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ABSTRACT

This document contains information about the medical transition of youth with disabilities from child-centered to adult health care. The generic characteristics and needs of young people with long-term illnesses and disabilities are especially emphasized. Guidance is provided for appropriate health care of the adolescent during the transition process, for the development of transition programs, and for the preparation of physicians who wish to provide health care for this population group. The document examines the benefits of transition to adult-based health services; reviews generic health needs such as guidance on nutrition and fitness, sexuality, substance use, psychosocial needs, self-care, and empowerment; providing services within the health care system; and adaptation of services. The report concludes that adolescents with chronic illness and disabilities must have a well-defined primary health care program, which covers the same areas of medical and psychosocial concern as programs for adolescents without disabilities. Appendixes discuss the Federal commitment in this area; examine the need for improved training of physicians; offer statistical tables of health, education, and employment data; list 37 references; and describe 15 information centers and programs. (JDD)

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PREFACE

The term transition, used in the context of adolescence, refers to the movement of young patients from pediatric, or child-centered care, to the adult health service. It is important to provide an overview of the principles involved so that physicians may review their services for relevance and acceptability in meeting the difficulties which may occur during this period of adjustment.

This document contains information about the medical transition of youth with disabilities[*] from child-centered to adult health care. The generic characteristics and needs of young people with long-term illnesses and disabilities are especially emphasized. Guidance is provided for appropriate health care of the adolescent during the transition process, for the development of transition programs, and for the preparation of physicians who wish to provide health care for this population group.

The intended audience is physicians in both the public and private sectors who provide services for adolescents and their families. This includes pediatricians, family practitioners, specialists in adolescent medicine, internists, and their colleagues in other specialty fields. This material should also be useful information for providers in other health disciplines such as psychology, nursing, social work and nutrition, and professionals who provide related services, such as special education personnel and child development specialists. It is hoped that administrators and program managers may also find this information helpful.

The document may offer information for new program development or may serve as a measure of comprehensiveness and appropriateness of services for programs already in existence.

This document is not intended to be a definitive textbook on adolescence, nor does it not provide requirements, standards, or regulations for the clinical care of young people with disabilities. Instead, it is hoped that the generic nature of this guidance will encourage physicians in various specialties to develop more specific recommendations appropriate to the unique needs of their own patient populations.

The Maternal and Child Health Bureau (MCHB) has developed this document within the context of family-centered, community-based, coordinated and culturally competent care.

The challenge to formulate appropriate health services before, during, and after transition has not been fully explored or implemented. It is hoped that this document will both stimulate transition efforts and clarify some of the issues involved.

Audrey H. Nora, M.D.
Acting Director
Maternal and Child Health Bureau
Summer 1992

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[*] *Throughout this document, youth with disabilities encompasses all adolescents and young people with chronic illnesses and other physical and mental conditions who are sometimes referred to as youth with special needs.*

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INTRODUCTION

Purpose

- To increase provider awareness and encourage the transition of youth with disabilities from child-centered to adult-oriented care and to place this transition within the context of overall adolescent development.

- To improve health care and medical services for adolescents with special health care needs during the process of transition.

- To assure that the essential elements of health care are available to young people as they move from child-centered programs to adult-oriented services.

- To promote the principle of uninterrupted and coordinated medical services during this critical period of change.

Target Audience

This document is directed primarily to those physicians who are responsible for the health and medical care of young people with disabilities or chronic illness during the transition period. These physicians are usually pediatricians, internists, family physicians, obstetricians gynecologists, psychiatrists, and specialists in adolescent medicine. This does not exclude physicians in other specialized medical fields whose involvement is vital but occurs at less frequent intervals. All physicians may benefit from an overview of the principles of transition and existing methods of implementing services during the process.

"*Moving On*" will have equal application to the public and private sectors, and be relevant for developing transitional medical health services in academic settings, health maintenance organizations and private practice.

Scope

It is tempting to discuss the multiple factors which influence adolescent adjustment, particularly for those young people with chronic illnesses and disabilities who require support from a variety of educational, vocational, and social services in addition to planned health care. However, this document will concentrate only on those areas which are directly concerned with the provision of health and medical care.

Developmental needs and the relevant responses from health care services form a central theme for this document. Adolescents with disabilities or chronic illness have essentially the same behaviors and preferences as their peers without disabilities and must, therefore, be offered the same individual consideration; this is over and above the specialized medical services necessary to address the particular health care needs related to their illness or disability

The medical contribution to successful health care transition must include planning, coordination, and direct involvement of the adolescent and the family. Professional communication across the potential gap in services is of the utmost importance if continuity of care is to be assured. The substantive components of medical transition must include the continuous provision of comprehensive primary care and the prompt attention to complications and intercurrent illnesses.

In this document, reference is made to the "generic" nature of problems experienced by youth with disabilities. This term is intended to acknowledge that there are needs which are experienced universally by adolescents with chronic illness or disabilities, regardless of their medical diagnoses or categorization. It is the goal of the document to address these broad needs and show how the deleterious effect of these shared difficulties can be reduced

All adolescents should have the opportunity to reach their full adult potential.

The prospect of transition from child-centered to adult-based health services raises many issues and concerns for adolescents, their families, and their care providers.

The health problems of adult life are usually not discussed with young children directly, even when they are exposed to such situations within the family; any necessary physical care and advice is provided with the parent serving as intermediary. As children mature, they need direct personal services in these areas, and these must be available as part of ongoing routine health care. It is not possible to cover all these issues in a child-centered setting. However, adult services have the capacity to address the problems of grown up people with a variety of problems including weight control, sexuality, family planning, sexually transmitted diseases, prenatal care, marital upheavals or depressions.

The terms "child-centered" and "pediatric," as used in this document, are intended to denote the main focus of care which may be the child, the adolescent, or the adult and are not meant to imply that all child-centered care is provided by pediatricians.

While some health care professionals as well as families feel there is no need for such a change, the rationale for what may be perceived as a major upheaval is justified as follows:

Benefits of Transition

Full Participation in Society

All adolescents should have the opportunity to reach their full adult potential and should receive the support which enables them to do so. The transition to adult health care is an important part of the overall transition to adulthood. Continued child-centered care may convey an unintended message about the future, and may affect the attainment of appropriate adolescent independence. In an age-appropriate setting, however, young people are more likely to become mature, to develop a sense of responsibility, and demonstrate adult behavior.

Transition services that include training in decision-making skills, assertiveness, and self-advocacy assist and empower adolescents to be in control of their own health care. This process, which involves a partnership with their families and health care providers, can further empower adolescents to seek independence in other aspects of their lives.

A Positive Future

The transition to adulthood acknowledges that there is a future for the adolescent despite a disabling condition and provides a powerful statement of confidence and a positive commitment to living.

Age-Appropriate Care

Young adults need health care that is based on their total needs which include such issues as health promotion, nutrition, and sexuality. Adult-oriented care, not child-centered care, is most appropriate for adult patients. Compliance is improved when treatment plans are appropriate for both chronological age and developmental level; relevant care in the adult sector is more likely to provide treatment schedules that are suited to the needs of young adults. Thus, complications may be identified early and appropriate measures taken.

Young adults need health care that is based on their total needs including health promotion, nutrition, and sexuality.

A transition program provides a process where adolescent and young adult concerns (e.g. legal status, vocational training, employment, and independent living) may be addressed. Finally, if no alternative plan is offered, young people may be lost to the system and fail to seek any health care except in emergency or crisis situations. Formal connections with the adult health care system help to ensure acceptable, and, therefore regular health care. Otherwise health care may be reduced to crisis management or episodic emergency room encounters.

New Challenges for Providers

Providing transitional health care for youth with disabilities presents a unique opportunity for professional development. Both child-oriented and adult-centered providers must be involved in the transition process if it is to be successful. Pediatric staff can share their knowledge of both medical and developmental management with staff in the new setting; adult providers can be fully updated on the care of childhood conditions so that they can eventually assume care of young adults with diverse chronic conditions. Adult providers must become skilled in managing a group of conditions which were once considered to be exclusive to childhood. This collaboration enhances the professional development of all participants through increased contacts with a broader network of colleagues (Gobel 1988). Both pediatricians and adult care physicians will benefit from this interaction. At adolescence, services must be age-appropriate and pediatricians should still be able to deal with problems as they arise. However, during adulthood, pediatricians are not the most appropriate providers as the health problems encountered are likely to be beyond the scope of a child-centered environment.

> ***"I want to live like other teens."***
> ***...15-year-old youth***

ADOLESCENTS: MORE ALIKE THAN DIFFERENT

Although adolescents and young adults with disabilities have varying needs, they have much in common with their peers who have no disabilities. Independence, peer relationships, and sexuality are major concerns for young people regardless of their health status. Normal developmental needs and transitions experienced by youth without disabilities also affect the lives of youth with disabilities and chronic illnesses (Blum, 1984). The timing of some developmental tasks may be different, occurring earlier or later, for adolescents with certain medical conditions.

MULTIPLE TRANSITIONS OF YOUTH

Most adolescents experience several transitions: from home to community; from family to peers; and from school to work. Some transitions involve a complete break with the past, while others incorporate parts of the past into a new life. For example, few adults continue to see pediatricians after establishing themselves in the adult health care system (Council on Child and Adolescent Health, 1988). In contrast, most youth continue to maintain close relationships with their parents even when they develop strong identification with their peers and later start their own families.

Adolescents often go through these multiple transitions simultaneously, and health status can have a major impact on all transitions. Therefore, transition to adult health care should be clearly linked to other aspects of the transition to adult life (Allen, 1985).

Any transition from one situation to another should involve planning and assessment. It is important to define goals, set objectives, examine the options, and make choices. Change often involves trial and error, success and failure. Assessing the effect of the change is an important part of the process.

CURRENT TRANSITION EFFORTS

Transition from child-oriented health care may proceed smoothly or be quite difficult, but it will occur...by design or default. Ideally, transition for young people with special health needs begins in early adolescence and continues until the adolescent is firmly established in the adult health care system (Schidlow and Fiel, 1990). Transition should occur according to a preconceived plan which is individualized and responsive to the needs of the young person and the family. Preparation is essential, as is the involvement and collaboration of the young person, the family, and the relevant medical providers.

At present, transition from child-based to adult-oriented health care proceeds more by inertia than by intention. Organization and planning for transition are typically lacking except in programs which have specialized adolescent resources, and there is little uniformity in the services provided to adolescents and young adults with special health care needs. Many young adults continue to receive pediatric care in child-oriented settings. While this may include special provisions for adolescents or involve specialists in adolescent medicine, transition to the adult sector is slow to take place. However, although this transition is occasionally formalized as a comprehensive transition plan (again, sometimes involving specialists in adolescent medicine), more often it is an informal arrangement among providers in pediatrics and colleagues in adult medicine. When transfer to adult-oriented care is delayed, adolescents and young adults may leave child-based care without any planned referral to the adult health care system. At such times, care becomes episodic, special needs are neglected, and primary care is ignored.

GENERIC HEALTH NEEDS OF ADOLESCENTS DURING TRANSITION

In order that physicians may appreciate the dimensions of transition, an overview of the individual health care needs of adolescents is provided. All health services and adaptations of the system must relate to these basic needs shared by all adolescents. Attention to these needs is especially important for youth with disabilities.

Primary Health Care Needs

Though frequently considered to be unusually healthy, all adolescents have a variety of health care problems and concerns and thus have distinctive health care requirements. Some are age-related, while others are related to their inclination toward risky behaviors and experimentation. Examples of other primary health care needs include dental problems, changes in vision, skin conditions, respiratory and other infections. Adolescents tend to underreport symptoms, under use health care services, and to be skeptical of the health care system. As a result, medical problems may go undiagnosed or untreated. Because youth with disabilities will share many of the same health care concerns with their peers, and because these aspects of primary care of youth with special health care needs are frequently ignored, special attention must be paid to assuring that these issues are integrated into the transition care plan.

Profile of Readiness

Physical growth, sexual maturation, and psychosocial development are all crucial aspects of adolescence. Growth and development should continue to be monitored closely. For some adolescents with chronic conditions, developmental processes may be delayed or occur early. It is especially important to make an early identification of those adolescents who are not reaching age-appropriate milestones. The individual's readiness for transition to adult health care services and the timing to initiate this process will depend very much on the evaluation of biological and psychosocial maturity.

Nutrition & Fitness

All adolescents are at nutritional risk. Chronic conditions may be exacerbated by nutritional deficiency (e.g., inflammatory bowel disease), nutritional excess (e.g., activity-limiting or wheelchair conditions), or nutritional indiscretion (e.g., diabetes mellitus). Weight concerns are common, especially among young girls, and may interfere with assuring adequate nutrition (Moses, Banilivy & Lifshitz, 1989; Casper & Offer, 1990). Anorexia nervosa and bulimia nervosa, while less common, do occur. Nutritional assessment should be integral to the care of adolescents whose conditions are compromised by poor eating habits. Eating disorders, which can be fatal, should be investigated aggressively when suspected.

Discussion of fitness and exercise should complement any nutritional discussion as the benefits for youth with disabilities are the same as for all others. Physical fitness should be a goal, and appropriate exercise encouraged for all adolescents.

Sexuality

Adolescence is also a time of emerging sexuality; most youth have their first sexual intercourse before age 18 (Hofferth, Kahn & Baldwin, 1987). Sexuality is also an important concern for adolescents with a chronic condition. Despite illness or disability, they may become sexually active and are thus vulnerable to all of the consequences of sexual activity, including sexually transmitted diseases, HIV infection, abuse, and pregnancy. Youth with disabilities may perceive themselves to be unattractive or sexually immature and this self-assessment may be reflected in their behavior; self-doubts about sexuality may result in avoidance of intimate relationships, or on the other hand may heighten interest in sexual experimentation.

> *"I'm 21 years old and no one has ever talked to me about sex. I don't even know if I can have a child and I never felt comfortable asking."*
> *...Young college student with spina bifida*

Adolescents with chronic health conditions are less likely than their peers to receive sex education, and they rarely receive sex education which is specific to their condition (Neinstein and Katz, 1986; Thornton, 1981). This information must be provided to adolescents with special needs, accompanied by candid discussion of the specific risks they may face. Lack of information may cause adolescents with disabilities to become vulnerable to sexual exploitation and victimization. Contraceptive counseling should be offered when appropriate, and explicit information on the vital role of condoms in disease prevention should be provided routinely.

Substance Use

Substance use and abuse is another high risk behavior that is prevalent in adolescents. Data from the National High School Senior Survey suggest that alcohol use is widespread among youth, over one-third of adolescents smoke regularly, and more than half have at least experimented with an illicit drug (Johnston, 1990).

While comparable data are not available specifically for chronically ill youth, it is likely that their behavior would be the same. They should be counseled about the hazards of substance abuse, and in particular, cautioned when substance use compromises the care of their specific conditions (e.g., persons with cystic fibrosis who smoke marijuana).

Psychosocial Needs

While it was once believed that chronically ill youth were at increased risk for serious emotional illness, it is now recognized that depression and similar conditions probably occur no more frequently in adolescents with chronic conditions than in other adolescents (Cappelli, McGrath, Heick, MacDonald, Feldman, & Rowe, 1989). Still, youth with chronic illnesses or disabilities have a variety of psychosocial needs that should be addressed. Health care for adolescents with chronic conditions should include screening for psychosocial maladjustment. Paradoxically,

> *"My teenage daughter comes home from school every day with nothing to do. Friends and fun are what she needs."* ...*Parent*

psychosocial concerns appear to be greatest in adolescents with the least visible and limiting conditions (McAnarney, Pless, Satterwhite & Friedman, 1974; Hodgman, McAnarney, Myers, Iker, McKinney, Parmelee, Schuster & Tutihasi, 1979; Jessop and Stein, 1985).

Social isolation is a common experience for many chronically ill youth who feel stigmatized by their condition, and find it difficult to develop and maintain friendships and have little opportunity to develop social skills. Likewise, self-esteem may be low, particularly when an adolescent's condition significantly limits their ability to participate in valued activities.

As adolescence continues, youth with chronic conditions may remain overly dependent on parents and other family members and may be slow in developing appropriate self-reliance. Health endangering behaviors, such as sexual experimentation and substance use, may be an adolescent's only means of asserting independence and experimenting with new roles. Amongst all adolescents, suicide remains the third leading cause of death; therefore, providers should be alert to this possibility and identify adolescents who may be at highest risk. Young people who have survived critical episodes of illness may have a marked sensitivity about death and dying.

Injuries remain the predominant cause of adolescent deaths. Adolescents should be counseled on personal safety, including the regular use of seat belts. Excessive risk-taking should be identified and addressed.

Additional Needs

Adolescents entering adulthood have a variety of other needs during transition, which include educational, vocational, or rehabilitation requirements. Concerns about financial matters, transportation, and preparation for independent living are frequently expressed. Lack of appropriate services to address these needs delays the beginning of independent functioning. While in some settings it may not be the responsibility of health care providers to address these issues, providers should nevertheless ensure that timely, comprehensive services are available and referrals are made when necessary. It is essential to establish a climate within the medical setting which encourages young persons to bring these concerns to light; youth need to feel comfortable before asking questions about personal matters.

Self-Care & Empowerment

Adolescents should gradually take on the responsibility for health care previously assumed by their parents and other family members. They should become increasingly independent in meeting their daily needs and managing their own medical conditions. Young adults need to be increasingly involved in the review and modification of their care plans, and should become confident to express their opinions about the timing and methods of investigations and treatment. This assertion of personal views is usually a new experience, and the adolescent may feel initially apprehensive. This is precisely why planning for transition should not be left to the eleventh hour. It will be difficult for some young people to realize that they have a right to influence their care through participation in discussions with their providers. Eventually, however, they learn that their views are welcomed and respected. Acquiring a sense of control over their medical management can empower young people and allow them to view their health care as less rigid and flexible enough to match their chosen lifestyles. Health

> *"As you develop…you really want to talk to the doctors yourself. I know that at first they only wanted to talk to my parents. I was glad when someone finally talked to me and explained what was going on. I know this is my disease and my responsibility."*
>
> *…Older adolescent*

professionals should be prepared to allow increased empowerment, and should foster the young person's ability to make choices and assume some control over their situations.

Importance of Information

Moving into a new situation gives rise to many questions and uncertainties. When these questions remain unanswered, adolescents in the midst of transition may continue to feel unclear about the implications of their future health care. There will be questions about their illness related to prognosis, limitations of activity, the logistics of the new service plan, and the availability of other resources for both health maintenance and emergencies.

Having been accustomed to a certain style of care as a younger child, even a slight modification of the routine may be interpreted as a reduction of care and attention. This apprehension, even when unfounded, may detract from the whole family's attitude toward transition.

The Need To Talk

As the time for transition approaches, adolescents may want to talk about their reaction to these new arrangements. The need to ventilate feelings may not be expressed directly; still the change of health care providers and different medical routines may be perceived as the loss of the safety net which supports their medical condition.

Relationships between teenagers and parents may have become strained as adolescence progresses, and there is a heightened drive for independence. However, when adolescents realize that the parental role in health care will be gradually diminished, they may feel insecure and inadequately prepared to take on this responsibility. Parents, too, may feel hesitant about relinquishing their protective role.

> *"I'm not certain when I should stop being the concerned parent and let my son learn to become more independent."* ...Parent

At 16, Alison needed to understand why surgery was necessary.

PROVIDING SERVICES WITHIN THE HEALTH CARE SYSTEM

There are many obstacles to transition from pediatric to adult health care for adolescents with special health care needs (Cameron, 1985). Perhaps the greatest difficulty is that of "recognizing a need for change in the context of chronicity": that is to say, when managing a long-term medical condition in a program which is working well, why not leave well enough alone? (Hull and Hall, 1988). Providers, youth, and their families are sometimes so absorbed in the routines and demands of daily living that they do not always recognize the need for a new approach until a crisis occurs. Other barriers include:

General Resistance to Change

Many young people, families, and providers tend to believe that what has been satisfactory in the past will continue to be effective indefinitely. Close bonds often are formed among health care practitioners, young people, and their families especially when life threatening illnesses are involved. When service systems change, these links may be weakened. Young people and their families may be satisfied with their care and feel safe in the child-oriented setting and may be afraid to move to an unfamiliar adult-oriented setting. During this time, parent advocacy groups could be supportive by focusing attention on the benefits of health transition, and helping young people and their families to begin planning for their move to the adult world.

Financing Services

Financing health care and related services continues to be a problem. Many youth are uninsured or underinsured. The numerous sources of financing are often confusing, and families become frustrated in their search for adequate health care coverage. For some adolescents, there may be limited provisions for "in hospital" care, and for others primary health care services may not be reimbursed in full. Insurance companies may offer more complete coverage for institutional care than they give for the same services provided in the community or in the home. Health care for children is normally covered by parents' insurance policies or public programs. This coverage, however, is often less than adequate. The situation worsens when

> *"I have a disability which requires medication costing $800.00 per month. It's under control and I did well in college. I just graduated from business school summa cum laude. I'm having a hard time finding a job because businesses don't want to add me to their health insurance. I don't know whether to be honest and tell them about my condition or lie..."*
>
> *...Midwest college graduate, 1990*

young adults lose this family coverage and cannot find new insurance plans for themselves due to pre-existing condition clauses, lack of employment benefits, or inadequate public programs to serve the adult population (McManus, 1989).

While the financing of community-based care has not been fully implemented, many options have been studied. Expanded Medicaid coverage, the use of Medicaid waivers, long-term care insurance, and State risk pools are some alternatives. Further development of financial options for adolescents and young adults is urgently needed. It is hoped that some form of universal health insurance will be introduced which will increase access, and provide more complete coverage for the health and medical needs of young people. Various proposals for reform of the health care system have been introduced in Congress including recommendations by the American Academy of Pediatrics. As the cost of medical care continues to escalate, provision of funds to support programs to provide this care is a concomitant factor if services are to be available for all adolescents.

Professional Issues

Some pediatricians may be reluctant to transfer care to adult practitioners. Pediatricians have, in the past, cared for adolescents and young adults who have conditions that were rarely seen in adult practice. Some, therefore, believe that adult providers cannot be appropriate caregivers for these young people.

Adult practitioners may be unwilling to assume medical responsibility for youth with disabilities. They may feel unprepared to manage certain conditions, or may not have the motivation to provide the needed time-intensive care. Additionally, they may lack the facilities and resources to provide appropriate services.

Health care providers spent time working with Alison to ensure that she understood the procedure.

System Issues

Because adolescents and young adults with chronic illnesses or disabilities have only recently been recognized by service delivery systems, no standards exist to guide the planning and evaluating of transition services (Capelli, MacDonald, & McGrath, 1989). Providers and programs that do offer transition services are often isolated from each other and lack the opportunity to share their experiences. We have yet to identify all the various models and program characteristics which give the best results. Evaluation of health status outcomes and the relationship to other variables is also incomplete.

ADAPTATION OF SERVICES

PRINCIPLES OF TRANSITION CARE

Transition As a Process, Not an Event

Transition should permit a gradual introduction to the adult health care setting while maintaining the security of familiar child-centered care. Adolescents have varying needs, and the process must allow flexibility to meet individual requirements. Ongoing assessment allows modification of the care plan in response to changes in health status, care needs, functional ability, and new advances in therapy. Both child-centered and adult-oriented providers should be involved in planning for transition and monitoring its progress.

Individually Timed Transition

The biological, psychological, and social changes of adolescence are variable in their timing and progression. Transition should occur when adolescents and their families are ready and prepared for it. Currently, there is no simple tool to evaluate transition readiness. However, health care providers can determine individual readiness using criteria such as medical status, developmental level, emotional stability, knowledge of the disease process, success at self-care, and assumption of other adult responsibilities. It is helpful to establish an age at which all adolescents will be assessed for transition readiness. In this way, the chance of this evaluation being overlooked will be minimized. At some point, the care must be transferred.

Eventual Transition From Child-Centered Care to Adult Care Is the Premise on Which All Care Is Based

The concept of transition should be introduced early, allowing all participants to become accustomed to the idea that health care will eventually be provided in the adult setting. It is unrealistic to expect adolescents, their families, or health care providers to accept transition if it is introduced with little warning or during a time of crisis.

> *"It never occurred to me that my daughter would grow up. When our pediatrician suggested we begin planning for the future, I was initially apprehensive. Looking back, I can see that it helped our family to be supportive of our daughter's move to a more independent lifestyle."*
>
> *...Mother of a 24-year-old young woman who has epilepsy*

Care Coordination Is an Essential Element of Transition

A care plan should be developed to define the sequence of events during transition. One person should be responsible for coordinating all health care and related services. This contact person will have an increasingly important role as transition proceeds and responsibility for care is extended throughout both the child-centered is extended throughout both the child-centered and adult health care systems. Coordinated transition efforts take time, effort, and the collaboration of many professional disciplines in both the child-centered and adult systems.

Youth, their families, and national consumer organizations must work together with providers and public and private agencies to foster a commitment to transition services.

MAJOR COMPONENTS OF TRANSITION CARE

Primary & Preventive Care

Too often, adolescents with chronic conditions get exemplary care for their specific illness or disability but little or no preventive health care or health supervision (Palfrey, Levy & Gilbert, 1980; Carroll, Massarelli, Opzoomer, Pekeles, Pedneault, Frappier, & Onetto, 1983). Immunizations may be overlooked, recommended health screening is not performed, and little attention is paid to developmental progress.

This neglect can be exacerbated if transition planning does not explicitly include continuing primary care which can be provided by a family practitioner, a primary care internist, an adolescent medicine specialist, or by an internal medicine subspecialist committed to primary care (Aiken, Lewis, Craig, Mendenhall, Blendon & Rogers, 1979; Goldberg & Dietrich, 1985).

In situations where the medical condition is stable, frequent visits to the specialist are not usually indicated. However, regular contacts with the primary care physician may give an early warning of medical deterioration or complications. Sometimes the primary provider becomes the care coordinator and advocate.

Adolescents must have individual care plans which ideally are initiated prior to transition from child-centered services and carries them through transition to an established place in the adult health care system. The plan should be a collaborative effort with stated goals and allow for changes and modifications; it should be accompanied by a profile of the adolescent and the family stating strengths and limitations.

Assessment of Psychosocial Needs

Primary care contacts provide an opportunity to assess the adolescent's adjustment to their environment and pinpoint any problems that may compromise a sense of well-being and ability to function well. It is a chance to discover more about the family background, peer relationships, and the adolescent's plans for further education, vocational training, or work.

The primary care setting is an appropriate place to explore with the young person any problems related to sexual identity and activity, substance use, feelings of social isolation, depression, or rejection by peers. Relationships with parents and siblings are often a source of concern and frustration.

Health Education

Knowledge does not guarantee good health habits. However, lack of information, or misinformation, will almost certainly interfere with the achievement of goals in the treatment plan, and the development of health-enhancing behaviors. General and condition-specific health information should be provided to adolescents. Education should be developmentally appropriate and youth-oriented. It should reflect adolescents' more mature cognitive abilities, their capacity for learning new skills, and their evolving system of values.

Health information should be presented as the foundation for a more independent life-style. Much of the information will be consistent with material provided previously. However, earlier educational efforts were directed to parents. Adolescents and young adults should be encouraged and assisted to become informed and effective participants in their own health care. For example, for adolescents with inherited conditions, genetic counseling probably was offered to parents in the context of the parent's own family planning. Genetic counseling now must be offered explicitly to the adolescent with a view to improving their ability to make informed decisions and choices.

The choice of the individual responsible for providing health education depends in part upon the available staff. It is advisable to have definite teaching commitments from the individuals who will cover those important topics so that the information is sure to be conveyed. Health educators are able to provide group sessions, and many public health nurses are skilled in this field; representatives of national consumer and parent groups may also offer assistance.

Preparation for Self-Care

As soon as possible, adolescents with disabilities should be encouraged to participate as fully as possible in their own care. This means providing patients with complete, age-appropriate, understandable explanations of their medical conditions, and full information about diagnostic and therapeutic procedures to be performed. It also includes asking even young patients, along with their families, to consent to medical and surgical procedures. Additionally, adolescents should participate in decisions about diagnostic assessments, treatment plans, and other care. Parents and families should be helped to appreciate this gradual transfer of responsibility so that they will support and reinforce this concept.

Providers should negotiate health care treatment plans with adolescents, taking into account their preferences and life-styles. In some cases, the physician will need to accept less than ideal forms of care when the adolescent is non-compliant with a conventional treatment plan that he finds to be unrealistic, excessive, or aversive. Health care providers need to accept that multiple approaches exist for any given problem and must be willing, when necessary, to trade their concept of "ideal" care for acceptable treatment that acknowledges the priorities and desires of adolescents (Coupey & Cohen, 1984).

Alison signs the consent form herself!

Other Factors Which Create More Responsive Transition Services

Relating to the Adolescent and Young Adult

Physicians who care for young people should appreciate the way in which adolescents prefer to relate to their health professionals. Adolescents generally should be seen by themselves, in a relaxed environment, where their confidentiality can be respected. Care providers should not be surprised to encounter health compromising attitudes typical of all young people reflecting normal adolescent ambivalence. The professional should be tactual and non-judgmental when information is questioned or challenged.

Providers should encourage young adults to participate actively in developing their own care plan. All issues introduced by the adolescent should be taken seriously even when they appear to be inconsequential or of minor significance. Frequently, the apparently minor nature of these personal concerns obscures their real importance to the adolescent; such problems must be dealt with before more serious issues can be fully addressed. Moreover, health care providers can enhance their credibility by the understanding and successful management of an adolescent's more commonplace complaints such as menstrual cramps or acne.

Professional relationships with adolescents require a pragmatic approach and skilled communication techniques. Previously, discussion was probably directed to parents, so that young adults have had little experience in communicating with their health care provider. Providers must be patient and allow time for the adolescents to express themselves. Confidentiality boundaries should be established at the beginning of the relationship. When discussing sensitive or personal subjects, providers must be open-minded and non-judgemental of adolescent values. There is a need for direct communication throughout childhood and adolescence.

Sensitivity is needed in the interpretation of medical information, for effective counseling, as well as for all discussions of care and management. Adherence to treatment plans is likely to be greater when information is understood, dialogue is encouraged, the provider demonstrates a genuine interest and concern for the young person, and is willing to minimize the number of ground rules. The aim of the provider will be to create an environment that invites questions and comments from the young person.

PREPARING ADOLESCENTS AND THEIR FAMILIES FOR TRANSITION

Regardless of health status, adolescents should be expected to become adults and assume adult responsibilities. Of the multiple transitions of adolescence, transition to adult health care is an especially important milestone in the successful passage to adulthood. Parents experience transition concurrently; as they gradually relinquish responsibilities for their children's health care, they are able to move to a new phase in their own lives. Adolescents and their families have various needs and expectations during this process.

INFORMATION ABOUT THE ADULT HEALTH CARE SYSTEM AND HOW IT FUNCTIONS

Helping youth gain access to and understanding of the adult service system is crucial. Adolescents and their families need to be assured that they will move on to other services, and that they are not being "abandoned" by their previous providers. They need to know that they will receive high quality care in the adult system. Detailed information on primary care, specialized health care, related services, availability of providers, and system and care coordination in the adult-based system should be provided.

FAMILY CONCERNS

As adolescence proceeds, parents must start to view their offspring as maturing adults rather than fully dependent children. Stepping back is difficult for all parents; it can be even more of a problem for parents whose children have chronic illnesses or disabilities, and who may perceive their children as particularly vulnerable. Parents can obtain information and support through informal parent-to-parent contacts, and parent counseling and advocacy groups. Formal counseling may be useful for some families where the parents find the relinquishment of their protective role particularly troublesome. The physician must be familiar with various sources of parental support so that prompt referrals may be made when indicated.

Siblings may react in different ways to an adolescent's transition. Although no documentation is available, some will want to participate in the process; others will not. Siblings may feel jealous of, or neglected by, the extra attention the adolescent receives from parents and providers. Sibling support groups can help families in the transition process.

Often, adolescents and their families feel overwhelmed as they enter a new, sometimes confusing system of care. Adolescents and young adults should have a case manager assigned who could act as an advocate, if necessary, as they proceed through the transition process. They need to know that they can count on a previously identified person who is well acquainted with them for assistance: frequently this will be the care coordinator.

Transition planning strategies will vary with differences in family circumstances, and the priorities and level of function of the young person. In order to meet the needs of the adolescent, the family's needs must also be individually assessed and considered. This includes an awareness of cultural factors and characteristics, and an assurance that services will be responsive to these factors.

COMMUNITY-BASED SERVICES

Many programs for adolescents have a close connection with community-based health services in terms of both patient care and funding. Some of the overarching values, concepts, and principles of health care offered in the community are described. Increasing cooperation between the private sector and public programs suggest that a clearer understanding of the framework in which MCHB programs operate may be of value to those who are not familiar with Title V programs.

Recent legislation (see Appendix #2) and evolving approaches to the delivery of health care have resulted in the development of systems of care which are family-centered, community-based, coordinated, comprehensive, and culturally competent. As these systems are being developed, it is critical to include provision of services for adolescents with disabilities. The services already in place for children with long-term medical conditions generally require substantial modification if they are to be extended appropriately for teenagers and young adults.

Community-based services will promote the concept of a "health home" within easy reach of the adolescent's family residence. Medical and other social services can be made available by increased interagency collaboration at the local level. Young people with a broad range of disabilities can be encouraged to participate in community activities without leaving their home territory.

The OBRA requirements of family centered, community-based, care can be met with less difficulty in the primary care setting.

CULTURALLY COMPETENT CARE

Families seeking transition services come from different cultures and backgrounds. Differences in language, communication styles, concepts of family, disability and health care, perceptions of time, views of officials and agencies, as well as immigration status and geographic isolation, all may create frustration or misunderstanding.

Cultural competence incorporates the commitment to respect beliefs and values of other cultures. It also includes the ability to translate knowledge and understanding into action by adapting the environment or creating culturally appropriate interventions.

Families seeking transition services come from different cultures and backgrounds. In recovery, Alison was comfortable with a nurse who recognized that Alison depends on sign language to communicate.

ALTERNATIVE APPROACHES FOR HEALTH CARE DELIVERY DURING TRANSITION

The transfer of adolescents with disabilities to the adult health care system may occur in many different settings, and the medical care may be offered by physicians from different professional backgrounds. The essential components of transition care must be available regardless of the setting. The style and form of care will depend upon the available resources. Evaluation of existing models and methods is missing from the literature so that firm standards of care are yet to be formulated.

Four examples of transition services are described, but other patterns of care are appropriate. The models described have applicability to both the public and private sectors.

INTERDISCIPLINARY TEAM MODEL

An interdisciplinary team provides an effective method for ensuring comprehensive and coordinated care to any population with special needs. A care coordinator typically organizes the interdisciplinary team which includes patients and their families and some or all of the following: physicians (including pediatricians, internists, family practitioners, specialists in adolescent medicine, and other medical specialists), nurses, therapists, psychologists and psychiatrists, social workers, nutritionists, educators, vocational rehabilitation and pre-vocational counselors, genetic counselors, and interpreters. Continuity through transition is accomplished when both the child-centered and adult health care systems participate as members of the same team, or when child-centered and adult teams operate in tandem. Interdisciplinary teams strengthen communication among providers and help to assure access to the wide array of health care services.

The interdisciplinary team represents an ideal of service delivery but is often not a feasible staffing pattern outside a teaching center or other large institution. However, the basic nurse/doctor team with part-time medical specialists and non-medical health professionals may be an effective alternative approach.

Helping adolescents grow into adult health care takes long-term commitment. Alison has made a positive start.

Generic Services Model

Transition services are coordinated by pediatricians, internists, family physicians, or physicians specializing in adolescent medicine without regard for the specific underlying condition. Specialty medical care is provided concurrently by pediatric and/or internal medicine specialists. When transition needs have been met, the adolescent graduates to adult-oriented primary care and specialty services. The strength of this approach is that a generalist physician provides the care coordination.

Programs for Young People with Specific Disabilities

Here adolescents pass through the transition period under the care of pediatric specialists who focus on their specific chronic medical condition and work in collaboration with their counterparts in the adult service. This method may have advantages for young people with conditions such as hemophilia, diabetes or cystic fibrosis, as continuity of the specialist's care is assured; however, comprehensive primary and preventative care is often missing.

Family Practice

Family Practice groups are established throughout the United States. The goal is to include all family members regardless of age and to treat and prevent medical problems within the context of the family. Children, adolescents, and adults are all welcome. Family Practitioners are generalists, but through wide experience, referral to specialists is kept to a minimum. Children and adolescents who have disabling conditions are usually cared for within the group with back-up support and advice from a tertiary care physician who provides tests requiring complex technology, and procedures involving hospitalization or special post-operative care. The developmental approach to children's care is emphasized and carried through to adolescence. At this stage, psychosocial and life-style issues are considered the essential framework for medical care and "Adult Problems" such as weight control, STD and AIDS, substance use, contraception, and pre-natal care are within this context. There is no break in the chain of care unless the family moves away, although the style of services is appropriately tailored to the chronological and developmental age of the patient. Transition of young people with disabilities occurs as a gradual process, and the teenager and his family are guided into new roles and responsibilities but continue to see the same physician.

The strong arguments for Family Practice are the continuity of care, the knowledge, and understanding of a family over a period of time, and the involvement of that family in a supportive role. There is a convenience factor when most aspects of medical care may be obtained at one location.

ADOLESCENT TRANSITION PROGRAMS

The following examples serve as illustrations of transitional efforts. They are not intended to reflect the totality of what is occurring in the area of transition or the preferred approaches. They do represent imaginative methods of expanding existing services to adolescents with special needs without necessarily involving additional funds.

Adolescent Employment Readiness Center
Children's Hospital National Medical Center
Washington, DC

This program provides comprehensive health and medical services for children and adolescents with rheumatic diseases. An adolescent employment readiness center extends care to young people with other chronic illnesses. The project increases awareness of the need for prevocational guidance among public school personnel, health professionals, employers, adolescents, and their parents. The special education system designated to offer prevocational guidance has been largely ineffective for many youth with chronic illnesses who may not be receiving special education services.

A prevocational team includes a vocational rehabilitation counselor, social worker/financial counselor, physical and occupational therapist, educational coordinator, and psychologist. Individual services include work assessment, work readiness programs, referral to appropriate community resources, and assistance in summer jobs placement.

Education services include: a) group vocational and career conferences for teens and adults, b) educational and vocational advocacy seminars, c) school and community seminars on chronic illness and employment, and d) educational programs for professionals and employers. A research design undergirds the project utilizing a matched group comparison and longitudinal data collection.

Benefits

The hospital-based project is studying the effects of providing pre-vocational counseling and education in a health setting. There is an opportunity to relate vocational choices directly to individual preferences and functional level. A service designed for one set of medical conditions is opening up supportive resources for any adolescent with a chronic illness.

Transition Program for Teenagers With Chronic Illness and Developmental Disabilities
North Shore University Hospital/Cornell University Medical School
New York State

This program offers services to adolescents with a wide range of chronic medical conditions, and draws special attention to the importance of primary care and service coordination during transition. The interface between pediatricians and internists has been well developed. Adolescent services are integrated with an active teaching program and research activities.

Benefits

The program director is a specialist in adolescent medicine and on the staff of the Pediatric Department. Physicians in training, including physicians in internal medicine, gain experience from an active program in adolescent medicine including an inpatient unit for adolescents, a hospital outpatient clinic, an outreach clinic, and a school-based health clinic. A two year fellowship in adolescent medicine is offered, and residents from internal medicine rotate through the service. As trainees, physicians in internal medicine become acquainted with the transition concerns of adolescents with disabilities and are introduced to the care of this population.

Referrals are made from the North Shore University Hospitals Birth Defects Clinic, community agencies, general pediatrics, and group homes in New York. There is a generic approach to care and young people are not excluded from services on account of specific developmental disabilities or multiple problems. In this project, a university based unit of adolescent medicine has broadened its interests to focus on issues of coordination and continuity of care as patients move from pediatrics to internal medicine.

Transition of Patients From Pediatric to Adult Care at Temple University Philadelphia, Pennsylvania

The cystic fibrosis program at St. Christopher's Hospital in Philadelphia has been a leader in the movement toward a comprehensive health approach to chronic disease. This approach has led to an established pattern of transition from pediatric care to adult health services. A recent goal of the program was to evaluate the feasibility of duplicating the program for young patients with other medical conditions such as chronic heart disease, chronic renal disease, sickle cell anemia, hemophilia, and spina bifida. The concept of the multidisciplinary team approach has been adopted in the adult program and has been found successful. This adult team regularly communicates with its counterparts in the pediatric institution.

While it has been difficult to recruit staff to work with this team approach for a small proportion of their overall time, the problem has been overcome by buying time from the team's respective disciplines.

Benefits

Emphasis is placed on the pre-planning necessary for coordinated care. Coordination between the administrative staff and both hospitals has strengthened this process and has provided a pattern for other forms of cooperation. Faculty back-up has been assured, and department chairmen have supported the concept so that adequate physician time has been available. A transition team has been recruited and trained.

A strong nurse coordinator is identified to bridge the gap from pediatrics to the adult side. There is comprehensive training or the adult care team which takes into consideration their limited knowledge of "pediatric" disease.

The Hemophilia Model The New York Consortium Cornell and Mt. Sinai

Since the 1960's, a system of regionalized care using a multidisciplinary approach has been in place for the care of individuals with hemophilia. The New York consortium has built on this system by developing an organized plan of transition for young males with hemophilia. Cornell serves mainly children while Mt. Sinai Hospital continues to focus on adults with hemophilia. Physicians and other team members from both institutions work closely together, and this cooperative approach has been successful.

Benefits

Persons with hemophilia are at higher risk of being HIV positive and in some cases developing clinical signs of the disease. The multidisciplinary hemophilia centers are well positioned to handle this major complication. The medical, psychosocial, educational, and sexual needs and concerns of patients already receive regular review by trained and empathetic staff. Therefore, the mechanism for counseling patients about this issue is already in place.

CONCLUSION

Adolescents with chronic medical, mental, and emotional disabilities are an underserved group in the health care system. This gap in services is particularly evident when the time arrives for young people to move from child-centered health care to adult-oriented health services. Efforts have been made to formalize this transition process, but so far there are insufficient data upon which to make definitive recommendations for the structure of transition health care.

However, these principles of transitional care outline the essential components for an effective program. These basic concepts allow for interpretation in a variety of settings in the public and private sectors.

Adolescents with chronic illness and disabilities must have a well-defined primary health care program. This will not differ markedly from that encouraged for adolescents without disabilities, and will cover the same areas of medical and psychosocial concern. When primary care is not available, the specialist's services may not be sufficient to meet the adolescent's health needs or to allow them to function at their full potential in adult society.

Much of the care required by adolescents with disabilities is time-intensive for the physician, and not easily reimbursable. Ways to expand counseling with respect to the financing of care must be explored and implemented.

As the health care system evolves, physicians must insist that the transition needs of adolescents are recognized and appropriate services are provided. Transition programs must be evaluated so that effective and practical ways of providing health care for this high risk group of young people can be developed.

As questions arise and assistance is required, inquiries can be directed to the National Center for Youth with Disabilities (NCYD), a project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota. NCYD is a national information and resource center, funded by MCHB, which focuses exclusively on adolescents and young adults with chronic illnesses and disabilities and the issues that surround their transition to adult life.

Appendix 1

TRANSITION FOR ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS BACKGROUND

Surgeon General's Conference

In March 1989, C. Everett Koop, M.D., then U.S. Surgeon General, convened an invitational conference together with the Maternal and Child Health Bureau and Georgetown University Child Development Center's National Center for Networking Community Services to address the issues of transition for adolescents with special needs. The Surgeon General's conference, "Growing Up and Getting Medical Care: Youth with Special Health Care Needs" included participants from various medical specialties who care for adolescents with special health care needs. The conference examined approaches for providing smooth passage for these adolescents as they transfer from child-centered care to the adult health care system. Achieving a clear interface between services offered by physicians in both the child and adult health care system was a central issue of the meeting. With this type of coordination, most health practitioners could effectively develop a deliberate plan to ensure continuity of care.

The development of generic principles for the transition process was the major conference recommendation. The federal Maternal and Child Health Bureau accepted this mandate and selected a small group of consultants, chosen for their expertise in the concerns of adolescence and in community programs, to work with the Bureau on this document. It is anticipated that this material will be helpful in planning and implementing health care transition programs for adolescents with special needs.

For further details see "Growing Up and Getting Medical Care: Youth With Special Health Care Needs, A Summary of Conference Proceedings" (March 1989). This document was published by the National Center for Networking Community-Based Services at the Child Development Center of Georgetown University. The Surgeon General's Conference was funded by MCHB.

Appendix 2

LEGISLATIVE PERSPECTIVE AND FEDERAL COMMITMENT

Since 1935, Title V of the Social Security Act, which authorized the Maternal and Child Health Services, has provided the legislative foundation for expressing this nation's commitment to the health of mothers and children. The legislative commitment has influenced the development of two major programs: programs that deal with the health care of mothers and children and services for children with special health care needs. Traditionally, Maternal and Child Health programs are supported and implemented at the state and community levels. Over the years, adolescents have gained some increased visibility in both programs. However, adolescents have not received the full scale programmatic development offered to other groups included in the MCHB legislation.

The Maternal and Child Health Bureau, through its discretionary grant authority, Special Projects of Regional and National Significance (SPRANS), stimulated the development of regionalized systems of care for infants, children, and their families with special health care needs. The cornerstone of this legislation and the long term practice of regionalization is a comprehensive, coordinated approach to service delivery.

Innovations in service delivery are discovered and validated through MCHB-supported research activities. Sustained research, training, and information dissemination programs are critical to the success of a program of services for adolescents.

The Omnibus Budget Reconciliation Act of 1989 (OBRA '89) amended the Maternal and Child Health Services Block Grant by calling for the development of systems of care that affect the nation's mothers and children, and for children who have special health care needs. This legislation makes it clear that adolescents with special health care needs, along with all other children and families, must receive special support from the national Maternal and Child Health initiatives. The legislation includes four broad areas:

(1) *The extension and improvement of state-based services for mothers and children;*

(2) *The implementation of family-centered, community-based, comprehensive, coordinated care;*

(3) *The provision of health and rehabilitative services to children under 16 who would not receive full services from Medicaid, but would be eligible for SSI;*

(4) *Assurance of care coordination services.*

These areas of emphasis demonstrate that the national Maternal and Child Health program is focused on the total continuum of needs of mothers and children, including those of adolescents.

The nation's continuing commitment to the health of mothers, children, and adolescents, including adolescents with special health care needs, is reflected in the U.S. Public Health Service's *Health Objectives for the Year 2000:*

(1) All states will establish a statewide network of comprehensive, community-based health care systems that serve women of reproductive age, infants, children, adolescents, and children with special health care needs; the systems will assure family-centered, culturally competent, coordinated services.

(2) All children from birth to age 21, including those with special physical or mental health care needs, will have a source of health care financing that includes comprehensive preventive, diagnostic, and therapeutic benefits.

The MCHB initiative for adolescents includes collaboration with many federal programs. Significant private sector leadership has been provided by the Society for Adolescent Medicine and the American Academy of Pediatrics. These groups have demonstrated a sensitivity to the unmet needs of adolescents with disabilities.

The American Medical Association, through its staff, House of Delegates, and committee structure, has fostered commitment to reassessing the needs of adolescents. These organizations and others have collaborated with the MCHB to ensure a national focus on the health issues of adolescents with special reference to adolescents with special health care needs. Collaboration also has included voluntary organizations such as the March of Dimes, the National Hemophilia Foundation, and the Arthritis Foundation; these organizations have enabled the MCHB to extend its resources while supporting its overall goals.

Appendix 3

PREPARING PHYSICIANS TO CARE FOR ADOLESCENTS IN TRANSITION

Need for Improved Training of Providers

Lack of appropriate training for health care providers limits the ability to offer comprehensive, age-relevant, and developmentally-appropriate health care services to adolescents with chronic conditions. This deficiency clearly exists in the pediatric sector; half of all pediatricians report insufficient training in the care of adolescents with chronic illness (Blum, 1987).

Lack of training is even more prevalent in the adult health care sector where physicians are unfamiliar with adolescents as a group in addition to the chronic conditions that affect them. Physicians in adult medicine, without adequate preparation, rightfully feel uncomfortable managing the health care problems of adolescents. Moreover, those physicians who care primarily for adults may have had little experience with medical conditions that once were thought of as "diseases of childhood." Yet, overall survival to adulthood for these conditions is nearly 90 percent (Gortmaker & Sappenfield, 1984)

As adolescents with chronic conditions progress beyond the purview of the pediatrician, practitioners in adult medicine face new medical challenges. Improved training for health care providers is imperative if transition to adult health care is to become the norm for adolescents with chronic medical conditions

Professional Attitudes

A change in attitude and approach is the first step in improving the transition from child-centered to adult health care. Successful transition requires that adolescents and their families, physicians, and other health care providers believe that regardless of medical diagnosis, young adults are best served by health care in an adult setting. The concept is simple; gaining acceptance for the idea, however, may be more difficult.

Attitudinal change begins with awareness and education. The issue of adolescents in transition should be raised at all levels of medical practice:

- Transition should be introduced to medical students and to students in other health professions.
- Transition should be discussed and supported in position statements by professional organizations such as the American Academy of Pediatrics, the American College of Physicians, the American Medical Association, the American Academy of Family Physicians, and the Society for Adolescent Medicine.

- Transition should be on the agenda of the subspecialty professional organizations in both pediatrics and adult medicine. Liaison between pediatric specialty organizations and their adult medicine counterparts would be especially useful in developing strategies for the transition of individuals with particular conditions.

- Transition should be explored and supported by foundations and other scientific organizations interested in specific medical conditions. For example, recent guidelines published by the Cystic Fibrosis Foundation address transition directly:

  > "The goal is to ensure that the changing needs of the growing population of adult patients are met by caregivers. Adult patients have specific needs different from those of pediatric patients. Centers should have clear plans, including the identification of appropriate caregivers and preparation for transition to adulthood and adult care" (Cystic Fibrosis Foundation Center Committee, 1990).

- Transition issues with their families and care providers should be discussed by adolescents with chronic conditions. Support groups and consumer organizations also offer an excellent opportunity for discussion of transition. The Spina Bifida Association, for example, has made transition issues for young adults a major focus of their annual meetings (Spina Bifida Association of America, 1990).

Training Curriculum

Improved training in adolescent health issues is required for all health and medical professionals who care for young people. This has been recognized in official statements of the American Academy of Pediatrics and the American College of Physicians (American Academy of Pediatrics, 1978; American College of Physicians, 1989).

Professional schools as well as post-graduate residency training programs have started to respond by including adolescent health care in their educational programs. Still, most practitioners have not had the benefit of such training and report deficiencies in their ability to care for adolescents (Blum, 1987). For now, continuing medical education can help fill this void. A variety of textbooks, journal articles, and monographs on adolescent health are also available. The *Journal of Adolescent Health*, the official publication of the Society of Adolescent Medicine, makes a noteworthy contribution.

In the absence of a standardized curriculum, physicians and other health care professionals who care for adolescents with special needs should become familiar with the following subjects:

- *The usual progression of adolescent growth and development*
- *Adolescent psychosocial development*
- *Adolescent sexuality and its consequences*
- *The major morbidities of adolescence*
- *The impact of chronic conditions on development and the family*
- *Risk-taking behaviors of adolescents*
- *Culturally competent care*
- *The legal aspects of providing care to adolescents*

Training also should emphasize the benefits of care coordination. Postgraduate training can provide the opportunity to serve as care coordinator for a small number of patients. Health care curricula also need to include successful counseling theories, practice, and techniques.

All physicians need more structured training in the continuous and comprehensive care of individuals with special needs. This training should begin in medical school and continue throughout postgraduate education. It should avoid the tunnel vision sometimes imposed by the medical model, de-emphasize specific conditions, and focus instead on serving the frequently experienced problems of people with chronic illness and disabilities.

Preparing physicians in adult medicine to manage adolescents with disabilities should begin during medical school and be continued during residency training. Training should continue into subspecialty fellowship training. For example, adult cardiology fellows should be taught to care for adults with congenital heart diseases, and adult pulmonary fellows should be taught to care for adults with cystic fibrosis.

Physicians who have already completed training can employ innovative strategies to develop their skills. These might include preceptorships on pediatric wards and in pediatric clinics, collaborative arrangements with pediatricians or other physicians, or other forms of continuing medical education.

Pediatricians need to involve their adult medicine colleagues in the care of their adolescent patients and be available for consultation. Case discussions, clinical conferences, teaching rounds, and other meetings should be designed to facilitate the participation of appropriate adult health care providers.

Appendix 4

STATISTICAL TABLES—HEALTH, EDUCATION AND EMPLOYMENT DATA

HEALTH

TABLE 1:

Approximately 2 million children, or about 6 percent of the adolescent population, are identified as having limitations of activity (disabilities), and research indicates an upward trend in prevalence due to a variety of factors.

Table 1

Prevalence and rate per 1,000 persons of selected chronic conditions for persons 10-24 years of age: United States, 1986-1988

(Based on total U.S. population 10-24 year olds: 53,654,000)

Chronic Conditions	Prevalence 10-24 years old	Rate per 1,000 persons
Arthritis	633,000	11.8
Asthma	2,696,000	502
Cerebral palsy	65,000*	1.2*
Cleft palate	46,000*	0.9*
Congenital heart disease	144,000	2.7
Diabetes	218,000	4.1
Epilepsy	273,000	5.1
Hearing impairments	1,425,000	26.6
Liver diseases (including cirrhosis)	33,000*	0.6*
Malignancies-all sites	21,000*	0.4*
Mental retardation	698,000	13.0
Multiple sclerosis	9,000*	0.2*
Paralysis of extremities, complete or partial	97,000	1.8
Speech impairments	561,000	10.5
Spina bifida	11,000*	0.2*
Visual impairments	1,003,000	18.7

*Does not meet standards of statistical reliability.

Source: Unpublished data from the National Health Interview Survey, National Center for Health Statistics. Compiled with the assistance of John Gary Collins, Division of Health Interview Statistics.

TABLE 2:

Although many children with disabilities continue to lead foreshortened lives, the survival rates for youths with disabling conditions are increasing. This increases the need for health care coverage, educational and recreation/leisure resources, adaptive assistance, and employment services. These 11 representative conditions, which likely represent the more severe illnesses, account for only about 20 percent of all U.S. children with chronic health conditions.

Table 2

Prevalence Estimates for 11 Childhood Chronic Diseases, Ages Birth to 20 Years, United States[1]

Disease	Estimated Proportion Surviving to Age 20* (percentage)
Asthma (moderate and severe)	98
Congenital heart disease	71
Diabetes mellitus	95
Cleft lip/palate	92
Spina bifida	50
Sickle cell anemia	90
Cystic fibrosis	60
Hemophilia	90
Acute lymphocytic leukemia	71
End stage rental disease	90
Muscular dystrophy	25

*Estimate refers to the survival expected of a birth cohort to age 20, given current treatments

Source based on

[1] Gortmaker, S.L., Sappenfield W. Chronic childhood disorders: Prevalence and impact. *Pediatric Clinics of North America* 1984 31(1). 3-18 with revisions as noted

[2] Moller, J., Anderson R., 1000 Consecutive children with a cardiac malformation 26-37 year follow-up, (submitted for publication).

[3] Birth through 14 years of age *Cancer Statistical Review*, National Cancer Institute, May 1989, NIH Pub No. 89-2789

[4] Actuarial 2 year survival data for patients ages 10-19 with end stage renal disease begun on treatment (transplant or dialysis). US Renal Data System. *USROS 1989 Annual Report*, NIH, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda MD, 1989

TABLE 3:

Degrees of limitation affect adolescents' school attendance, access to and usage of health care, ability to acquire and maintain insurance coverage, employability, and self-care. It also affects the timing of the achievement of developmental milestones

Table 3

Prevalence of Disability According to Degree of Limitation for Adolescents 10 to 18 Years of Age, United States, 1984

Degree of Limitation	Percent of Distribution	Estimated Prevalence (thousands)
Unable to conduct major activity	0.5	165
Limited in kind or amount of major activity	3 7	1185
Limited in other activities	2.0	629
Not limited	93 8	29,862

Source: Newacheck, P W (1989) Adolescents with special health needs Prevalence severity, and access to health services United States 1984. *Pediatrics*, 84 (5), 872–881 Reproduced by permission of *Pediatrics* 1989

TABLE 4:

When comparing youth with and without disabilities, youth with disabilities make greater use of health and hospital services.

Table 4

Use of Medical Services According to Disability Status for Adolescents 10 to 18 Years of Age, United States, 1984

	Disability Status (%)		
Medical Service	All Adolescents	Adolescents With Disabilities	Adolescents Without Disabilities
Physician*			
<1 year (%)	71.5	86.6	70.5
1–2 years (%)	15.1	8.0	15.6
>2 years (%)	13.4	5.4	13.9
Mean number of physician contacts/year	3.0	8.0	2.7
Hospital			
Hospital episodes/100 persons/year	5.0	18.1	3.8
Hospital day/1000 persons/year	272	1,646	181

*Interval since last physician contact

Source. Newacheck, P. W. (1989). Adolescents with special health needs. Prevalence, severity and access to health services. United States, 1984. *Pediatrics*, 84 (5), 872–881. Reproduced by permission of *Pediatrics*, 1989

TABLE 5:

Youth with disabilities were twice as likely as youth without disabilities to be covered exclusively by public health care plans and less likely to be covered exclusively by private plans. This has broad implications for health care financing and policy issues.

Table 5

Health Care Coverage Characteristics According to Disability Status for Adolescents 10 to 18 Years of Age, United States, 1984

	Distribution (%)		
Coverage Status of Adolescents With Known Coverage Status*	All Adolescents	Adolescents With Disabilities	Adolescents Without Disabilities
Private only	74.0	64.6	74.7
Public only	10.0	18.6	9.4
Both private and public	1.9	3.0	1.8
None reported	14.1	13.8	14.1
Totals	100.0	100.0	100.0

*Persons with unknown health care coverage status excluded.

Source: Newacheck, P. W. (1989). Adolescents with special health needs. Prevalence, severity, and access to health services. 1984. *Pediatrics*, 84 (5), 872–881. Reproduced by permission of *Pediatrics*, 1989

Table 6a:

Except for youth who are deaf/blind or multiply-handicapped, the vast majority of youth with disabilities are able to get places outside the home and dress and feed themselves.

☐ *Very well/Pretty well

▨ **Not very well/Not at all well

Table 6a

Self-Care Skills of Youth with Disabilities
Percentage of Youth Able to Get Places Outside the Home

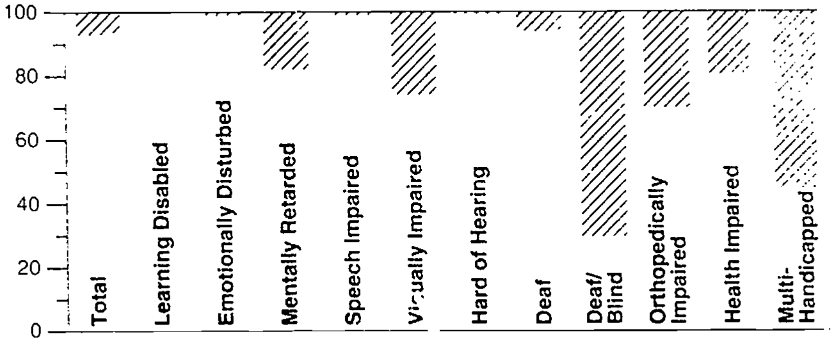

Table 6b:

Table 6b

Self-Care Skills of Youth with Disabilities
Percentage of Youth Able to Dress Themselves Completely

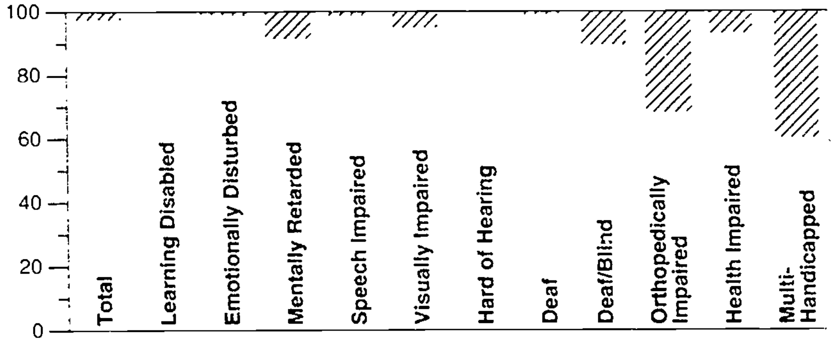

Table 6c:

Table 6c

Self-Care Skills of Youth with Disabilities
Percentage of Youth Able to Feed Themselves

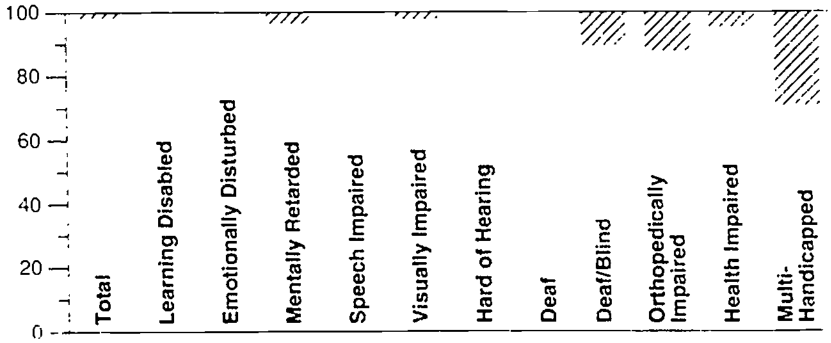

TABLE 1:

The school environment is an important factor in understanding the school experiences of youth with disabilities. Significant variation in placement patterns exists across handicapping conditions. Students with learning disabilities or speech impairments were served primarily in regular classes or resource rooms (77% or 92% respectively). Nationally, 56% of the students with mental retardation were placed in separate classes.

Most youth with disabilities (89%) attended comprehensive secondary schools whose student bodies were primarily students without disabilities. Overall, 28% of youth with disabilities attended school with fewer than 500 students; 39% attended schools between 500 and 1100 students and about 33% attended schools with more than 1100 students.

Table 1

Enrollment in Regular Education Courses by Students with Disabilities Attending Regular Secondary Schools

(Age Group 13-23 in 1985-1986)

		PRIMARY DISABILITY CATEGORY										
	Total	Learning Disabled	Emotionally Disturbed	Mentally Retarded	Speech Impaired	Visually Impaired	Hard of Hearing	Deaf	Deaf/ Blind	Ortho-pedically Impaired	Health Impaired	Multiply Handi-capped
Percentage of youth enrolled in:												
No Regular education classes	16.9	9.5	18.3	31.9	12.1	15.9	11.5	34.2	72.5	28.1	27.1	69.1
Regular education for nonacademic courses only	24.0	20.0	16.6	41.6	9.4	6.3	23.5	19.6	25.5	13.9	10.5	10.0
Some regular education courses (subjects unknown)	5.7	6.3	4.8	4.6	7.1	3.0	5.7	2.8	0.0	6.8	3.1	8.6
Regular education for academic courses	44.1	54.1	47.9	19.6	45.1	49.9	50.0	39.8	0.0	36.6	33.5	10.1
All regular education classes	9.3	10.2	12.4	2.3	26.4	28.9	9.2	3.6	2.1	14.6	25.8	2.1
No. of Respondents	**5170**	**872**	**503**	**828**	**405**	**425**	**543**	**410**	**22**	**509**	**287**	**366**

Using a 2-tailed test, the sampling errors at the 95% confidence level for the full sample range is from ± .6% to ±1.4%. For disability categories, the range is from ±2% to ±5% for most categories. For the deaf/blind category the range is up to ±19%.

Source: Educational Programs and Achievements of Secondary Special Education Students: Findings from the National Longitudinal Transition Study. March, 1989. Mary Wagner, Ph.D. and Debra M. Shaver. Based on students' most recent school year.

TABLE 2:

Schools provide a wide variety of services which enable students to learn in the classroom. Overall, slightly over half (52.8%) of the special education students did not receive additional services other than the basic special education services, although this figure varies markedly by type of disability.

Table 2
Services Received by Secondary Students with Disabilities
(Age Group 13-23 in 1986-87)

		PRIMARY DISABILITY CATEGORY										
	Total	Learning Disabled	Emotionally Disturbed	Mentally Retarded	Speech Impaired	Visually Impaired	Hard of Hearing	Deaf	Deaf/Blind	Ortho-pedically Impaired	Health Impaired	Multiply Handi-capped
Percentage of youth *receiving* in the past year from or through their school:												
No additional services	52.6	61.0	54.3	40.0	43.4	39.6	30.1	26.0	30.4	32.6	44.0	16.7
Speech or language therapy	16.5	9.6	6.4	27.8	44.6	10.6	50.2	56.5	25.8	20.1	15.9	57.0
Personal counseling or therapy	14.6	12.1	31.0	13.7	5.1	15.9	13.8	27.4	14.2	13.6	14.7	23.0
Occupational therapy or life skills training	22.8	17.0	15.5	36.9	16.6	32.1	20.9	39.1	41.0	34.1	27.7	53.3
Help from tutor reader/ interpreter	13.0	13.9	9.3	10.8	6.9	23.6	32.9	45.1	22.8	15.5	15.4	12.8
Physical therapy mobility training	4.9	2.0	1.8	9.5	1.4	18.0	3.4	8.7	32.2	35.4	10.3	32.6
Hearing loss therapy	1.2	0.0	0.2	1.0	1.0	2.2	41.6	52.7	54.1	0.6	1.1	6.1
Help in getting or using transportation	9.5	2.0	6.2	22.4	3.7	31.1	21.1	24.9	41.8	45.4	19.1	55.5
No. of respondents	**8169**	**1152**	**762**	**1165**	**573**	**850**	**748**	**893**	**96**	**748**	**460**	**722**

Using a 2-tailed test, sampling errors at the 95% confidence level for the full sample are ±1% or lower. For disability categories they range from below ±1% to ±5%.

Source: Educational Programs and Achievements of Secondary Special Education Students: Findings from the National Longitudinal Transition Study, March 1989. Prepared by Mary Wagner, Ph.D. and Debra M. Shaver. Based on parent reports or student school records.

TABLE 3:

These data provide nationally representative estimates of the per-pupil expense of educating students with disabilities. The total cost of educating a child with disabilities in a self-contained program is 2.5 times the cost of educating a regular education pupil. The costs below reflect only special education services, not additional regular education services.

The total cost of educating a pupil in resource programs is about $1,700.00 less than educating students in self-contained classes and about 1.9 times the cost of educating a regular education pupil. Sixty-eight percent of pupils in special education received their instruction through resource programs. Preliminary analyses do not indicate significant differences between elementary and high school costs.

Table 3

Average (Weighted) Per-Pupil Expenditures for Special Education Programs by Individual Handicapping Conditions and Program Type* (1985-86)
(Age Group 6-21)

Condition	Program Type (per pupil expenditures) Self-Contained (more than 15 hours/week)	Resource (less than 15 hours/week)
Learning Disabled	$3.083 00	$1 643 00
Autistic	7 582.00	NA**
Serious ly Emotionally Disturbed	4.857 00	2.620.00
Mentally Retarded	4.754 00	2.290.00
Speech Impaired	7.140 00	647.00
Visually Impaired	6 181 00	3.395.00
Hard of Hearing	6.058.00	3.372 00
Deaf	7.988 00	NA**
Deaf–Blind	20.416 00	NA**
Orthopedically Impaired	5.248.00	3.999.00
Other Health Impaired	4.782 00	NA**
Multihandicapped	6.674 00	NA**
Non-Categorical	3.684 00	1.731 00

*Sample size and standard error vary by condition and program type
**Not available

Source: Moore. M T Strang E W Schwartz. M . and Braddock. M (1988) *Patterns in special education service delivery and cost* Washington D C Decision Resources Corp

TABLE 4:

Research indicates that special education students drop out of school at a higher rate than the regular education population. Concern for high school dropouts is predicated on a belief that leaving high school before graduation is harmful for the individual and for the society. While some studies indicate that not all dropouts are behind in school or have substandard test scores, and that some at least have an equal or greater sense of self-esteem and control than high school graduates, most evidence supports the understanding that dropping out has negative personal and social consequences.

The major consequence of dropping out of school for youth with disabilities include poor employment potential, fewer opportunities for further education, and lower wage earnings for those employed.

Table 4

Number and Percentage of Handicapped Students 16–21 Years Old Exiting the Educational System, by Handicap and by Basis of Exit

U.S. and Insular Areas
During the 1986–87 School Year

	Graduated with Diploma		Graduated with Certificate		Reached Maximum Age for Services		Dropped Out		Other Basis of Exit		Total Exiting the System	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
All conditions	96.210	45 9	27 355	13 1	5.351	2 5	52.571	25 1	27 955	13 3*	209 442	100 00
Learning disabled	53.713	54 5	10 016	10.2	1.012	1 0	25.728	26 1	8 015	8 1	98.484	100.00
Emotionally disturbed	10 537	37 0	1 757	6 2	594	2 1	11 942	42 0	3 620	12 7	28.450	100 00
Mentally retarded	19.104	38 6	12.080	24 4	2.787	5 6	10 214	20 7	5 284	10 7	49 469	100 00
Speech impaired	4 967	48 6	906	8.9	262	2 6	1 929	18 9	2 155	21 1	10 219	100 00
Visually impaired	782	63 7	133	10 8	28	2 3	151	12 3	134	10 9	1 228	100 00
Hard of hearing & deaf	2 376	59 6	843	21 1	75	1 9	391	9 8	302	7 6	3.987	100 00
Deaf-blind	108	46 7	57	24 7	34	14 7	13	5 6	19	8 2	231	100 00
Orthopedically handicapped	2 214	45 9	460	9 5	56	1 2	1.140	23 6	953	19 8	4 823	100 00
Other health impaired	999	45 1	379	17 1	65	2 9	367	16 5	407	18 4	2 217	100 00
Multihandicapped	1 410	13 6	724	7 0	438	4 2	696	6 7	7 066	68 4	10 334	100 00

Source: OSEP State-Reported Data Produced by Ed-SEP Data Analysis System (DANS) October 1 1988

*Initially [illegible] schools report these students dropped out Subsequently 65% of parents report students had other reaso

TABLE 5:

Two common paths open to youth in the early years out of secondary school involve pursuing post-secondary education or training, or securing employment. Fewer students with disabilities than students without disabilities attend post-secondary education schools/programs.

Table 5

Postsecondary Education Participation of Special Education Exiters

	Percentage of 1985–1986 Exiters Taking Courses From:				
Disability Category	Any Post-secondary Institution	Vocational or Trade School	2-Year College	4-Year College	Sample Size
All conditions	14.6	8.1	5.9	2.1	1265
Learning disabled	16.7	9.6	6.9	1.9	245
Emotionally disturbed	11.7	8.8	4.1	1.3	131
Mentally retarded	5.8	4.3	1.2	.6	164
Speech impaired	29.3	7.0	19.3	8.3	83
Visually impaired	42.1	2.9	15.2	27.5	110
Deaf	38.5	7.0	19.0	15.2	154
Hard of hearing	30.1	11.6	12.7	7.0	101
Orthopedically impaired	28.0	9.0	10.4	9.5	105
Health impaired	30.7	13.2	12.1	7.6	65
Multiply handicapped	3.8	[illegible]	4.0	[illegible]	[illegible]
Deaf blind	8.3	8.8	0.0	0.0	27

Sampling errors for all conditions are <±1%. For disability categories sampling errors range from ±1% to ±5%.

Source: OSEP National Longitudinal Study SRI International, December, 1988. From the 11th Annual Report to Congress on the Implementation of the Education of the Handicapped Act. Based on parent reports.

TABLE 6:

Although mean ACT composite scores for specially tested students with disabilities are lower than normative data, the differences in several cases are minimal. Differences exist by type of disability and reflect a continuing need for schools to address issues related to the preparation of students with disabilities for postsecondary education.

Table 6

Mean ACT Scores for High School Students with Disabilities Requiring Special Testing: 1989–1990

	Normative Data	Deaf	Dyslexic	Learning Disability	Visual Disability	Physical Disability
Mean ACT Scores Composite	20.6	16.4	17.8	16.4	19.7	18.9

TABLE 7:

National Longitudinal Transition Study data show that socioeconomic status, as measured by income and head of household's education, is an important correlate of dropping out of school for all students.

Table 7

Factors Associated With Dropping Out of Secondary School for Youth with Disabilities

1985–1986 1986–1987

Individual/Family Characteristics	Percentage of Exiters Who Dropped Out
Gender	
Male	38
Female	34
Urbanicity	
Urban	40
Suburban	29
Rural	36
Ethnicity	
White	34
Black	36
Hispanic	44
Other	23
Household Income	
< $12 000 per year	42
$12.000 to $25.000 per year	38
>$25.000 per year	20
Head of Household Education	
Not a high school graduate	44
High school graduate	27
Some college courses or 2-year college degree	28
College degree or more (graduate courses graduate degree)	18

Source: OSEP National Longitudinal Transition Study SRI International. December. 1988 From the 11th Annual Report to Congress on the Implementation of the Education of the Handicapped Act Based on parent reports

TABLE 8:

Just as there is variation by disability in the percentage of students dropping out, so too are there differences in reasons for dropping out. Recent research suggests that school practice or culture, such as the structural organization of schools, the establishment of a social bond between students, and the norms governing the institution, may influence the decision to drop out or stay in school.

Table 8

Parental Reports of Reasons Why Adolescents Drop Out of Secondary School (1985-86)

	Primary Handicapping Condition											
Reason For Dropping Out (percents)	Total	Learning Disabled	Emotionally Disturbed	Mentally Retarded	Speech Impaired	Visually Impaired	Hard of Hearing	Deaf	Deaf Blind	Orthopedically Impaired	Health Impaired	Multiply handicapped
Pregnancy/ childbearing	7.8	8.9	5.8	6.7	0.0	24.0	34.2	15.4	a	0.0	2.0	0.0
Poor grades, not doing well in school	28.1	32.7	19.1	26.3	30.0	15.7	12.6	11.3	a	15.6	8.9	0.0
Wanting/needing a job	9.4	10.9	5.0	12.0	0.0	0.0	7.0	0	a	0.0	0.0	0.0
Moving	1.2	0.0	7	5.5	10.0	0.0	1.5	2.6	a	4.2	4.2	0.0
Didn't like school	30.4	31.2	32.3	24.9	41.7	29.9	25.6	38.6	a	21.5	19.6	17.9
Illness/disability	5.2	2.8	6.9	7.7	4.2	16.4	13.3	3.5	a	32.7	49.1	39.6
Behavioral problems	16.6	14.4	26.8	13.6	12.1	0.0	3.3	2.6	a	0.0	4.9	4.4
Didn't get program youth wanted	3.3	5.0	1.2	0.0	0.0	5.3	3.8	2.6	a	0.0	0.0	10.3
Other	33.4	38.9	28.0	19.3	40.6	17.2	29.1	40.9	a	34.4	18.5	50.3
Number of respondents	**363**	**88**	**92**	**44**	**19**	**14**	**24**	**20**	**2**	**21**	**16**	**23**

a Numbers too few to report

Source: Dropouts The Relationship of Student Characteristics Behaviors and Performance for Special Education Students March 1989 Paul Butler-Nalin, Ph D and Christine Padilla

EMPLOYMENT

TABLES 1a, 1b, 1c, 1d, 1e:

Persons are classified as having a work disability if they are identified as having a work disability in either of the direct items on the U.S. census or if they meet any of the following criteria:

1. Did not work in previous week because the person has long-term physical or mental illness or disability which prevents the performance of any kind of work (based on response to "main activity last week" question on the basic U.S. Bureau of Census, Current Population Reports questionnaire).
2. Did not work at all in previous year because the person was ill or disabled (based on response to "reason did not work last year" question in March Supplement).
3. Under 65 years of age and covered by Medicare.
4. Under 65 years of age and a recipient of Supplemental Security Income.

Table 1a

Prevalence of Work Disability Among
Persons 16–24 Years of Age, March, 1989

MALES & FEMALES		MALE		FEMALE	
Total N	Percent	Total N	Percent	Total N	Percent
32.646.000	3.5	16.147.000	3.6	16.499.000	3.4

Table 1b

Labor Force Participation Rates Among
Persons 16–24 Years of Age, March, 1989

MALE		FEMALE	
With Disabilities	Without Disabilities	With Disabilities	Without Disabilities
30.2	81.9	27.8	41.5

Table 1c

Unemployment Rates Among
Persons 16–24 Years of Age, March, 1989

MALE		FEMALE	
With Disabilities	Without Disabilities	With Disabilities	Without Disabilities
17.2	6.2	18.5	3.9

Table 1d

Percent of Persons 16-24 Years of Age
Working Year Round Full-Time in 1988

MALE		FEMALE	
With Disabilities	Without Disabilities	With Disabilities	Without Disabilities
6.0	27.6	4.6	20.5

Table 1e

Mean Earnings in 1988 of Persons 16-24 Years of Age

ALL WORKERS		YEAR ROUND FULL-TIME	
MALES			
With Disabilities	Without Disabilities	With Disabilities	Without Disabilities
$4.897	$8.716	$14.770	$16.058
FEMALES			
With Disabilities	Without Disabilities	With Disabilities	Without Disabilities
$4.130	$6.763	$12.562	$14.098

Source: John M. McNeil, Bureau of Census, 1988 (unpublished data) produced with the assistance of Bob Bennefield

TABLE 2:

Data from the U.S. Department of Education find many similarities between current and former special education students in terms of the number of hours they are employed.

Table 2

Employment Characteristics of Youth With Disabilities

	<10 hrs per week	10–20 hrs per week	21–34 hrs per week	35 hrs per week	Number of Respondents
All Disabled Youth With Disabilities					
In School	23 0	27 7	24 3	25 0	1055
Out Less Than 1 Year	10 6	16 1	21 1	52 2	496
Out More Than 1 Year	6 0	8 3	20.4	65 3	533
Learning Disabled					
In School	21 0	27 6	24 9	26 6	218
Out Less Than 1 Year	9 8	14 4	17 8	58 0	107
Out More Than 1 Year	3 8	5 6	21 6	69 0	158
Emotionally Disabled					
In School	26 0	24 6	30.9	18 5	121
Out Less Than 1 Year	12 1	14 2	27 4	46 3	76
Out More Than 1 Year	8 6	19 1	16 4	55 9	56
Mentally Retarded					
In School	30 9	30 8	13 7	24 6	91
Out Less Than 1 Year	12 0	21 8	27 1	39 0	65
Out More Than 1 Year	12 0	9 1	16 0	62 9	65
Speech Impaired					
In School	25 7	29 7	25.4	19 1	80
Out Less Than 1 Year	18 6	30 2	22 0	29 2	49
Out More Than 1 Year	7	17 6	21 0	60 6	44
Visually Impaired					
In School	23 3	24 0	18 5	34 2	96
Out Less Than 1 Year	8 5	14 2	13 3	63 9	32
Out More Than 1 Year	11 8	23 3	12 8	52 2	36
Deaf Blind	*	*	*	*	10

Source: Appendix C OSEP Longitudinal Study *Survey Methodology*. SRI International. 1988.

*Numbers are too small for statistical validity.

TABLE 3:

Rates of being employed vary widely by disability category. For example, 57% of youth with learning disabilities were employed, compared to 31% of youth with mental retardation and 14% of youth with orthopedic impairments.

Table 3

Employment Characteristics Of Youth With Disabilities Out Of Secondary School More Than 1 Year

	Percent Working For Pay			
Disability Category	Part–Time	Full–Time	Average Hourly Wage	Sample Size
All conditions	17 2	29 2	$4 35	1326
Learning disabled	19 3	37.9	4 63	249
Emotionally disturbed	21 5	18 5	3 94	136
Mentally retarded	11 6	19 8	3 68	174
Speech impaired	21 2	28 8	4 09	86
Visually impaired	14 3	10 0	3 12	112
Deaf	14 7	23 6	4 08	156
Hard of hearing	22 6	22 9	4 08	100
Orthopedically impaired	12 6	1 3	3 30	114
Other health impaired	14 9	13 9	3 54	65
Multiply handicapped	4 4	1 3	3 39	104
Deaf blind	9 5	0 0	--	30

Using a 2–tailed test with 95% confidence, the confidence interval for all conditions is ±1 . For disability categories, the confidence intervals range from ±1% to ±5%

Source: OSEP The Transition Experiences of Youth With Disabilities A Report from the National Longitudinal Transition Study. March 1989 Mary Wagner Ph D SRI International

TABLES 4a and 4b:

The Job Training Partnership Act (JTPA), which is administered by the Department of Labor, was enacted in 1983 to provide job training and employment seeking skills to economically disadvantaged individuals who need training or other labor market services to obtain employment. Since implementation, the Title IIA program provides training to adults and youth with disabilities. Job training services include job search assistance, remedial education, and training for specific occupations. Services are provided in each state by local Service Delivery Areas (SDAs), designed by state governors. Nationwide, there are over 600 SDAs.

JTPA is a highly decentralized program. Generally, individuals are eligible for JTPA if they are economically disadvantaged—a group that is defined primarily by household income but which also includes welfare and food stamp recipients and persons with handicaps. In addition, the act allows SDAs to enroll a small percentage of individuals who are not economically disadvantaged.

JTPA is a performance-oriented program. The basic measures of performance are increases in employment and earnings and decreases in welfare dependency among participants. The act requires the Secretary of Labor to establish national performance standards and provides for rewards to SDAs that exceed these standards and for sanctions to those which fail to meet them for two years.

Table 4a

Distribution of JTPA Terminees with Disabilities by Selected Characteristics

	Program Year 1988 (July 1988 – June 1989)	
SELECTED CHARACTERISTICS & PROGRAM OUTCOMES	Youth with Disabilities	All Other Youth
Total Trainees	45,100	255,700
Sex		
Male	62	47
Female	38	53
Minority Status		
White (excluding Hispanic)	75	44
Black (excluding Hispanic)	14	37
Hispanic	7	15
Other	3	3
Age at Enrollment		
Younger than 19	78	59
19–21	22	41
Economically Disadvantaged	97	95
Receiving AFDC	5	23
Receiving Public Assistance (including AFDC)	14	41
Education Status		
Student dropout	15	32
Student (high school or less)	70	35
High school graduate (or more)	15	31

Note: Percentage distributions may not add precisely to 100 due to rounding

Source: Unpublished data from the U S Department of Labor prepared with the assistance of Greg Knorr

Table 4b

Distribution of JTPA Terminees with Disabilities by Program Outcomes

	Program Year 1988 (July 1988 – June 1989)	
SELECTED CHARACTERISTICS & PROGRAM OUTCOMES	Youth with Disabilities	All Other Youth
Total Trainees	45,100	255,700
Program Activity		
Classroom training	23	35
On-the-job training	9	17
Job search assistance	10	10
Work experience	22	13
Other services	36	26
Median Length of Stay (in days)	129	112
Average Entered Employment Rate		
Overall	54	59
Classroom training	50	50
On-the-job training	76	80
Job search assistance	72	78
Work experience	55	47
Other services	46	56
Youth Positive Termination Rate	69	72
Average Hourly Wage at Termination		
Overall	$4.23	$4.53
Classroom training	$4.47	$4.81
On-the-job training	$4.10	$4.79
Job search assistance	$4.49	$4.34
Work experience	$4.09	$4.09
Other services	$4.10	$4.26

Note: Percentage distributions may not add precisely to 100 due to rounding

Source: Unpublished data from the U S Dept of Labor with the assistance of Greg Knorr

Appendix 5

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Appendix 6

RESOURCES

This is not meant to be an exhaustive list of resources but rather to provide some of the major organizations as a starting point.

National Rehabilitation Information Center (NARIC)
8455 Colesville Road
Suite 935
Silver Spring, MD 20910-3319
1-800-34-NARIC or 301/588-9284
(both are Voice/TDD)
Contact: Information Specialist

NARIC has compiled two unique databases, ABLEDATA and REHABDATA, which provide extensive information on disability-related products and research as well as other related resources.

National Information Center for Children and Youth with Disabilities
U.S. Department of Education
7926 Jones Branch Drive
Suite 1100
McLean, VA 22101
1-800-999-5599 or 703/893-8614

The National Information Center for Children and Youth with Disabilities (NICHCY) provides free information to assist parents, educators, advocates, and others in helping children and youth with disabilities become participating members of the community. NICHCY provides personal responses to specific questions, referrals to other organizations/sources of help, prepared information packets, publications on current issues, and technical assistance to parents and professional groups.

Center for Adolescent Mental Health and Health Promotion (CAMH)
Columbia University
School of Social Work
622 West 113th Street
New York, NY 10025
Contact: Trellano Constantino
212/280-3035

CAMH is a national information dissemination service. They publish Adolescent Mental Health Abstracts on a quarterly basis. They also abstract articles dealing with developmental disabilities, learning disabilities, and mental health problems.

Clearinghouse on Disability Information
Department of Education
Switzer Building, Room 3132
330 "C" Street, S.W.
Washington, DC 20202
Contact: Donald Barrett
202/732-1245

This clearinghouse responds to inquiries on a wide range of topics. Information is especially strong in the areas of federal funding for programs serving individuals with disabilities. They publish a newsletter which focuses on federal activities and new activities.

HEATH Resource Center
National Clearinghouse on Post-Secondary Education for Individuals with Handicaps
One Dupont Circle, Suite 800
Washington, DC 20036
202/939-9320 (Voice/TDD)
1-800-544-3284

HEATH is a clearinghouse and information exchange center for resources on postsecondary education programs for persons with disabilities.

National Center for Youth with Disabilities
Box 721 UMHC
University of Minnesota
Harvard Street at East River Road
Minneapolis, MN 55455
1-800-333-6293, 612-626-2825,
or 612-624-3939 (TDD)
Contact: Information Specialist

The National Center for Youth with Disabilities (NCYD) is an information and resource center focusing on adolescents with chronic illness and disabilities and the issues that surround their transition to adult life. NCYD maintains a computerized database of information from national and international sources to assist researchers, planners, service providers, parents, and youth. The database contains bibliographic literature, information on innovative programs from the public and private sectors, training materials, and a technical assistance network. Among the Center's publications are a newsletter highlighting critical issues and a series of topical annotated bibliographies.

NCYD bibliographies include:

- *Transition from Pediatric to Adult Health Care for Youth with Disabilities and Chronic Illnesses*
- *Adolescents with Chronic Illnesses—Issues for School Personnel*
- *Promoting Decision-Making Skills by Youth with Disabilities—Health, Education, and Vocational Choices*
- *An Introduction to Youth with Disabilities (In English or Spanish)*
- *Substance Use by Youth with Disabilities and Chronic Illnesses*
- *An Introductory Guide for Youth and Parents (In English or Spanish)*
- *Issues in Sexuality for Adolescents with Chronic Illnesses and Disabilities*
- *Vulnerability and Resiliency: Focus on Children, Youth, and Families*
- *Youth with Disabilities and Chronic Illnesses: International Issues*
- *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*
- *Issues in Nutrition for Adolescents with Chronic Illnesses and Disabilities*

Programs that focus on transition:

Chicago Children's Diabetes Center
Frank K. Thorp, MD
Herold Kevan, MD
The University of Chicago
LaRabida Children's Hospital,
East 65th St. at Lake Michigan
Chicago, IL 60649
312 363-1975

The Chicago Children's Diabetes Center provides comprehensive medical services for youth with diabetes from infancy to young adulthood. Emphasis is placed on goals of individualized self-management of each child's diabetes with diabetes education based on the young person's developmental level and stage of cognitive development. Educational services are available for low literacy families and social service intervention is provided for dysfunctional families. During each routine clinic visit, different topics are covered at an age-appropriate level. Screening for long-term complications of diabetes is accomplished through physical examination and laboratory studies; early aggressive intervention is instituted if abnormalities are found. A transitional care program is available for adolescents with diabetes for uninterrupted medical care and support as they go on to the adult diabetes clinics.

Young People with Physical Disabilities Program (YPPD)
Deborah O'Neil
Fabienne Kirk
The Door—A Center of Alternatives
121-6th Avenue
New York, NY 10013
212/941-9090

The Door's "Young People with Physical Disabilities Program" is a model project in which inner-city adolescents between ages 12 to 21 with various physical and sensory disabilities are integrated into the Door's mental health, health, educational, vocational, artistic, and social services programs and workshops. In the YPPD, youth mainstream alongside their non-disabled peers accessing the total comprehensive service center. A special project focuses on transition and independent living skills, including O.T., transportation training, and goal-setting/decision-making.

The Bridge Program—Adolescent to Adult
Daniel Schidlow, MD
Stanley Fiel, MD
Temple University
School of Medicine
Broad & Ontario Streets,
Philadelphia, PA 19140
215/221-3332

The Bridge Program was developed to study the issue of transition in the health care delivery system. The goal was to develop an appropriate adult health care delivery model and study this process and the process of transitioning patients from a pediatric hospital to an adult hospital in separate locations. The objectives of the project were to examine the following four issues:

1) The effect of transition on patients and their families; 2) Determining services needed in the adult care setting in order to provide appropriate care; 3) Determining whether interinstitutional issues can be overcome to develop such a program; and 4) studying the financial impact on patients and institutions. A manual for professionals on transition planning is available.

Rheumatology Transition Program
Patty Rettig, RN, MSN
Children's Seashore House
Children's Hospital of Philadelphia,
34th St. & Civic Center Blvd.
Philadelphia, PA 19104
215/895-3845

This is a structured, multidisciplinary transition program from pediatric to adult health care for youth with rheumatic diseases. Scope of program includes pre-transition assessments and interventions, including counseling and referral regarding education, career, sexuality, and other future-planning issues. Follow-up care is transferred to an internist-rheumatologist and is done by members of pediatric team. The program serves approximately 100 youth ages 17–20. Adolescents attend the "transition clinic" for several visits prior to transfer of care. The adult rheumatologist comes to the pediatric rheumatology clinic once a month for the transition clinic.

Transitional Adolescent Diabetes Program
Donald Orr, MD
Gray Deborah, RN
Riley Hospital
Department of Pediatrics
A-5857, 702 Barnhill Road
Indianapolis, IN 46202
317/274-8812

This is an interdisciplinary demonstration project to deliver and model developmentally appropriate diabetes-related care for young adults and their families. The clinic serves as a training site for residents in pediatrics and internal medicine and for clinical research on transition issues. It focuses specific attention on vocation/education/career transition into the adult health care system and includes an interdisciplinary diabetes team providing care in a large college health service.

Speak Up For Health
Ceci Shapland
PACER Center
4826 Chicago Ave. So.
Minneapolis, MN 55417
612/827-2966

This is a 3-year pilot program designed to help adolescents become advocates in the health care system. It also assists parents in guiding their sons and daughters to become as independent as possible in meeting their own health care needs. Speak Up For Health prepares adolescents for transition to adult health care services. Services include individual assistance, workshops, and written materials. Future training materials include a manual for parents (March, 1992), a manual for adolescents (January, 1993), and a video.

Transition of Adolescents and Young Adults to the Next Steps

Mary Ann Kimball, ACSW
Clinical Center for the Study
of Development and Learning
CB #7255, BDRC
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-7255.
919/966-5171

The adaptations required as young persons with developmental disabilities begin to move into adulthood present new challenges and opportunities for both them and their families. This transition period requires careful direction and planning to assure optimal achievement and fulfillment of important life experiences. The program can provide help to adolescents and young adults, as well as their families, employers, and service agencies, as they make decisions and develop transition plans. TRANS serves people with mental retardation, cerebral palsy, autism, and a variety of developmental disabilities requiring life-long care

Adolescent-Adult Transition Program

James Farrow, MD
University of Washington
CDMRC-WJ10
Seattle, WA 98195
206/685-1273 or 206/685-1358

A model program developed to assist young adults with special health care needs (ages 16–25) to make the transition from pediatric to adult health care settings and to determine the issues involved in health care transition. Fifty-five young adults were enrolled and successfully referred to adult health care systems. The final phase of the project involved a conference and publication of a monograph. The project has ended, but staff members are willing to consult with interested health care providers.

Transitional Cardiology Program

Roger A. Hurwitz, M.D.
Pediatric Cardiology
Riley Hospital
702 Barnhill Road
Indiana University Medical Center
Indianapolis, IN 46202-5225
317/274-8906

The Transitional Cardiology Program provides continuity care within the University framework for young patients with chronic cardiac conditions and facilitates the transition from pediatric to adult care. Created through the joint efforts of the cardiology divisions of the Department of Pediatrics and Medicine, the clinic provides multidisciplinary care. The clinic facilitates the transfer to an adult medicine environment, assures that the young person gets expert care in all areas of cardiology, and access to other areas of medicine. Educational experiences are built into the program for patients and medical personnel.

MOVING ON