517, Developmental Disabilities Services and Facilities Construction Act

Provided additional federal funds for expansion of UAFs to all children with developmental disabilities.

1972 PL 92-603, Amended the SSA

Created Supplemental Security Income payments for individuals with disabilities; criteria for adults was "interference in substantial gainful activity;" for children: "comparable criteria." Regulations published in 1977.

1973 PL 94-103, The Developmentally Disabled Assistance & Bill of Rights Act, amended Section 504, Rehabilitation Act

"To prevent discrimination against all handicapped individuals regardless of their need for or ability to benefit from vocational rehabilitation services...."

"No otherwise handicapped individual ... shall solely by reason of his handicap, be excluded form the participation in, be denied the benefits of, or be subjected to discriminations" under any federal program or program receiving federal funds.

1975 PL 94-142, The Education for All Handicapped Children Act

Synthesized existing state practices; built on role of federal government in educating minority children; established minimum standards. Components: non-discriminatory testing/evaluation; LRE; due process rights; free education; appropriate education (IEP).

1976 Head Start mandated to include children with disabilities

1980 PL 97-35, Omnibus Reconciliation Act of 1981

Created the Maternal and Child Health Block Grant.

SELECTED LEGISLATIVE CHRONOLOGY, CONTINUED

1985 PL 99-272, Amended the SSA, changing name of the CCS to CSHCN

1986 PL 99-457, Education of the Handicapped Amendments

Created the Early Intervention Program, also known as the Infant and Toddler Program, which mandated states to develop a statewide service program for infants and children from birth through age 2; created the Individualized Family Service Plan; specified responsibilities for service coordinators.

1989 PL 101-239, Omnibus Reconciliation Act of 1989

Re-defined mission of state CSHCN programs to develop community based systems of care that are family-centered and culturally competent.

1990 Supreme Court Decision: Sullivan v. Zebley

Overturned existing rules for determining eligibility for SSI payments; mandated eligibility decisions to be based on functional criteria suitable for children.

1990 PL 101-336, The Americans with Disabilities Act

Employers may not discriminate against an individual in hiring or promotion; may not have tests to screen out persons with disabilities; must make "reasonable accommodations, such as job restructuring or equipment modifications; do not have to impose "undue hardship" on business operations; affects all employers with 15+ employees as of 7/26/94.

Public accommodations (e.g., restaurants, hotels, retail stores) may not discriminate; aids and services must be provided, unless an undue burden results; physical barriers must be removed if readily achievable; new facilities must be accessible.

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MODULE E

COMMUNITY-BASED SYSTEMS OF CARE: ISSUES OF CULTURE, COLLABORATION, AND COORDINATION

CONTENT

In this module students examine what community-based care is within a culturally appropriate framework, and its dependence on collaboration, communication, and service coordination. This module also addresses the questions: What is a system of care for children with special needs and their families? How do you know one when you see it? What is the role of the community in articulating needs, organizing services, and leveraging resources? Criteria for assessing community-based programs are also covered, including the extent to which it is family-centered, flexible, and part of a linked network of agencies and programs. To be effective, community-based care must be responsive to the mix of cultures and subcultures that may exist within the community. Therefore, issues related to cultural competence are also addressed. Particular attention is paid to communication and linkages among families, schools, primary care services, and specialty centers.

RATIONALE

Many professionals concerned with this population of children are likely to be involved in establishing community-based programs at some point. To prevent continued fragmentation of services, new programs and efforts must pay greater attention to issues of coordination and integration into the existing system of care. Topics such as cultural sensitivity, a single point of entry, interagency collaboration, accessibility, and service coordination are fundamental to developing a reasonable system of care. There is particular need for future leaders of state CSHCN programs to understand 1) potential sources of tension between state and local service planning and 2) state programs' responsibilities for developing community-based data sets, combining and leveraging resources in new ways for community services, and contributing actively to new policy development at the community level.

SPECIFIC OBJECTIVES

1. Students will identify key components of a community-based system of care, including strategies for linking state agencies in a manner that will support integrated, community-based programs.

2. Students will define critical aspects of "cultural competence" and how programs can take these into account in providing services.

3. Students will review and critique specific community-based programs related to children with special health care needs and their families, using identified criteria.

4. Students will be able to define critical steps for establishing a community-based system of care for a particular group of children and their families.

CONCEPTS AND DEFINITIONS

Culture can be defined as a set of values and practices that guide human behavior, as shared language and beliefs, as shared rituals and traditions, or as the way life choices and possibilities are defined.

Cultural competence has been defined as a "set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency or those professionals to work effectively in cross cultural situations" (Cross et al., 1989). From a programmatic perspective, it refers to the ability of a program's staff to Honor and respect beliefs, interpersonal styles, attitudes, and behaviors of families who are clients as well as the multicultural staff who are providing services (Roberts et al., 1990).

Cultural sensitivity can be defined as an appreciation and respect for cultural and subcultural variations in language, beliefs, and behaviors; in theory, cultural sensitivity should lead to "cultural competence."

A collaboration can be defined as a partnership in which persons have equal status, different responsibilities, and a common cause (Ireys, 1992). See Bishop (1993) for definition of the principles of family-professional collaboration. See Jones and Hutchins (1993) for strategies to promote interagency collaboration.

Service coordination/case management has been defined in numerous ways (for a good review see Bailey, 1989). It generally refers to activities on behalf of, or in conjunction with, a child or family to link, coordinate, or orchestrate needed services. From a comprehensive vantage point, activities of a service coordinator include out-reach and identification, assessment, service identification and planning, linking clients and services, linking services to each other, client advocacy, and evaluating service delivery. From a narrow perspective, case management has been defined as monitoring of services received by and planned for a client in order to avoid inappropriate service use.

INSTRUCTOR GUIDELINES

Strategies to convey the content of this module and accomplish the specific objectives include:

> Use the following handouts 1) to begin a discussion of what "culture" is and how different cultures approach the varied issues in providing health care to children with disabilities and chronic illnesses at a community level and 2) to identify needed steps in developing a community-based intervention.
>
> Compare and contrast programs based in rural settings with those in urban settings to illustrate issues in system development and program coordination.
>
> Identify a particular program in your community and examine it in relation to whether it is accomplishing its stated goals and to the principles of community-based care.
>
> Have students select a SPRANS-funded program listed in the Abstracts of Active Projects Supported by the Maternal and Child Health Bureau and develop a strategy for evaluating the program.
>
> Identify a child with a chronic illness or disability; examine the agencies and programs that the child and family interact with; document how these agencies and programs do and do not relate to each other; and illustrate how the number and type of agencies change as the child and family ages.
>
> Have students serve, together with family members, as the "board of directors" of a private, philanthropic organization whose mission is to support community-based programs for children with special needs; submit several examples of community based programs as if they were applying for funds and instruct the group to decide which program they would fund, and why.

STEPS IN PLANNING A COMMUNITY PROGRAM

I. Convene Planning Group

  A. Who is going to be in it?

  B. What is "the problem" and who gets to decide?

II. Collect Information to Inform the Planning Process

  A. What information is needed and how will it inform the problem solving process?

    1. Possible purposes:

      a. identify new problems
      b. assess change in old problems
      c. improve or deepen understanding of needs

  B. Review existing or previous policies, projects, and data sets.

    1. Child health indicators
    2. Education data
    3. Provider data
    4. Sources of financing
    5. Access indices
    6. Indices of family involvement

  C. Needs assessment (adapted from Monohan & Craik, 1994)

    1. What is a need?

      a. Normative need: expert opinions, standards
      b. Perceived need: wishes or expectations of the population
      c. Expressed need: need as defined by use; use "expresses" (reflects) need
      d. Comparative need: relative use/access of services across populations

STEPS IN PLANNING A COMMUNITY PROGRAM, CONTINUED

2. Community needs assessment

    a. Why do a needs assessment?
    b. What is the community?
    c. Whose needs are being assessed?
    d. Is the assessment of needs or unmet needs?
    e. Who says who needs what?

3. Primary data collection methods

    a. Testimony
    b. Panels
    c. Focus, nominal, community groups and forums
    d. Systematic surveys

III. Identification and Analysis of Program Options

A. Outline Options

1. Regardless of feasibility, what are all the different strategies or programs that could address the identified problem? These usually fall along the continuum from "do nothing" to "institute an entirely new program."

B. Assess each option using specified value and operational criteria. For example, each proposal can be assessed in respect to the following components (adapted from Bronheim, Keefe, & Morgan, 1993):

1. Can the family find the system and the system find the family? (This component involves issues related to child find, identification, and outreach.)

2. Do the services that families need exist in the community and can they be easily used by those who need them? (This component involves issues of availability, access, and having a medical home.)

STEPS IN PLANNING A COMMUNITY PROGRAM, CONTINUED

3. Do families have help coordinating services and does the system have help coordinating itself? (This component involves interagency collaboration, co-location of services, and strategic planning.)

4. Does the program support families and give them a say in how the system works? (This component involves family support, parent-to-parent connections, parent-professional collaboration.)

IV. Monitor and Evaluate

A. Program Evaluation

1. Define the purpose of the evaluation.

2. How will the group know whether the program is working as planned?

3. Who will do the monitoring?

4. How will the program be sustained and modified to address new emerging issues?

B. Informing the Community and the Broader Public

1. How should the media be involved and when?

2. What kinds of reports will be published and who is the audience?

3. Who are the key opinion leaders that need to know?

CORE READINGS

Concepts and Issues

Hobbs, N. Perrin, J. & Ireys, H. (1985). Chronically ill children and their families. Chapter 5, Health and Social Services. San Francisco, CA: Jossey-Bass.

Steele, B. (1989). Developing community networks: A guide to resources and strategies. Washington: D.C.: Association for the Care of Children's Health.

Cultural Competence

Roberts, R., Barclay-McLaughlin, G., Cleveland, J., Colston, W., Malach, R, Mulvey, L., Rodriguez, G., Thomas, T. & Yonemitsu, D. (1990). Developing culturally competent programs for families and children with special needs. Washington, DC: Georgetown University Child Development Center, Center for Child Health and Mental Health Policy.

Family-Professional Collaboration

Leff, P. & Walizer, E. (1993) Building the healing partnership: Parents, professionals, and children with chronic illnesses and disabilities. Cambridge, Mass: Brookline Books.

Service Coordination/Case-Management

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Perrin, J., Shayne, M., & Bloom, S. (1993). Home and community care for chronically ill children. New York: Oxford University Press.

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Elder, J.O. & Magrab, P. (1980). Coordinating services for handicapped children. Baltimore: Paul H. Brooks.

Georgetown University Child Development Center (ongoing). The Rainbow Series. Workbooks for providing services with children with special needs and their families. Georgetown University Child Development Center, 3800 Reservoir Road, NW, Washington, D.C. 20007. See list in Section V.

Gittler, J. (1988). Community-based systems of comprehensive services for children with special health care needs and their families. Iowa City, IA: National Maternal and Child Health Resource Center, The University of Iowa.

Healy, A.H. (1983). The needs of children with disabilities: A comprehensive view. Iowa City, IA: Division of Developmental Disabilities, The University of Iowa Hospitals and Clinics.

Hazel, R. Barber, P. Roberts, S., Behr, S. Helmstetter, E. & Guess, D. (1988). A community approach to an integrated service system for children with special needs. Baltimore, MD: Paul Brooks.

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SUPPLEMENTARY READINGS, CONTINUED

Hunt, M. Cornelius, P. Leventhal, P., Miller, P., Murray, T. & Stoner, G. (1989) Into our lives. Tallmadge, Ohio: The Family Information Network.

Johnson, B. & Steele, B. (1983). Community networking for improved services to children with chronic illnesses and their families. Children's Health Care, 12, 100-102.

Jones, V. & Hutchins, E. (1993). Finding common ground: A call for collaboration. Arlington, VA: National Center for Education in Maternal and Child Health.

Kisker, C.T. (1983). The needs of children with cancer: A comprehensive view. Iowa City, IA: Division of Developmental Disabilities, The University of Iowa Hospitals and Clinics.

Monahan, C. & Craik, D. (1994). A community planning model to develop Comprehensive, community-based, family-centered care for children with special health care needs. Focus for Children Project, University of Illinois at Chicago, Division of Specialized Care for Children, Research and Development, 1919 W. Taylor Street, Chicago, Illinois 60612.

Morris, H. (1983). The needs of children with cleft lip and palate: A comprehensive view. Iowa City, IA: Division of Developmental Disabilities, The University of Iowa Hospitals and Clinics.

New England SERVE. (1988). Enhancing quality: Standards and indicators of quality are for children with special health care needs. Boston, MA: New England Serve.

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Perlman, R., & Giele, J.Z. (1983). An unstable triad: Dependents' demands, family resources, community support. Home Health Care Services Quarterly, 3, 12-44.

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SUPPLEMENTARY READINGS, CONTINUED

Cultural Competence/Diversity

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Lynch, E. & Hanson, M. (1992). Developing cross-cultural competence: A guide for working with young children and their families. Baltimore: Paul H. Brookes.

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Family-Professional Collaboration

Anderson, B. (1985) Parents of children with disabilities as collaborators in health care. Coalition Quarterly, 4(2&3), 1-4.

Bishop, K.K., Woll, J and Arango, P. (1993). Family professional collaboration for children with special health care needs and their families. The Family Professional Collaboration Project, Burlington, Vermont. [NCEMCH]

Service Coordination/Case-Management

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Franklin, J., Solovitz, B., Mason, M., Clemons, J., & Miller, G. (1987). An evaluation of case management. American Journal of Public Health, 77, 674-678.

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National Commission to Prevent Infant Mortality. (1988). One-stop shopping: The road to health mothers and children. Washington, DC: NCPIM

National Health/Education Consortium. (1992). Creating sound minds and bodies: Health and education working together. Washington, DC: Policy Studies Associates, Inc.

Pierce, P. & Freedman, S. (1983). The REACH Project: An innovative health delivery model for medically dependent children. Children's Health Care, 12, 86-89.

Pierce, P.M., & Giovinco, G. (1983). REACH: Selfcare for chronically ill children. Pediatric Nursing, 9, 37-9.

Raulin, A., & Shannon, K. (1986). Case managers for technology-dependent children. Pediatric-Nursing, 12, 338-340.

Spitz, B. (1987). A national survey of Medicaid case-management programs. Health Affairs, 61-70.

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Strayer, F., Kisker, C.T. & Fethke, C. (1980). Cost effectiveness of a shared management delivery system for the care of children with cancer. Pediatrics, 66, 907-911.

Examples of Community-based Programs

Affleck, G., Tennen, H., Rowe, J., Roscher, B., & Walker, L. (1989). Effects of formal support on mothers' adaptation to the hospital-to-home transition of high-risk infants: The benefits and costs of helping. Child Development, 60, 488-501.

National Center for Education in Maternal and Child Health. (1991). Abstracts of Active Projects Supported by the Maternal and Child Health Bureau (DHHS Pub. No. HRSA-MCH-91-3). Washington, DC: Superintend of Documents. [NCEMCH]

Stein, R.E.K. (1978). Pediatric home care: An ambulatory "special care unit." Journal of Pediatrics, 92, 495-499.

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Institute of Child Heath Policy. (1992). The children's medical services program: Investment in the future: Assuring quality care for children with special needs 1992-1997. Gainesville, FL: Institute of Child Health Policy, State University System of Florida. [NCEMCH]

Iscoe, L., & Bordelon, K. (1985). Pilot parents: Peer support of parents of handicapped children. Childrens Health Care, 14, 103-109.

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Pathfinder Resources, SPRANS/MCHIP Exchange. (1992). Getting help: Developing community-based systems of care for children with special health needs. St. Paul, MN: SPRANS/MCHIP Exchange, Pathfinder Resources.[NCEMCH]

Salisbury, C. & Intagliata, J. (Eds.). (1986). Respite care: Support for persons with developmental disabilities and their families. Baltimore: Brooks Publishing Co.

MODULE F

HOW CULTURES, SERVICE SYSTEMS, AND FAMILIES ADAPT TO CHILDREN WITH SPECIAL NEEDS:

CONCEPTUAL MODELS AND PERSONAL ACCOUNTS

CONTENT

One of the most pressing issues in this field concerns how children and families respond to the demands of a disability or chronic illness. How do they cope? What aspects of the health care system and the surrounding community shapes a family's response to a child's chronic condition? How do cultures differ in their understanding and response to a family who has a child with special health care needs? Investigators in the field have developed conceptual frameworks that attempt either a) to identify the important factors affecting adaptation to a child's chronic illness or disability or b) to chart the evolution of responses in the child and family, including the siblings. This module includes a critical review of several conceptual frameworks and evidence for their accuracy through empirical studies and personal accounts from families. In addition, it introduces the issue of how cultural background influences adaptation.

RATIONALE

Public programs offer assistance to individuals and families in need. Yet, many programs are based on concepts and assumptions that are inconsistent with how families respond to the stressors in their lives within a cultural context. A child's chronic illness or disability may be only one stressor in a family, and often not the most critical one. Thinking about how families with particular cultural and ethnic heritages respond to stressors is an important first step in planning effective public programs. This module provides an opportunity to conceptualize "adaptation to a child's chronic condition," to identify the medical, social, and cultural factors that influence adaptation, and to examine whether existing conceptual models fit the first-person accounts and empirical reports.

SPECIFIC OBJECTIVES

1. Students will be able to identify and discuss critical concepts frequently invoked to explain how families and children respond to the demands of a chronic illness. These concepts include risk and protective factors, "adaptation," "resiliency," and "condition parameters."

2. Students will be able to compare and contrast models that have been proposed to explain the process of how families adapt to the demands and stressors associated with a child's chronic illness.

3. Students will identify specific ways in which cultural background may affect adaptation.

KEY CONCEPTS AND DEFINITIONS

Risk and protective factors typically refer to attributes of the person, family, or environment that are associated with particular outcomes. For children with special needs, one outcome of interest, for example, is self-esteem. Risk factors for poor self-esteem may include tension in the family, little availability of peer support, or parental depression. Protective factors (i.e., factors associated with positive high self-esteem) may be a cohesive family unit or competence in one particular area of achievement.

Adaptation is a nonspecific term used to convey a broad range of meanings related to social and psychological functioning. Some authors use it to convey positive response, in which adaptation is equated with positive "coping." Others use it in a more generic fashion to convey the way in which a person or a family may respond over a long period of time to a health condition; in this usage, one can have a positive or negative adaptation.

Resilience has been defined as the capacity to respond effectively to and recover from serious threats to personal safety and well-being. Much of the early literature in this field focused on risk factors for poor outcomes. Attention to resilience is reflects a growing awareness of the importance of "protective" factors -- i.e., attributes that increase the likelihood of a positive response or outcome to the stresses associated with a child's disability or chronic illness.

INSTRUCTOR GUIDELINES

Accomplishing the specific objectives of this module will be greatly facilitated by direct experiences with a family of a child with a disability or chronic illness. This experience can be provided in numerous ways, such as:

Involve families of children with special health needs as speakers, small group leaders or discussants to illustrate how they responded to the diagnosis of a chronic illness or disability and to ongoing care-giving demands.

Have students present a conceptual model from the literature to the class. Have the class discuss its limitations and strengths with input from a family member of a child with special health needs. If appropriate, have students consider the family they have visited and whether the presented model pertains to situations they observed.

Discuss the ways in which a disability or chronic illness might have influenced the family or community in a positive fashion, and why.

CORE READINGS

Models of Adaptation

Institute of Medicine. (1991). Disability in America: Toward a national agenda for prevention. Chapter 3: A Model for disability and disability prevention. Washington, DC: National Academy Press.

Patterson, J.M. (1991). A family systems perspective for working with youth with disability. Pediatrician, 18, 129-141.

Turnbull, A.P., Patterson, J.M., Behr, S.K., Murphy, D.L., Marquis, J.G. & Blue-Banning, M.J. (Eds.) (1993). Cognitive coping, families, & disability. Baltimore, Maryland: Paul H. Brooks.

Personal Accounts

Massie, P. (1985). The constant shadow: Reflections on the life of a chronically ill child. In N. Hobbs & J.M. Perrin (Eds.) Issues in the care of children with chronic illness: A sourcebook on problems, services, and policies. San Francisco: Jossey-Bass.

May, J. (1990). Fathers of children with special needs: New horizons. Bethesda, MD: Association for the Care of Children's Health.

Cultural Diversity

Groce, N. & Zola, I. (1993). Multiculturalism, chronic illness, and disability. Pediatrics, 91(5, Part 2), 1048 - 1055.

McCubbin, H.I., Thompson, E.A., Thompson, A.I., McCubbin, M.A., & Kasten, A. (1993). Culture, ethnicity, and the family: Critical factors in childhood chronic illness and disability. Pediatrics, 91(5, Part 2), 1063-1070.

SUPPLEMENTARY READINGS

Models of Adaptation

Berdie, J. & Selig, A.L. (1981). Family functioning in families with children who have handicapping conditions. Family Therapy, 8(3), 187-195.

Drotar, D., Baskiewicz, A., Kennell, J., & Klaus, M. (1975). The adaptation of parents to the birth of an infant with congenital malformation: A hypothetical model. Pediatrics, 56, 710-717.

Kopp, C.B. (1982). The role of theoretical frameworks in the study of at-risk and handicapped young children. In Bricker, D.D. (Ed.). Intervention with at-risk and handicapped infants: From research to application. Baltimore, MD: University Park Press.

Moos, R.H. & Schaefer, J.A. (1984). The crisis of physical illness: An overview and conceptual approach. In R.H. Moos (Ed.). Coping with physical illness 2: New perspectives (pp. 3-25). New York: Plenum Press.

Patterson, J. (1988). Families experiencing stress: The family adjustment and adaptation response model. Family Systems & Medicine, 5, 202-237.

Pless, I.B. & Pinkerton, P. (1975). Chronic childhood disorders: Promoting patterns of adjustment. Chicago: Year Book Medical Publishers.

Thompson, R.J., Gil, K.M., Abrams, M.R., & Phillips, G. (1992). Stress, coping, and psychological adjustment of adults with sickle cell disease. Journal of Consulting and Clinical Psychology, 60, 433-440.

Turnbull, A.P. & Turnbull, H.R. (1986). Family life cycle. In Families, professionals, and exceptionality: A special partnership (pp. 85-112). Columbus: Merrill Publishing Company.

Wallander, J.L., Varni, J.W., Babani, L., DeHaan, C.B., Wilcox, K.T., & Banis, H.T. (1989). The social environment and the adaptation of mothers of physically handicapped children. Journal of Pediatric Psychology, 14, 371-387.

Westbrook, L.E., Bauman, L.J., & Shinnar, S. (1992). Applying stigma theory to epilepsy: A test of a conceptual model. Journal of Pediatric Psychology, 17, 633-3-649.

SUPPLEMENTARY READINGS, CONTINUED

Personal Accounts

Covelli, P. (1976). Borrowing time: Growing up with juvenile diabetes. New York: Crowell.

Deford, F. (1983). Alex: The life of a child. New York: Viking Press.

Dorris, M. (1990). The broken cord. Harper & Row.

Featherstone, H. (1980). A difference in the family. New York: Basic Books.

Turnbull, A. & Turnbull, R. (Eds.). (1985). Parents speak out (2nd Edition). Columbus, Ohio: Charles E. Merrill.

Leff, P.T. & Walizer, E.H. (1992). Building the Healing Partnership. Brookline Books.

Massie, R. & Massie, S. (1975). Journey. New York: Knopf.

Miller, N.B. & "The Moms" (1994). Nobody's Perfect. Baltimore, Maryland: Paul H. Brooks.

Simons, R. (1987). After the Tears. San Diego, California: Harcourt, Brace, Jovanovich.

Cultural Diversity

Anderson, P.P., & Fenichel, E.S. (1989). Serving culturally diverse families of infants and toddlers with disabilities. Washington, DC: National Center for Clinical Infant Programs.

Bowe, F. (1985). Black adults with disabilities. Washington, DC: President's Committee on Employment of the Handicapped.

Bowe, F. (1985). Disabled adults of hispanic origin. Washington, DC: President's Committee on Employment of the Handicapped.

SUPPLEMENTARY READINGS, CONTINUED

Brookins, G.K. (1993). Culture, ethnicity, and bicultural competence: Implications for children with chronic illness and disability. Pediatrics,91(5, Part 2), 1048 - 1055.

Center for Child Health and Mental Health Policy. (1992). Toward a culturally competent system of care: Volume II. Washington, DC: Georgetown University Child Development Center, Center for Child Health and Mental Health Policy.

Cross, T.L., Bazron, B.J., Dennis, K.W., & Isaacs, M.R. (1989). Towards a Culturally Competent System of Care. CASSP Technical Assistance Center, Georgetown University.

Gartner, A., Lipsky, D.K. & Turnbull, A.P. (1991). Supporting families with a child with a disability. An international outlook. Baltimore, Maryland: Paul H. Brooks.

Lynch, E. & Hanson, M. (1992). Developing cross-cultural competence: A guide for working with young children and their families. Baltimore: Paul H. Brookes.

Malach, R.S., Segel, N. & Thomas, T. (1989). Overcoming obstacles and improving outcomes: Early intervention services for Indian children with special needs. Bernadillo, NM: Southwest Communication Resources. [NCEMCH]

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MODULE G

DEVELOPMENT IN THE CONTEXT OF A CHRONIC ILLNESS OR DISABILITY

CONTENT

The presence of a chronic illness is likely to shape a child's development as a person. What are the stage-specific developmental issues that intersect with the demands and routines of chronic illness care? In what ways is cognitive, emotional, and social development influenced by the presence of a chronic illness or disability? Do children with these conditions develop according to a healthy logic of their own, as opposed to an "abnormal" developmental course? How do children, adolescents and young adults in this population negotiate key developmental transitions? What factors hinder or promote ongoing development? This module addresses these issues.

RATIONALE

Public health programs in the field of maternal and child health share a common commitment to fostering the family's capacity to promote their child's development. Unfortunately, many public health programs ignore processes of child development. In the field of children with special needs, programs may be implemented by individuals who have erroneous or vague assumptions about the developmental integrity of children who are biologically "different." This module is critical to students in the field of children with special health care needs because it explores what is known about the cognitive, social, and emotional development of these children, and the way in which advances in medical technology alter risks for various developmental outcomes. It pays particular attention to key developmental tasks and transitions as they relate to this population of children and considers what services promote their resolution and prevent the occurrence of secondary disabilities.

SPECIFIC OBJECTIVES

1. Students will be able to identify social and biological factors that threaten the resolution of core developmental challenges for infants, children, and adolescents with chronic illnesses and disabilities.

2. Students will be able to identify key developmental transitions for children with special needs and what circumstances or interventions promote successful transition.

3. Students will be able to identify how at least one major advance in medical technology changed the biological and social risks for poor developmental outcomes of infants, children, or adolescents with special health care needs.

KEY CONCEPTS AND DEFINITIONS

Developmental transition may refer to 1) biologically-determined processes, such as puberty, 2) socially-determined changes, such as the transition from one school to another, 3) individual growth in cognitive capacity, such as the capacity to consider future events realistically. The concept of transition and "transition-readiness" may also refer to movement from one service system to another (e.g., changing from the infant and toddler program to the school-based special education system; or from adolescent medicine to adult-oriented medicine).

Imaginary audience is a term that refers to an adolescent's preoccupation in thinking that everyone else is scrutinizing his or her appearance and actions; this typically contributes to heightened self-consciousness and may have particular salience for adolescents with disabilities and chronic illnesses.

The personal fable refers to an adolescent's conviction that he or she is special and will therefore has a special destiny (or special luck, protection, or talent). The characteristics of the personal fable for adolescents with special needs can have important implications for adherence to treatment regimens and preparation for adult roles.

INSTRUCTOR GUIDELINES

This module is based on the assumption that students have a basic understanding of child development. (If students have had no instruction in this area, we strongly suggest covering key concepts by assigning readings from an appropriate text.) The task of conveying the developmental impact of a chronic illness or disability is enormous in view of the multiple areas (cognitive, social, emotional, family) of development that could be covered. Assuming limited time, we recommend the assignment of one or two of the broad overview readings that we list under Core Readings. Students wishing to pursue a particular topic or developmental stage further can select additional readings from the appropriate supplementary reading list. The supplementary reading lists in this section are meant to be starting points for further study and do not provide comprehensive coverage of the domain.

Class discussion of general developmental issues can be focused in any of the following ways:

Select a condition and trace its impact or the child and family through the developmental stages.

Select one developmental stage and consider how a particular condition could affect different developmental domains.

Select a particular issue (e.g., peer relations) and consider how different chronic conditions might shape development across the life span in relation to this issue.

Ask students to develop a service program that would be responsive to developmental issues. What would such a program look like?

Invite an adult who has had a chronic condition to speak about how it influenced his or her development.

READINGS: General Overviews of Developmental Issues

Eisenberg, M.G., Sutkin, L.C., & Jansen, M.A. (Eds.). *Chronic illness and disability through the life span: Effects on self and family*. New York: Springer.

Gliedman, J. & Roth, W. (1980). *The unexpected minority: Handicapped children in America. A report of the Carnegie Council on Children*. Chapter 3. New York: Harcourt, Brace & Jovanovich.

Magrab, P.R. (1985). Psychological development of chronically ill children. In N. Hobbs & J.M. Perrin (Eds.). *Issues of care of children with chronic illness: A sourcebook on problems, services, and policies*. San Francisco: Jossey-Bass.

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Lapham, V. & Shevlin, K. (1986). *The impact of chronic illness on psychosocial stages of human development*. Washington, DC: National Center for Education in Maternal and Child Health.

Yoos, L. (1987). Chronic childhood illnesses: Developmental issues. *Pediatric Nursing*, *13(1)*, 25-28.

READINGS: Specific Developmental Stages

Developmental Issues in Infancy

Aylward, G., Pfeiffer, S., Wright, A., & Verhurst, S. (1989). Outcome of low birthweight infants published in the last decade: A meta-analysis. Journal of Pediatrics, 115, 515-520.

Behrman, R.E. (Ed.). Drug exposed infants. The Future of Children, 1(1).

Gottfried, A., Wallace-Lande, P., Sherman-Brown, S., King, J., Cohen, C. & Hodgman, J.E. (1981). Physical and social environment of newborn infants in special care units. Science, 214, 673-675.

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See also annotated bibliographies produced by the National Center for Youth with Disabilities, Box 721, UMHC, Harvard Street at East River Road, Minneapolis, MN 55455. See Section V for list.

MODULE H

EMPOWERMENT AND BEYOND

CONTENT

This module addresses issues in disability from the vantage point of the more vocal groups advocating for individuals with special health needs and their families. The concepts of advocacy and empowerment are examined in relation to interactions between individuals in this population and the medical system, the community, and employers.

RATIONALE

One can argue that current efforts to reform federal and state policies for children and young adults with disabilities and their families only tinker with the existing system and are wholly inadequate in view of the extent to which these individuals' civil rights are denied. Moreover, the country as a whole remains fixated on rigid stereotypes of beauty, competence, and physical power. Without vigorous advocacy at all levels, individuals with disabilities will be second class citizens forever. To avoid complacency and move beyond what some have called conventional enlightenment, students in the field must understand the concept of empowerment and be responsive to the justified indignation of the more passionate advocates in this arena.

SPECIFIC OBJECTIVES

1. Students will discuss the concepts of advocacy and "empowerment" as they relate to this population of children, adolescents, and young adults with special needs and their families.

2. Students will consider how families and individuals with disabilities can be integrated at all levels of policy and program development.

3. Students will become familiar with some of the less traditional publications in the field and will be able to articulate key issues from the perspective of the more radicalized disability groups.

KEY CONCEPTS AND DEFINITIONS

Empowerment has been defined as "a mechanism by which people, organizations, and communities gain mastery over their affairs" (Rappaport, 1987, p. 122). Zimmerman (1994, p. 5, 7) notes that "psychological empowerment includes beliefs about one's competence and efficacy, and a willingness to become involved in activities to exert control in the social and political environment.... [It is] a construct that integrates perceptions of personal control with behaviors to exert control." In discussing components of empowerment, Riger (1993) makes a distinction between perceptions of greater power and actual power to change how resources are distributed or decisions are made. She asks (p. 282): Do "attempts to enhance a sense of empowerment create the illusion of power without affecting the actual distribution of power"?

INSTRUCTOR GUIDELINES

Several of the more effective advocacy groups, such as the World Institute on Disability, include individuals who are commanding speakers. Inviting such a person to speak in a class can be a valuable learning opportunity. Other strategies include:

Interviewing parents who have had experience in advocacy.

Inviting business leaders who have had to respond to the requirements of the American Disabilities Act to speak to the class.

Asking individuals with disabilities to come to the class to discuss issues of independent living, continued education, career development, and discrimination.

Inviting parents who have played important roles in policy development to speak with the class.

Examining a program that seeks to "empower" a group of persons. What was the goal of the program? What were the components of the empowerment process?

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SECTION III

ADDITIONAL MODULES

ADDITIONAL MODULE

HEALTH CARE REFORM

CONTENT

In the spring of 1994, elements of health care reform were still being debated vigorously. Certain aspects of the President's proposed plan were widely seen as contrary to the best interests of children with special health needs and other groups requiring long-term care. In fact, children with chronic illnesses and disabilities were largely overlooked in all of the early proposals. This module lists many of the published articles and manuscripts addressing the pertinent issues within the debate on health care reform.

RATIONALE

All public health professionals will be affected by the forces that health care reform will hasten or set in motion. Understanding the history of critical issues will assist in responding to their implications.

SPECIFIC OBJECTIVES

Students will identify critical issues in the debate on health care reform as it pertains to this population of children and their families, including issues related to

exclusionary clauses;

payment for services that maintain health or prevent secondary conditions, in addition to services that enhance functioning;

financing long-term care services in the community;

addressing issues of access to needed specialty services, and coordination with local primary care services; and

maintaining a role for existing public health programs.

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ADDITIONAL MODULE

YOUNG ADULTS WITH SPECIAL NEEDS

CONTENT

This module addresses the complex set of interacting issues that arise during the transition to adulthood for youth with special health care needs. This module covers topics of intimacy, sexuality, career decisions, financing of health coverage, and independent living.

RATIONALE

With advances in medical technology, the life expectancy of children with special needs has continued to expand with earlier and more aggressive treatments. Future professionals in this field need to be aware of the issues surrounding the transition to adulthood to assure that the benefits of medical progress and supportive services in childhood are not eviscerated by major inadequacies in the service system for adults.

SPECIFIC OBJECTIVES

1. Students will be able to discuss barriers for young adults with special needs in the following areas: sexuality, career choice, adult medicine, financing of health coverage, independent living, and having children.

2. Students will be able to identify methods for resolving these the barriers.

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See also selected CYDLINE Reviews from the National Center for Youth with Disabilities, Box 721 UMHC, Harvard Street at East River Road, Minneapolis, Minnesota 55455.

ADDITIONAL MODULE

PEDIATRIC AIDS[*]

CONTENT

This module will cover the risk factors, epidemiology, and clinical course for pediatric HIV infection and pediatric AIDS. The impact of pediatric AIDS and HIV infection on the family and their social, emotional, and psychological needs will also be discussed.

RATIONALE

Pediatric AIDS will be a critical chronic health problem well into the twenty-first century. As future public health leaders, students need to know the risk factors for pediatric AIDS and HIV infection, the epidemiology and clinical course of pediatric HIV infection and pediatric AIDS. Students must also be aware of the impact of HIV infection on child and family.

SPECIFIC OBJECTIVES

1. Students will be able to identify the risk factors for pediatric HIV infection and pediatric AIDS.

2. Student will be able to describe the clinical course of pediatric HIV infection and pediatric AIDS.

3. Students will be able to discuss the impact of HIV infection on development in the social and familial context.

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[*] Most of the listed readings in this section were provided courtesy of Dr. John Santelli.

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Wilcox, B. (1990). Federal policy and adolescent AIDS. New Directions for Child Development, 50, 61-70.

For further information and resources, contact:

Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI)
110 Greene Street, Suite 303
New York, New York 10012
Elaine Wells, Project Director
Betsy Kase, Information Services Coordinator
(212) 431-8541
(800) 42-HANDI
(212) 421-0906 FAX

HANDI's mission is to develop and maintain a comprehensive resource collection on hemophilia and HIV and to respond to requests for information.

National Pediatric HIV Resource Center
15 South Ninth Street
Newark, New Jersey 07107
201/268-8273

The Resource Center promotes the development of culturally sensitive, family-centered, coordinated, community-based systems of care for children with HIV infection and their families by serving as a resource to programs at the local, state, and national levels. The Resource Center also provides state-of-the-art information regarding the management and treatment of children with HIV infection including the psychosocial impact of the disease on them and their families. The Resource Center has developed training programs for health professionals serving HIV/AIDS affected children, adolescents, women, and families.

ADDITIONAL MODULE

NEEDS ASSESSMENT

CONTENT

The focus of this module is the identification of the strategies, rationale, and data utilized in the design of a needs assessment related to the population of children with special needs and their families. The principles and practices involved in planning and implementing a needs assessment are covered as they apply to this population. Students can practice the skills taught in this module by planning a mock needs assessment for a particular state or region.

RATIONALE

Needs assessments are now required by law for State Programs for Children with Special Health Care Needs. Advanced students who plan to pursue a career in the field of children with special needs and their families will require the knowledge base and skills to conduct needs assessments related to children with special needs and their families.

OBJECTIVES

1. Students will be able to identify potential approaches and data sources for needs assessment.

2. Students will be able to evaluate a needs assessment in relation to its strengths and weaknesses and how it addresses federal requirements.

READINGS

Black, T., Prestridge, S. & Anderson, J. (1981). The development of a needs assessment process. Chapel Hill, NC: Technical Assistance Development System.

Epstein, S.G., Taylor, A.B., Walker, D.K., Crocker, A.C., Gardner, J., Halberg, A.S., Mailloux, S.E.H., Murphy, A. & Tuttle, G.A. (1988). Project SERVE: A needs assessment and state planning model for Massachusetts. In R.E.K. Stein (Ed.). Caring for children with chronic illness: Issues and strategies. Springer Publishing Company.

Farel, A. (1993). Needs assessments in MCH Programs. In R. Nelson (Ed.), Maternal and child health practices, 4th Edition. Oakland, CA: Third Party.

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Texas Department of Health. (1990). Chronically ill and disabled children's services program: Strategic plan documents. Austin, TX: Texas Department of Health. [NCEMCH]

Walker, D.K., Epstein, S.G., Taylor, A.B., Crocker, A.C. & Tuttle, G.A. (1989). Perceived needs of families with children who have chronic health conditions. Children's Health Care, 18(4), 196-201.

Work Group on Systems Development, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau. (1991). Needs assessment and the development of community-based service systems: An annotated bibliography of resources. Rockville, MD: Maternal and Child Health Bureau, U.S. Department of Health and Human Services.

ADDITIONAL MODULE

PROGRAM EVALUATION

CONTENT

The focus of this module is the identification of the strategies, rationale, and data utilized in the design and assessment of public health programs for the population of children with special needs and their families. It addresses principles and practices involved in planning, implementing, and evaluating programs for children with special needs and their families. Students can practice the skills taught in this module by conducting a mock evaluation of a Special Project of Regional or National Significance (SPRANS), as listed in the publication produced by the National Center for Education in Maternal and Child Health.

RATIONALE

Over the last several years, many programs in this field have undertaken evaluations of new or existing projects. Yet, in general, evaluation in this area remains comparatively limited in scope and sophistication. Skills in planning and conducting feasible evaluations will be critical as the demands for program accountability increase.

OBJECTIVES

1. Students will develop skills to identify and critically analyze the goals of specific programs for children with special needs and their families.

2. Students will be able to identify the parameters and appropriate data used to monitor and assess programs for children with special needs and their families.

3. Students will be able to evaluate critically program evaluations relevant to this population of children.

4. Students will design their own program evaluation of a previously describe SPRANS project or published description of a program for children with special needs.

READINGS

Field, T.M. (1986). Interventions for premature infants. Journal of Pediatrics, 109, 183-191.

Ireys, H. & Magrab, P. (1986). Evaluation of state programs serving children and youth with chronic conditions. In Wallace, H. et al. (Eds.) Handicapped children and youth: A comprehensive community and clinical approach. New York: Springer.

Provence, S. (1985). On the efficacy of early intervention programs. Journal of Developmental and Behavioral Pediatrics, 6, 363-366.

Jessop, D.J. & Stein, R.E.K. (1983). A service delivery program and its evaluation: A case study in the sociology of applied research. Evaluation of the Health Professional, 6, 99-114.

READINGS: SELECTED EXAMPLES OF PROGRAM EVALUATION

Affleck, G., Tennen, H., Rowe, J., Roscher, B., & Walker, L. (1989). Effects of formal support on mothers' adaptation to the hospital-to-home transition of high-risk infants: The benefits and costs of helping. Child Development, 60, 488-501.

Fireman, P., Friday, G.A., Gira, C., Vierthaler, W.A., & Michaels, L. (1981). Teaching self-management skills to asthmatic children and their parents in an ambulatory care setting. Pediatrics, 68, 341-348.

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Shonkoff, J., Hauser-Cram, P., Krauss, M., & Upshur, C. (1992). Development of infants with disabilities and their families. Monographs of the Society for Research in Child Development, 57(6), Serial No 230.

Stein, R.E.K. & Jessop, D.J. (1984). Does pediatric home care make a difference for children with chronic illness: Findings from the pediatric ambulatory care treatment study. Pediatrics, 73, 845-853.

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ADDITIONAL MODULE

RISK FACTORS FOR MENTAL HEALTH

CONTENT

Beyond the estimates of mental health risk in children with special needs, extensive research has identified the specific risk factors for poor mental health and the nature of the association between these risk factors and various mental health outcomes. This module covers conceptual and methodological issues in the measurement and analysis of risk factors for poor mental health in this population of children and their families.

RATIONALE

Estimates of mental health status in the population of children with special needs have been contradictory -- partly because investigators have used a variety of methods to measure mental health and diverse approaches to conceptualizing and assessing potential risk factors. Students who plan careers as policy makers, administrators, and researchers in the field of children with special needs must be aware of the conceptual and methodological issues surrounding the measurement and assessment of risk factors for poor mental health outcomes for these children and their families. This module is intended to provide a framework for students to pursue research on this topic.

SPECIFIC OBJECTIVES

1. Students will be able to a) identify specific methods for assessing mental health outcomes and behaviors in individuals with chronic conditions and b) discuss the limits of their confidence in any particular measurement approach.

2. Students will be able to identify risk factors for poor mental health outcomes.

3. Students will be able to identify a critical research question that relates a risk factor to a specific mental health outcome in children with special needs and to develop a proposal for carrying out research that will answer this question.

READINGS

Research on mental health risk factors related to children with special health care needs and their families has grown enormously since 1970. A comprehensive bibliography of pertinent readings as of 1985 is available from the Preventive Intervention Research Center for Child Health at the Albert Einstein College of Medicine, 1300 Morris Park Avenue, Bronx, New York 10461. In addition, annotated bibliographies of mental health issues related to adolescents with chronic illnesses and disabilities are published by the National Center for Youth with Disabilities (see Section V).

To keep the listing to a reasonable length. we included references that met at least one of three fairly arbitrary criteria. First, selections were chosen if they represented a systematic review of a particular set of articles. Second, selections were chosen to reflect efforts by individual scholars or teams of researchers who are systematically pursuing a program of research. The research may be driven by clinical observations or by particular theories (or by some combination), but each group has undertaken a sequence of efforts to answer a series of key questions. Third, we selected only references published in 1983 or later. <u>We emphasize that list of these readings should serve primarily as a point of departure for a comprehensive study of the issues. There are many other, extremely strong articles that are not listed here.</u>

Mental Health Epidemiology

Cadman, D., Boyle, M., Szatmari, D., & Offord, D.R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. <u>Pediatrics</u>, <u>79</u>, 805-813.

Gortmaker, S., Perrin, J., Weitzman, M., Homer, C., & Sobol., A. (1993). An unexpected success story: Transition to adulthood in youth with chronic health conditions. <u>Journal of Research on Adolescence</u>, <u>3</u>, 317-336.

Gortmaker, S.L., Walker, D.K., Weitzman, M., & Sobol, A.M. (1990). Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. <u>Pediatrics</u>, <u>85</u>, 267-276.

Pless I. B. & Nolan, T. (1991). Revision, replication, and neglect - Research on maladjustment in chronic illness. <u>Journal of Child Psychology and Psychiatry</u>, <u>30</u>, 347-365.

Mental Health Epidemiology, continued

Pless, I.B. & Pinkerton, P. (1975). Chronic childhood disorders: Promoting patterns of adjustment. Chicago: Year Book Medical Publishers.

Pless, I.B. & Wadsworth, M.E.J. (1989). The unresolved question: Long-term psychosocial sequelae of chronic illness in childhood. In R.E.K. Stein (Ed.). New directions in care of children with chronic illness New York: United Hospital Fund.

Risk Factor Identification and Model Testing

Jessop, D.J., Riessman, C.K., & Stein, R.E.K. (1988). Chronic childhood illness and maternal mental health. Journal of Developmental and Behavioral Pediatrics, 9(3), 147-156.

Jessop, D. & Stein, R. (1985). Uncertainty and its relation to the psychological correlates of chronic illness in children. Social Science and Medicine, 20, 993-999.

Lavigne, J. & Faier-Routman, J. (1992). Psychological adjustment to pediatric disorders: A meta-analytic review. Journal of Pediatric Psychology, 17, 113-157.

Patterson, J., McCubbin, H., & Warwick, W. (1990). The impact of family functioning on health changes in children with cystic fibrosis. Social Science and Medicine, 31(2), 159-164.

Patterson, J., Leonard, B., Titus, J. (1992). Home care for medically fragile children: Impact on family health and well-being. Journal of Developmental and Behavioral Pediatrics, 13, 248-255.

Stein, R. & Jessop, D. (1984). Relationship between health status and psychological adjustment among children with chronic conditions. Pediatrics, 73, 169-174.

Thompson, R.J., Gil, K.M., Abrams, M.R., & Phillips, G. (1992). Stress, coping, and psychological adjustment of adults with sickle cell disease. Journal of Consulting and Clinical Psychology, 60, 433-440.

Wallander, J.L., Varni, J.W., Babani, L., Banis, H. T., & Wilcox, K.T. (1988). Children with chronic physical disorders: Maternal reports of their psychological adjustment. Journal of Pediatric Psychology, 13, 197-212.

Risk Factor Identification and Model Testing, continued

Wallander, J.L., Varni, J.W., Babani, L., Banis, H.T., DeHaan, C.B., & Wilcox, K.T. (1989). Disability parameters, chronic strain, and adaptation of physically handicapped children and their mothers. Journal of Pediatric Psych, 14, 23-42.

Wallander, J.L., Varni, J.W., Babani, L., DeHaan, C.B., Wilcox, K.T., & Banis, H.T. (1989). The social environment and the adaptation of mothers of physically handicapped children. Journal of Pediatric Psychology, 14, 371-387.

ADDITIONAL MODULE

NUTRITION ISSUES

CONTENT

This module covers the nutritional concerns that may face children with special needs, including feeding problems, alterations in growth, drug/nutrient interaction, metabolic disorders, and caregiver-related problems. The role of the public health professional and public health programs in addressing these issues is also covered.

RATIONALE

Children with special needs are at increased nutritional risk because of feeding problems, drug/nutrient interactions, metabolic disorders, lack of mobility, and altered growth patterns. The nutritional status of these children can affect their ability to grow and develop. Appropriate nutrition programs and services can have a positive impact on the health of this population and help prevent further disabilities by improving overall health and nutritional status. All professionals who work with children with special needs and their families need to be aware of the impact nutritional status on these children and their families.

SPECIFIC OBJECTIVES

1. Students will be able to identify nutritional risk factors for children with special needs and how they may impair growth and development.

2. Students will be able to discuss how a child's nutritional problems may impact his/her care givers.

3. Students will identify reasons why the nutritional needs of children with special needs require an interdisciplinary, family-centered, and community-based approach in order to be addressed adequately.

4. Students will be able to discuss how nutrition services for children with special needs can be integrated into state programs.

READINGS

American Dietetic Association. (1987). Position of the American Dietetic Association in comprehensive program planning for persons with developmental disabilities. Journal of the American Dietetic Association, 87, 1068-1069.

American Dietetic Association. (1987). Nutrition in comprehensive program planning for persons with developmental disabilities: Technical support paper. Journal of the American Dietetic Association, 87, 1070-1073.

American Dietetic Association. (1989). Position of the American Dietetic Association: Nutrition services for children with special health needs. Journal of the American Dietetic Association, 89, 1133-1137.

Baer, M.T. (Ed.). (1982). Nutrition services for children with handicaps: A manual for state Title V programs. Los Angeles, CA: University Affiliated Training Program, Children's Hospital Los Angeles.

Baer, M.T., Farnan, S., & Mauer, A.M. (1991). Children with special health care needs. In C.O. Sharbaugh (Ed.) Call to action: Better nutrition for mothers, children, and families. (pp. 191-221). Washington, DC: National Center for Education in Maternal and Child Health.

Baer, M.T., Tanaka, T.L., & Blyler, E.M. (1991). Nutrition strategies for children with special needs: Identifying kids at risk. Los Angeles, CA: Center for Child Development and Developmental Disorders, Children's Hospital of Los Angeles.

Cronk, C., Crocker, A.C., Pueschel, S.M., Shea, A.M., Zackai, E., Pickens, G., and Reed, R.B. (1988). Growth charts for children with Down Syndrome: 1 month to 18 years of age. Pediatrics, 81, 102-110.

Ekvall, S.W. (Ed.). (1993). Pediatric nutrition in chronic diseases and developmental disorders: Prevention, assessment and treatment. New York: Oxford University Press.

Ekvall, S.W. & Stevens, F.S. (Eds.). (1989). Nutritional needs of the handicapped/chronically ill child: Nutrition program planning manual I; Clinical nutrition manual II; and Nutrition assessment manuals III. Cincinnati, OH: University Affiliated Cincinnati Center for Developmental Disorders.

Farnan, S. (1988). Role of nutrition in crippled children's services agencies. Topics in Clinical Nutrition, 3, 33.

READINGS, CONTINUED

Gandy, L.T., Yadrick, M.K., Boudreaux, L.J., & Smith, E.R. (1991). Serving children with special health care needs: Nutrition services and employee training needs in the school lunch program. Journal of the American Dietetic Association, 91, 1585-1586.

Hine, R.J., Cloud, H.H., Carithers, T., Hickey, C., & Hinton, A.W. (1989). Early nutrition intervention services for children with special health care needs. Journal of the American Dietetic Association, 89, 1636-1639.

Isaacs, J.S., Davis, B.D., & La Montagne, M.J. (1990). Transitioning the child fed by gastrostomy into school. Journal of the American Dietetic Association, 90, 982-985.

Kozlowski, B.W. (Ed.). (1982). Meeting nutrition services needs of clients of Crippled Children's Services and Supplemental Security Income Disabled Children's Programs. Washington, DC: U.S. Department of Health and Human Services, U.S. Government Printing Office.

Lucas, B.L. (1989). Serving infants and children with special health care needs in the 1990s--are we ready? Journal of the American Dietetic Association, 89, 1599-1601.

National Center for Education in Maternal and Child Health. (1991). Nutrition services for children with special health needs: Abstracts of active and completed projects FY 1985-1991. Washington, DC: NCEMCH.

National Center for Youth with Disabilities. (1990). Issues in nutrition for adolescents with chronic illnesses and disabilities. Minneapolis, MN: University of Minnesota, National Center for Youth with Disabilities.

Ohio State University, Nisonger Center. (n.d.). Nutrition and feeding problems of children with developmental disabilities; videotape. Columbus, OH: Nisonger Center, Ohio State University.[NCEMCH]

Tluczek, A. & Sondel, S. (1991). Project SPOON: Special program of oral nutrition for children with special needs. Madison, WI: University of Wisconsin Children's Hospital. [NCEMCH]

Wodarski, L. (1985). Nutrition intervention in developmental disabilities: An interdisciplinary approach. Journal American Dietetic Association, 85, 218-221.

ADDITIONAL MODULE

INTERNATIONAL ISSUES

CONTENT

This module presents models of care for children with special needs used in developed countries other than the United States. Systems of care for children with special health care needs will be compared and contrasted through case studies of selected industrialized countries.

RATIONALE

The United States is not alone in efforts to provide quality care to children with special needs and their families. Experience of other countries in dealing with issues of children with special needs and their families can be instructive in improving efforts in this country.

SPECIFIC OBJECTIVES

1. Students will be able to compare and contrast different models of care from other industrialized countries with the United States model.

2. Students will be able to discuss historical evolution of each country's model of care for children with special needs and to identify cultural, political, and social issues that may limit its applicability to the United States.

READINGS

Allan, D. (1984). Health services in England. In M.W. Raffel (Ed.). Comparative Health Systems (pp. 197-257). University Park: Pennsylvania State University Press.

Goodwin, S. (1990). Children with special needs in England and Wales: Impaired hearing, adolescent pregnancy, and myelomeningocele. Pediatrics, 86, 1112-1116.

Hardoff, D. & Chigier, E. (1991). Developing community-based services for youth with disabilities in Israel. Pediatrician, 18, 157-162.

National Center for Youth with Disabilities. (1990). Youth with disabilities and chronic illnesses: International issues. Minneapolis, MN: University of Minnesota, National Center for Youth with Disabilities.

Singh, T.H. (1989). Mental Health Act 1983: Guardianship order and definition of mental impairment. British Medical Journal, 299, 1284.

Verbrugge, H.P. (1990). Children with special needs in The Netherlands: Impaired hearing, adolescent pregnancy, and myelomeningocele. Pediatrics, 86, 1117-1120.

Young, E.W.D. (1983, Aug). The British and Swedish models: Caring for disabled infants. The Hastings Center Report, 15-18.

SECTION IV

EVALUATION METHODOLOGY

Evaluation is essential for continued improvement of instructional efforts and for identification of emerging educational needs. In this section, we outline principles for evaluating the curriculum described in Section II, and give examples of specific evaluation questions. These principles can serve as the foundation for evaluation strategies that are consistent with any particular educational setting.

Who Contributes to the Evaluation?

Under the usual circumstances, students who actually take the courses are the only ones who complete evaluations. For this curriculum, systematically-gathered information from all participants is considered to be important, including parents, guest speakers, and the primary instructor. Furthermore, most courses have target populations of students, but not all students in the population actually register. It would be most informative to inquire systematically about the reasons why students in the target population did not take the course. Similarly, for new courses, there are usually several cohorts of recently graduated students who did not have the opportunity to take the course. If resources permit, these students can be tapped for information concerning what would have been useful to them. Finally, under ideal circumstances, graduates of a course can be tracked and, after some period of time, surveyed concerning what they found useful from the course in their subsequent career paths.

What Should be Evaluated?

Increases in knowledge. The specific objectives in each module serve to define the content areas that we believe are most critical. Assessing knowledge in these areas requires testing for the acquisition of this content through the usual route of examinations and papers. In addition, students can rank each core topic on a five-point scale in relation to how much it enhanced his or her knowledge. If this question is asked, it is important to ask also about previous experiences with this population of children. For example, students can be asked whether they have had none, some, or much experience in clinical services, program involvement, or personal caring in relation to these children. This information would be useful in analyzing subjective judgements about gains in knowledge as a result of the course.

Knowledge can be understood or integrated in new ways -- an event that is often characterized by a sudden insight or an "a-hah" experience. The best courses provide at least some of these experiences to most students. Thus, in evaluating a course or seminar series, it is instructive to ask a question such as: "Did you have any experiences of sudden insight or a sense of seeing things differently (sometimes called an "a-hah" experience) at any point in the course? If so, describe it briefly."

Changes in beliefs and attitudes. Accurately assessing changes in beliefs and attitudes is difficult, in large part because it requires an instrument that can reliably and validly measure these characteristics in relation to a particular population or topic. Such instruments do not now exist in this area. Alternatively, it is possible to ask more open-ended questions related to participants' perceptions of how the course or field experience changed their beliefs and attitudes. Such questions might include the following: "Did participating in this course change your beliefs or attitudes toward children with special needs and their families? If so, how?" A related approach is to ask participants to indicate on a five-point scale how likely they might pursue further training in this area. Responses at the beginning of the course can be compared to those at the end. Again, these subjective judgements should be evaluated in relation to previous experiences with this population of children.

Presentation of material. Quality of the presentation is essential to assess along a number of dimensions, including whether the presenter was clear, organized, exciting, able to articulate goals for the presentation and to reach them, and able to communicate substantive ideas. Other aspects of the presentation to evaluate include the instructor's overall knowledge of the area, quality of audio-visual materials, usefulness of handouts, and general organization of content. In general, it is important to complete these evaluations as soon as possible after each presentation or class, rather than waiting until the end of a term or semester. Opportunities should be given to all participants to identify special strengths and weaknesses and to suggest other relevant ideas for presentation. In addition to evaluating individual classes or presenters, participants should evaluate the course or seminar as a whole.

Relevancy. Teaching is most effective when the material is highly relevant to the students. This observation underscores the importance of assessing for each course segment the students' perceptions of its relevancy to their lives in general and to their career plans in specific. This information may be critical to assure that information about children with special needs and their families is seen as critical to persons in many different career paths, not just those who are pursuing a career in the field of children with special needs and their families.

To gather information on issues of relevance, the following questions can be used: How relevant were the core topics to your work? What did you consider most relevant in this curriculum? What did you consider least relevant? To what extent is this area relevant to your professional identity as you see it now? In general, it is helpful to provide anchored response categories (e.g., 1 to 5 with numbers corresponding to statements such as "not at all" to "very relevant").

Field placements. Field placements will usually involve working either with program administrators or families. Their evaluation of the planning, content, and process of the experience is as important as the students' in maintaining high standards and responding to emerging issues and training needs. We provide an example of a field placement evaluation on the following pages. This form is relevant to a particular field experience in which families with children who have a serious on-going condition serve as hosts to students in a course. The course covers attitudes, programs and policies for children with special health needs and their families. The families, in addition to attending an organizational meeting at the beginning and a de-briefing meeting at the end of the term, agreed to host students for two four hour periods separated by about a month. The families were asked to include the student in a routine family event (e.g, a trip to the grocery store, a clinic visit, or a family dinner).

EXAMPLE OF A FIELD PLACEMENT EVALUATION

Student's Evaluation of Field Experience

To what extent have you had direct personal or professional contact with children who have chronic illnesses or disabilities?
(Check one in each category.)

Professional contact:

____ Considerable clinical contact as a physician, nurse, or other health professional.

____ Moderate clinical contact as a physician, nurse, or other health professional.

____ No or virtually no clinical contact as a physician, nurse, or other health professional.

Personal contact:

____ Considerable personal contact as a close relative (sibling, parent, or other close family member).

____ Moderate personal contact as a close relative (sibling, parent, or other close family member).

____ No or virtually no personal contact as a close relative (sibling, parent, or other close family member).

Were the objectives of the field experience made clear?

___ Yes ___ No

Were you provided with enough orientation before the visit?

___ Yes ___ No

Were preliminary activities or assignments helpful in preparing you for the field experience?

___ Yes ___ No

If yes, which ones?

Did the host family seem adequately prepared?

___ Yes ___ No

Was the second visit different that the first?

___ Yes ___ No

If yes, in what way?

Did visiting the families in any way change your beliefs and attitudes toward children with special health needs and their families?

___ Yes ___ No

If yes, in what way?

Did you have any experiences of sudden insight or a sense of "seeing things differently" at any point during the visits?

___ Yes ___ No

If yes, describe.

In terms of your own personality was this hard or easy for your to do?

Very Difficult		No Major Problem		Very Easy
1	2	3	4	5

How much did you like your host family?

Very little		Somewhat		Very much
1	2	3	4	5

Overall, the experience with the host family was:

Awful		OK		Wonderful
1	2	3	4	5

Would you do it again? Why or why not?

Other comments:

Evaluation by Family

Were the objectives of the field experience made clear to you?

___ Yes ___ No

Were you provided with enough orientation before the visit?

___ Yes ___ No

If no, what would have been helpful to you?

Did your student seem adequately prepared?

___ Yes ___ No

Was the second visit different that the first?

___ Yes ___ No

If yes, in what way?

How much did you like your student?

Very little Somewhat Very much

1 2 3 4 5

Were you satisfied with your working experience with the course instructor?

___ Yes ___ No

If no, why not?

In terms of your own personality was this hard or easy for your to do?

Very Difficult		No Major Problem		Very Easy
1	2	3	4	5

Overall, what were the best parts of the field experience for you?

Overall, the experience with the student was:

Awful		OK		Wonderful
1	2	3	4	5

Would you do it again? Why or why not?

Other comments:

SECTION V

SUPPLEMENTAL RESOURCES

A COMPENDIUM OF TEXTS

Biehl, R., Wallace, H., MacQueen, J., & Blackman, J. (1994). Children with Disabilities and Chronic Illnesses: Challenges and Solutions in Community Care. Oakland, California: Third Party Associates.

Blum, R.W. (Ed.). (1984). Chronic illness and disability in childhood and adolescence. Orlando, FL: Grune and Stratton, Inc.

Brooke, P. (1987). Federal policy toward mental retardation and developmental disabilities. Baltimore, MD: Paul H. Brookes Publishing.

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Health and Education Collaboration for Children with Handicaps (HECCH) (1990). The incidence and prevalence of conditions in children: A sourcebook of rates and state-specific estimates for DHHS Region IV. (2nd ed.). Chapel Hill, NC: University of North Carolina at Chapel Hill.

Hobbs, N., Perrin, J.M. & Ireys, H.T. (1985). Chronically ill children and their families: Problems, prospects, and proposals from the Vanderbilt Study. San Francisco: Jossey-Bass.

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Hostler, S. (1994). Family-Centered Care: An Approach to Implementation. Charlottesville, Virginia: University of Virginia.

Institute of Medicine. (1991). Disability in America: Toward a national agenda for prevention. Committee on a National Agenda for the Prevention of Disabilities, Division of Health Promotion and Disease Prevention, Institute of Medicine. Washington: National Academy Press.

Jackson, P. & Vessey, J. (Eds.). (1992). Primary care of the child with a chronic condition. St. Louis, MO: Mosby Year Book.

Rose, M. & Thomas, R. (1987). Children with chronic conditions: Nursing in a family and community context. Orlando, FL: Grune & Stratton.

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TEXTS, CONTINUED

Shelton, T.L., Jeppson, E.S., & Johnson, B.H. (1987). Family-centered care for children with special health care needs. Washington: Association for the care of children's health.

Seligman, M. (1983). The family with a handicapped child: Understanding and treatment. New York: Grune and Statton, Inc.

U.S. Congress, Office of Technology Assessment. (1987). Technology-dependent children: Hospital v. home care -- A technical memorandum, OTA-TM-H-38. Washington, DC: U.S. Government Printing Office.

Wallace, H.M. (1987). Handicapped children and youth. New York: Human Sciences Press Inc..

Zola, I.K. (1982). Ordinary lives: Voices of disability and disease. Cambridge, MA: Apple-wood Books.

Zola, I.K. (1982). Missing pieces: A chronicle of living with a disability. Philadelphia, PA: Temple University Press.

ANNOTATED BIBLIOGRAPHIES, RESOURCES LISTS, AND WORKBOOKS

American Association of University Affiliated Programs. (1990). Resource guide to organizations concerned with developmental handicaps. Silver Spring, MD: Author.[NCEMCH]

National Center for Education in Maternal and Child Health. (1992). Children with special health care needs: A resource guide. Washington, DC: National Center for Education in Maternal and Child Health.

Work Group on Systems Development, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau. (1991). Needs assessment and the development of community-based service systems: An annotated bibliography of resources. Rockville, MD: Maternal and Child Health Bureau, U.S. Department of Health and Human Services.

ANNOTATED BIBLIOGRAPHIES, RESOURCES LISTS, AND WORKBOOKS, CONTINUED

The National Center for Youth with Disabilities has produced the following annotated bibliographies on topics among youth with disabilities:

Adolescents with chronic illnesses-Issues for school personnel.

An introduction to youth with disabilities: Annotated bibliography

Issues in nutrition for adolescents with chronic illnesses and disabilities

Issues in sexuality for adolescents with chronic illnesses and disabilities

Promoting decision-making skills by youth with disabilities: Health, education and vocational choices

Race and ethnicity: Issues for adolescents with chronic illnesses and disabilities

Recreation and Leisure: Issues for adolescents with chronic illnesses and disabilities

Sports and athletics: Issues for adolescents with chronic illnesses and disabilities

Substance use by youth with Disabilities

Vulnerability and resiliency: Focus on children, youth, and families with disabilities

Youth with disabilities and chronic illnesses: International issues for Youth with Disabilities.

These documents are available from the National Center for Youth with Disabilities, University of Minnesota, Box 721-UMHC, Harvard Street at East River Road, Minneapolis, MN 55455. 1-(800)-333-6293 or (612) 626-2825.

ANNOTATED BIBLIOGRAPHIES, RESOURCES LISTS, AND WORKBOOKS, CONTINUED

The **Georgetown University Child Development Center** has developed the following workbooks (often refereed to as the Rainbow Series) on the implementation of services and programs for children with special needs:

Brokering power at the state level for child health care

Creating an information base for program collaboration

Community workbook for collaborative services to preschool handicapped children

Developing a community team

Developing collaborative services for seriously emotionally disturbed children

Developing culturally competent programs for families of children with special health care needs

Evaluating community collaboration: A guide to self study

The family as care manager: Home care coordination for medically fragile children

Getting children home: Hospital to community

A guide for developing self-help/advocacy groups for parents of children with special emotional problems

Power brokering in the community

Preparing to care for children with special health care needs: A workbook for the practicing pediatrician and the community

Planning services for rural children with special health care needs

These documents are available from Georgetown University Child Development Center, Center for Child Health and Mental Health Policy, 3800 Reservoir Road, NW, Bles Building CG-52, Washington, DC 20007.

ANNOTATED BIBLIOGRAPHIES, RESOURCES LISTS, AND WORKBOOKS, CONTINUED

The National Pediatric HIV Resource Center promotes the development of culturally sensitive, family-centered, coordinated, community-based systems of care for children with HIV infection and their families by serving as a resource to programs at the local, state, and national levels. The Resource Center also provides state-of-the-art information regarding the management and treatment of children with HIV infection including the psychosocial impact of the disease on them and their families. The Resource Center has developed training programs for health professionals serving HIV/AIDS affected children, adolescents, women, and families. The Center's address is:

15 South Ninth Street
Newark, New Jersey 07107
201/268-8251

BOOKS BY PARENTS

Covelli, P. (1976). Borrowing time: Growing up with juvenile diabetes. New York: Crowell.

Deford, F. (1983). Alex: The life of a child. New York: Viking Press.

Dorris, M. (1990). The broken cord. Harper & Row.

Featherstone, H. (1980). A difference in the family. New York: Basic Books.

Fraiberg, S. (1977). Insights from the blind: Comparative studies of blind and sighted infants. New York: Basic Books.

Galinsky, E. (1981). Between generations six stages of parenthood. NY: Times Books

Kisor, H. (1990). What's that pig outdoors? A memoir of deafness. New York: Penguin Books.

Lund, O. (1976). Eric. Lippencott.

Massie, R. & Massie, S. (1976). Journey. Warner Books.

Weissman, M. (1982). Intensive care. Random House.

SELECTED VIDEOTAPES

AIMS Media. (n.d.). Alcohol and pregnancy: Fetal alcohol syndrome and fetal alcohol effects. (VHS, 20 minutes). [#8494NR]. Chatsworth, CA: Author.

Association for the Care of Children's Health (n.d.). Family-centered, community-based care. Washington,DC: Author.

Association for the Care of Children's Health (n.d.). Seasons of caring. Washington,DC: Author.

Davoli, C. (1992). Medical evaluation of the child with multiple handicaps. Baltimore, MD: Kennedy Krieger Institute.

Duke University Medical Center, Division of Audiovisual Education. (n.d.). There is a future. Durham, NC: Author.

Jeppson, E.S. (1988). Family-centered care [film]. Washington, DC: Association for the Care of Children's Health.

Kennedy Krieger Institute. (1991). Delivering family-centered, home-based services. Baltimore, MD: Author.

McManus, M. (1990). Health care financing options for adolescents entering adult care. Iowa City, IA: University of Iowa. VHS video 1/2 inch, 46 minutes. [NCEMCH]

McManus, M., & Nelson, R. (1990). Health financing and transition. Iowa City: University of Iowa.

New York State Department of Health. Time out for families: Pediatric respite care. Albany, NY: New York State Department of Health. (20 minutes), 1/2 inch.[NCEMCH]

Ohio State University, Nisonger Center. (n.d.). Nutrition and feeding problems of children with developmental disabilities; videotape. Columbus, OH: Nisonger Center, Ohio State University.[NCEMCH]

State of the Art. (1990). Just Like You and Me: A Video About Epilepsy. State of the Art, 1736 Columbia Road, NW, Suite 110, Washington, DC 20009.

SELECTED VIDEOTAPES, CONTINED

Pacer Center, Inc. (1992). Speak up for health: Young people with chronic illness and disabilities speak about independence in health care.

University of Iowa, Iowa Child Health Specialty Clinics. (1989). Special needs adolescents: Planning for adult health care; 2 videotapes. Iowa City, IA: University of Iowa. [NCEMCH]

Uzee, P. They don't come with manuals. Fanlight Productions, 47 Halifax St. Boston, MA 02130.

COMMERCIALLY-RELEASED MOVIES

In many instances, these films provide a powerful experience that can be discussed by the class a whole. They also raise issues related to how individuals with disabilities are portrayed in a popular media.

Awakenings

Children of a Lesser God

Dominick and Eugene

Elephant Man

Gabby

My Left Foot

The Mask

Rain Dance

Rainman

LIST OF LAWS AND LEGISLATION

Federal Legislation for Children with Special Needs

A chronology of major health legislation. (1976). Health in America, 1776-1976 (DHEW Pub No. (HRA) 76-616) (pp. 195-211). Washington, DC: U.S. Department of Health Education and Welfare.

Ballard, J., Ramirez, B. & Weintraub, F. (1982). Appendix B: Federal laws for the handicapped. In Ballard, J., Ramirez, B. & Weintraub, F. (Eds.). Special education in America: Its legal and governmental foundations. Reston, VA: The Council for Exceptional children.

Public Law 93-112: Rehabilitation Act of 1973

Rehabilitation Act of 1973, Public Law 93-112, as amended in 19778, 1983, and 1986; 29 U.S. Code Sections 701 et seq.

Public Law 99-457: Education of the Handicapped Act Amendments of 1986

Early Intervention Program for Infants and Toddlers with Handicaps of 1986, Public Law 99-457, 34 Code of Federal Regulations Section 303 (1990).

Education of the Handicapped Act Amendments of 1986, Public Law 99-457, Section 101, 20 U.S.C. 1471-1485 (1986).

House Report 99-860. Committee on Education and Labor House of Representatives Report on the Education of the Handicapped Act Amendments of 1986. Washington, DC: 99th Congress, 2nd Session.

Public Law 101-336: American with Disabilities Act of 1990

American with Disabilities Act of 1990, Public Law 101-336, Sections 101 et seq.

Public Law 101-496: Developmental Disabilities Assistance and Bill of Rights Act of 1990

Developmental Disabilities Assistance and Bill of Rights Act of 1990, 42 U.S.C. 6000

Department of Health and Human Services, Office of Human Development Services. (November 20, 1989). 45 C.F.R. Parts 1385, 1386, 1387, and 1388: Developmental Disabilities Program. Federal Register, 54 (222). 47982-47986.

Title V of the Social Security Act: Maternal and Child Health Services Block Grant of 1989

Title V - Maternal and Child Health Services Block Grant of 1989, 501, 42 U.S.C. 701 (1989).

Title 45 - Public Welfare, Department of Health and Human Services; General Administration, Block Grants, 45 C.F.R. Subtitle A (10-1-89 Edition) 96 (1989).

Title IV of the Social Security Act: SSI - Medical Assistance Program

Chapter IV - Health Care Financing Administration, Department of Health and Human Services, Subchapter C - Medical Assistance Programs, 42 C.F.R. Ch. IV (10-1-89 Edition) Parts 430 to End.

LIST OF SPRANS/MCHIP NATIONAL CENTERS: AS OF MARCH 1994

Maternal and Child Health Policy Research Center
Institute for Health Policy Studies
1326 Third Avenue, Box 0936
San Francisco, CA 94143
Paul Newacheck, Dr. P.H., Director
(415) 476-3896
(415) 476-0705 FAX

Description: The Maternal and Child Health Policy Research Center was established in 1990 to address a range of information, financing, and delivery systems problems that impede access to care for children with special health care needs.

The National Center for Case Management and Automation
University Affiliated Program/ Children's Hospital of Los Angeles
P.O. Box 54700, Mail Stop 53
Los Angeles, CA 90054-0700
Lois Wainstock, M.A. and Dale Garell, M.D., Directors
(213) 913-4400
(213) 913-1003 FAX

Description: The National Center for Case Management and Automation (NCCMA) works to improve the capability of state and local agencies to promote coordinate access to systems of care by providing technical assistance for care management and automation planning and implementation. The Center provides onsite and telephone consultation, workshops and written materials are in development.

The National Center on Parent-Directed Resource Centers
535 Race Street, Suite 140
San Jose,.CA 95126
Florene Stewart Poyadue, Director
(408) 288-5010

Description: To help improve the life of children with special needs by facilitating the development and expansion of Parent-Directed Family Resource Centers.

LIST OF SPRANS/MCHIP NATIONAL CENTERS: AS OF MARCH 1994, CONTINUED

The National Center for Education in Maternal and Child Health
2000 15th Street North, Suite 701
Arlington, VA 22201
Rochelle, Mayer, Ed.D., Director
(703) 524-7802
(703) 524-9335 FAX

Description: The Center provides information, educational services, and technical assistance to organizations, agencies and individuals with maternal and child health interests. It collects information, produces publications and plans conferences.

National Network for Children with Special Needs
Georgetown University Child Development Center
Bles Bldg CG 52
3800 Reservoir Road, N.W.
Washington, DC 20007
Phyllis Magrab, Ph.D., Director
(202) 687-8635
(202) 687-1954 FAX

Description: The mission is to achieve comprehensive, coordinated services in the community for children with special needs and their families through improved collaboration among public and private agencies, states and localities, and parents and professionals. The Network project is composed of two major components: Child and Adolescent Service Systems Program (CASSP), which is directed by Sybil Goldman; and Children with Special Health Care Needs (CSHCN), which is directed by Suzanne Bronheim and Nancy Strifler.

National Center for Policy Coordination in Maternal and Child Health
Institute for Child Health Policy
5700 S.W. 34th Street, Suite 323
Gainesville, FL 32608
John Reiss, Ph.D., and Steve A. Freedman, Ph.D., Directors
(904) 392-5904
(904) 392-8822 FAX

Description: The purpose of the Center is to facilitate collaboration and the participation of the maternal and child health community in the coordinated development and implementation of maternal and child health policy at the state and federal level.

LIST OF SPRANS/MCHIP NATIONAL CENTERS: AS OF MARCH 1994, CONTINUED

National Resource Center for Childhood Rheumatic Diseases
Arthritis Foundation/AJAO/NRCCRD
1314 Spring Street N.W.
Atlanta, GA 30309
Daniel J. Lovell, M.D., M.P.H., Director
(513) 559-4676

Description: To provide resources, information and skill building programs for families and care providers of children with childhood rheumatic diseases.

National Resource Center for Community-Based Systems of Services for Children with Special Health Care Needs and Their Families
National Maternal and Child Health Resource Center
College of Law Building
The University of Iowa
Melrose & Byington
Iowa City, IA 52242
Josephine Gittler, J.D., John C. MacQueen, M.D., Directors
(319) 335-9067
(319) 335-9019 FAX

Description: The Center fosters and facilitates community-based service for children with special health needs and their families, and other populations of children and families. A community-based service system is defined as an organizational infrastructure at the community level for the delivery of health and other services (e.g., early intervention, educational vocational, social, mental health and family support services). The Center's activities develop service systems for a broad population of children and families, provide community-based services, provide comprehensive and coordinated services, and provide family-center and culturally-competent services.

National MCH Resource Center for Ensuring Adequate Preparation of Providers of Care
Children's Hospital of New Orleans
200 Henry Clay Avenue
New Orleans, LA 70118
A. Joanne Gates, M.D., M.B.A., Director
(504) 899-9511 x4386

Description: The mission of the National MCH Research Center is to provide technical assistance in the development of systems for the preparation of those who provide care for youth and children with special health conditions and their families.

LIST OF SPRANS/MCHIP NATIONAL CENTERS: AS OF MARCH 1994, CONTINUED

National Center for Family-Centered Care
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
William Sciarillo, Sc.D., Director
(301) 654-6549

Collaboration Among Parents and Professionals/National Parent Resource Center (CAPP/NPRC)
Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
Betsy Anderson, Project Director
(617) 482-2915
(617) 695-2939 FAX

Description: The purpose of the Collaboration Among Parents and Professionals/National Parent Resource Center is to develop a parent organized, nationally coordinated system that will maintain and strengthen parent and family involvement in health care.

New England SERVE: A Network for Implementing Family-Centered, Community-Based Care
101 Tremont Street, Suite 812
Boston MA 02108
Susan G. Epstein, M.S.W., Ann B. Taylor, Ed.D., Directors
(617) 574-9493
(617) 574-9608 FAX

Description: New England SERVE is a planning and technical assistance network of families, health care providers, and State Title V Programs for Children with Special Health Care Needs in the six New England states. All project activities will assist the efforts of families, providers,a nd policy-makers to move health care systems in each of the states toward the goals of family-centered and community-based care.

LIST OF SPRANS/MCHIP NATIONAL CENTERS: AS OF MARCH 1994, CONTINUED

National Center for Youth with Disabilities (NCYD)
University of Minnesota, Box 721-UMHC
Howard Street at East River Road
Minneapolis, MN 55455
Robert, W. Blum, M.D., Ph.D., Nancy A. Okinow, M.S.W., Directors
Elizabeth Latts, M.S.W., Information Specialist
1-800-333-6293
(612) 626-2825
(612) 626-2134 FAX

Description: NCYD is a collaboration of the Society for Adolescent Medicine (SAM) and the Adolescent Health Program (AHP) at the University of Minnesota. Established as a national information and resource center, NCYD focuses on adolescents with chronic illness and disabilities and is designed to enhance access to information. the goal is to improve the health and social functioning of youth with disabilities by: providing technical assistance and consultation on their health and social/development needs; disseminating information to those who define policy, plan and deliver services; and increasing collaboration among the health care system, other providers of services, families, and youth.

SPRANS/MCHIP Exchange:
A National Center for SPRANS/MCHIP Grantees (The Exchange)
Pathfinder Resources, Inc.
2324 University Avenue West, Suite 105
St. Paul, MN 55114
William F. Henry, M.A., Georgianna Larson, Directors
(612) 647-6905
(612) 647-6908 FAX

Description: The Exchange, under the direction of Pathfinder Resources, Inc. (Pathfinder), is a national center for the promotion of SPRANS/MCHIP grant activities. the goal is to assist SPRANS/MCHIP grants in producing effective products and publications and to ensure the availability of that information to the MCH community; so that grantees will be better able to develop and expand family-centered care within their states and regions.

LIST OF SPRANS/MCHIP NATIONAL CENTERS: AS OF MARCH 1994, CONTINUED

Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI)
110 Greene Street, Suite 303
New York, New York 10012
Elaine Wells, Project Director
Betsy Kase, Information Services Coordinator
(212) 431-8541
(800) 42-HANDI
(212) 421-0906 FAX

Description: HANDI's mission is to develop and maintain a comprehensive resource collection on hemophilia and HIV and to respond to requests for information. Information specialist and other staff conduct research and develop resource materials to meet needs as they arise.

Children with Special Health Care Needs-Continuing Education Institute
Children's Hospital of Columbus
700 Children's Drive
Columbus, OH 43205
Antoinette P. Eaton, MD, Project Director
Tammy Perakis Wallace, Project Secretary
(614) 461-2511
(614) 461-2633 FAX

Description: The goal of the Institute is to plan, promote, implement and evaluate ongoing nationally directed initiatives to maintain and strengthen leadership capabilities for key policy-making staff in States CSHCN programs.

A National Resource Center: Promoting Success in Zero to Three Services
National Center for Clinical Infant Programs
2000 14th Street, N., Suite 380
Arlington, VA 22001-2500
Virginia A. View, M.S.W., Director
(703) 528-4300
(703) 528-6848 FAX

Description: To identify and promote nationally examples of workable approaches to serving the needs of infants and toddlers with disabilities or who are at-risk and their families.

LIST OF SPRANS/MCHIP NATIONAL CENTERS: AS OF MARCH 1994, CONTINUED

National Maternal and Child Health Center on Cultural Competency
Texas Department of Health
1100 West 49th Street
Austin, Texas 78756-3179
John E. Evans, M.S., Director
(512) 458-7355

Description: The goal of this Center is to improve the quality of care for children with special needs by creating systems of care that are more culturally competent at the levels of policy, decision making, service delivery, and training of service providers. The Center promotes appropriate changes in state policies and procedures, supports a consortium of states to train key staff, and helps to develop demonstration efforts in states to encourage culturally competent models of service at the community level.

APPENDIX A

ADVISORY GROUPS

The National Advisory Group

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Rockville, MD

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Arlington, V.A.

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Baltimore, Maryland 21205

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Local Advisory Group, Continued

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Baltimore, Maryland 21229

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Towson, Maryland 21204

Tom Stengel
Baltimore County Infant and
Toddler Program
1 Investment Place, 10th Fl
Towson, Maryland 21204

Charlene Uhl
Advocates for Children
and Youth, Suite 500
300 Cathedral Street
Baltimore, Maryland 2120

REACTION SHEET

We are very interested in knowing the reaction of professionals and families to the content and format of this curriculum. We sincerely ask that anyone using the curriculum take the time to complete this brief reaction sheet. For more extensive comments, we encourage you to attach extra pages for your comments. if more than one person is using the same curriculum, please take a moment to duplicate the reaction sheet for all curriculum users so that we can obtain the greatest possible number of reactions. Please return completed reaction sheets to:

Henry T. Ireys
Assistant Professor
Department of Maternal and Child Health
and Pediatrics
Hampton House, Rm. 187
624 North Broadway
Baltimore, Maryland 21205

1. Overall, to what extent was the curriculum useful to you?

1	2	3	4	5
Not at all useful				Extremely useful

2. Please describe briefly how you used the curriculum:

3. From your perspective, did the core modules represent the major areas of the field? Were key topics left out? In what ways would you have divided the content areas?

4. To what extent did you find the evaluation section useful

1	2	3	4	5
Not at all useful				Extremely useful

5. Please indicate how you useful you found each section of the core modules. Use the following rating scale and place a number on each line. Leave the line blank if you can not rate the module.

1. Not useful at all
2. Somewhat
3. Very useful

Module	Content Description	Rationale	Specific Objectives	Instructor Guidelines
Beliefs and Values				
Issues in Epidemiology				
Use, Costs, Financing				
Laws, Legislation, and Policies				
Community-based Systems of Care				
How Cultures, Service Systems, and Families Adapt: Conceptual Models and Personal Accounts				
Development in the Context of a Chronic Illness or Disability				
Empowerment and Beyond				

Comments:

6. Please indicate how you complete and useful you found the reading lists to be. Use the following rating scales and place a number on each line. Leave the line blank if you can not rate the module.

1. Not complete at all	1. Not at all useful
2. Adequate coverage	2. Somewhat useful
3. Very complete	3. Very useful

Module	Core Readings Completeness	Core Readings Utility	Supplementary Readings Completeness	Supplementary Readings Utility
Beliefs and Values				
Issues in Epidemiology				
Use, Costs, Financing				
Laws, Legislation, and Policies				
Community-based Systems of Care				
How Cultures, Services Systems and Families Adapt: Conceptual Models and Personal Accounts				
Development in the Context of a Chronic Illness or Disability				
Empowerment and Beyond				

Comments:

7. To what extent was the Resource Section complete and useful?

1	2	3	4	5
Not at all useful				Extremely useful

1	2	3	4	5
Not at all complete				Extremely complete

Suggestions or comments on the resources section:

Information About You

1. How did you obtain this curriculum? (circle one)

I ordered it　It was sent to me unrequested

It was loaned to me　Other________________________

2. How will you use this curriculum? (circle one)

Personal reference　For training professionals

Other________________________________

If you will use this curriculum to train others, are you on the faculty of a college or university training program?
____ Yes ____ No

3. Are you a parent of a child with special needs?
____ Yes ____ No

4. Are you a professional providing services to children with special needs and their families?
____ Yes ____ No

5. Are you a student preparing to provide services to children with special needs and their families?
____ Yes ____ No

6. What title best describes you discipline? (circle one)

Early Intervention　Social Work　Medicine　Special Education

Speech/Languages Therapy　Physical or Occupational Therapy　Nursing

Psychology　Child Life　Public Health Administration　Nutrition

Other (describe)____________________________________

Thank you for completing this evaluation.