

## **1989 Conference Proceedings**

### ***Surgeon General's Conference***

Growing Up and Getting Medical Care:  
Youth with Special Health Care Needs

#### **A Summary of Conference Proceedings**

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Growing Up and Getting Medical Care:

Youth with Special Health Care Needs

What Are the Issues?

Suzanne M. Bronheim, Ph.D.

**[Executive Summary](#)**

The national agenda for children and adolescents with special health care needs is committed to improving services, preparing and training health care workers in the field, and encouraging appropriate research. This

agenda includes the issue of young people moving from pediatric services to adult health care. This period of transition can be an anxiety provoking time for adolescents, their families, and for those who work on their behalf, and further efforts must be made to bridge this potential gap in services.

In order to address this important health care concern, the Surgeon General convened a small invitational conference "Growing Up and Getting Medical Care: Youth with Special Health Care Needs" on March 13-15, 1989 at the Jekyll Island Club, Jekyll Island, Georgia. The ground work for this meeting had been laid at a previous conference: "Youth with Disability: The Transition Years," which was held in Minnesota in 1984. The focus of this earlier meeting was mainly to define the problem in broad terms and to identify the challenges for adolescents with special needs as they move onto the adult service system. At Jekyll Island, the Surgeon General hoped to see the development of specific strategies and action steps related to medical care.

It is agreed that during this period of transition, there is likely to be a hiatus in the provision and utilization of appropriate care. The young adult, the family, and health care providers are all affected by this change.

The young adult himself may have had little warning or preparation for leaving the familiar health environment he has grown to trust and depend upon, and now he must find his way to a new clinical setting where he is expected to behave independently and where the personal touch may appear to be missing. Even when there is intellectual recognition that an adult patient's role is now more appropriate when receiving health care, it is often hard to move ahead in a positive frame of mind.

Parents and other family members may feel threatened by approaching changes in the pattern of care, and resent the effort required to adjust to a new setting and different staff. They have weathered many crises and vital decision making with the support of the Pediatric team, and have come to regard this strong source of advocacy as a permanent arrangement. In contrast, they may perceive the internist as less involved and perhaps insensitive to the subtleties associated with these chronic medical conditions.

Health care Providers also may feel uncomfortable during the period of change. The pediatrician has seen the survival of the child with a handicap which has been a professional and personal achievement; it is therefore frustrating to relinquish such a patient to others who provide a service which may have a somewhat different focus and broader goals. The internist accepts the patient who has already been diagnosed and treated. Whatever he says or does will inevitably be compared with what has previously transpired in the child centered setting. As a rule, he does not have the back up of an interdisciplinary team. The medical condition may be one with which he has had little or no experience. To build a productive relationship under these circumstances could seem an unreasonable challenge. The care of adults in many settings tends to focus on the medical problem; whereas, pediatricians have learned to attempt a more holistic approach.

Issues in transition that must be addressed include the provision of services, financing of care, training of staff, and research.

Provision of services - various methods have been tried to assure a smooth transition; these models appear to have been successful, and point the way to building on existing resources in any given situation.

Financing of care - having determined that responsive health services are available, the most pressing issue in transition must be the financial capability to pay for this care. The young person who reaches the age of legal independence, but has a pre-existing condition, may find he is virtually uninsurable. Whether he is in full time education, employed, or at home, the procurement of adequate financial coverage is a major barrier to obtaining comprehensive health care.

Training of staff - those responsible before, during, and after transition need an orientation to the developmental characteristics of young people who are attempting to make this adjustment. Knowledge of some of the less common medical conditions should be made more available. The importance of a positive relationship between patients, their families, and care providers must be stressed. Understanding and assessment of the emotional, economic, and social needs of families should be developed in tandem with the monitoring of the long term

medical condition.

Research - there is a lack of precise information about landmarks in development which have a bearing upon the optimal timing for transition. The significance of the impact of various chronic medical conditions upon psychosocial development is unclear. Demographic data have been collected, but analysis which would give the information practical value has yet to be performed.

As a result of this conference, a number of action steps will be planned and implemented.

Conference participants will make their respective professional groups more aware of the importance of transition. This will be achieved through contact with professional organizations, newsletters, and presentation of papers.

Support groups who are already known to many families will be encouraged to work with official agencies on the health aspects of transition.

Generic guidelines will be developed which will recommend the scope for both individual and programmatic components of health care. These guidelines should provide a basis for assessment of an individual's readiness for transfer. Available options for the financing of needed services are to be a major inclusion.

A financing coalition will be developed with representatives from several national agencies and organizations. These experts will be selected because of their interest and experience with the predicament with which disabled adolescents are frequently faced. The group will concentrate upon exploring funding initiatives for transition and beyond, in keeping with emerging fiscal structures. Access to financial support and a standard benefit design will be pivotal points in these deliberations.

Strengthening of family empowerment teaching resources will be made available through support groups, voluntary organizations, and official agencies.

Training efforts will be encouraged to broaden the horizon of staff in both pediatric and adult settings about the significance of transition and health care beyond this point.

Universities will be encouraged to analyze existing data relative to transition issues. Information will be sought about the measurement of functional disabilities, the definition of disability in a socio-economic context, the effect of a disability on development, and other topics related to transition.

An adolescent may have any one of a great number of primary disabling conditions; however, there are wide areas of common needs which are shared by all regardless of the nature of their illness. These shared needs often relate to developmental delays which require special support at the time of transition, and about which too little is known.

The recognition of common needs has implications for staffing patterns, especially for those who provide counseling for psychosocial and family issues. The whole community of professionals must become increasingly aware that they may need to modify their attitudes around the process of transition, and build new skills into their repertoire in order to respond to both individuals and categorical groups of patients.

Introductory Remarks by  
C. Everett Koop, M.D.  
Surgeon General  
U.S. Public Health Service  
Department of Health and Human Services

As I end my career as Surgeon General and look back on my accomplishments, I share with you an enormous sense of satisfaction in what we have achieved for children with special health care needs and their families.

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We have established a national agenda for these children and their families which is to:

- Pledge a national commitment to all children with special healthcare needs and their families.
- Encourage building community-based service systems.
- Assist in ensuring adequate preparation of the professionals who provide care.
- Develop coalitions to improve the delivery of services.
- Establish guidelines to control costs of services.
- Encourage and support the development of adequate health care financing.
- Continue to conduct research and disseminate information.

This agenda is moving forward as evidenced by the more than 1,200 participants from medicine, health, education, social service fields, and families who joined us at the September 1988 Surgeon General's Conference in Washington, D.C. to share the progress we had made.

Before I leave my position, I would like to recall one major issue in the care of special children which has not been adequately addressed and which is a significant barrier to our adolescent and young adult population as they pursue independence. I refer to the obstacles they encounter and must surmount if the provision and quality of medical care is to continue from childhood through transition to adulthood.

I have invited you as leaders in the major organizations and professions which provide these services to help us solve that problem.

This Surgeon General's Workshop, which will probably be my last, is a personal effort to close the loop on the conference some of us had in June, 1984 at Wayzata, Minnesota -- A "Conference on Youth With Disabilities: The Transition Years." There, I was a speaker who asked "who are the disabled among us." I left the question unanswered but implied that some members of society were more handicapped than those we call disabled -- handicapped by attitude, prejudice and tunnel vision.

Today, I am your keynote speaker and in a sense, your host. It is necessary and potentially profitable, to hold this workshop to determine methods for improving the transition of disabled youngsters from Pediatric care to physicians in Adult Medicine and associated specialties.

What has been achieved already?

- There are programs that work and about them you will hear more.
- The issue of transition is being addressed by a number of regional and national programs, models, and networking services which will teach us how better to encourage adolescents to develop their full potential.
- There are societies and associations that foster the exchange of information among those of like mind, such as the Society for Adolescent Medicine
- There are some states that have coordinators for adolescent health programs.
- And some states have training and employment models

What is wrong with available transition services and concepts?

- Some physicians for adults and their associates have not yet acquired the medical expertise for working effectively with rare medical conditions which can affect the young adult population.
- Pediatric professionals may have become overprotective of their patients which tends to inhibit the development of independence for the patient.
- The patient may receive a negative message of survival if he stays in pediatrics indefinitely.

I personally spent much of my professional life making sure that children with surgical problems continued to

receive good comprehensive care in an adult world. We know that some physicians for adults and their associates have limited experience in caring for older children and adolescents and they must be given every opportunity to fill this gap in knowledge and skills.

We are not asking you to consider a series of problems with easy solutions. Our concerns are not amenable to a quick fix.

A basic underlying defect in the system has to do with the lack of a transition protocol for healthy adolescents from pediatric care to adult services. Part of that is because the population in general has its healthiest years in the decade after adolescence. Even individuals under the care of a family practitioner have little reason to seek his help and when an acute illness requires medical attention, it is likely that consultation will be with a different and unknown physician. How much more difficult for the youngsters with special needs when his/her acute illness demands entry to the adult system.

Some of the barriers to a successful transition of children with special health care needs have already been identified. Attitudinal barriers come first and they involve patients, parents, the pediatric caregivers and their adult counterparts. The pediatricians and internists in this audience have given much thought to these issues and therefore probably do not represent the profession as a whole.

Adolescents are having more trouble than they need with this aspect of growing up; however, they themselves do not lack enthusiasm to become involved in transition and can see future benefits in moving on to a state of greater autonomy.

Parents are understandably unwilling to leave the familiarity, security and expertise of child centered services and to enter an unknown territory, which usually seems to compare unfavorably with the known, at least in the initial phases.

Pediatricians and their associates, having a tremendous interest and investment in the recipients of their care, feel a proprietary responsibility that encourages them to cling to the patient even when they know it is in the patient's best interests to make a change. Sometimes it may seem that the immediate adult care is not entirely responsive.

The new responsible adult care giver has many hurdles to surmount. First, the idea that pediatricians play medical games with their patients and over-indulge their patient's parents; second, the fact that the parents know more than he/she does about the child, his problem, and the goals for his care; third, the idea that it is normal for parents to be anxious, to expect satisfactory explanations, and to wish for inclusion when decisions are made, which all takes valuable professional time.

The adult care giver will probably never have the same creative interest that was the vital ingredient of the former relationship, indeed it may have been the adhesive that held the situation together.

Some diagnoses I dealt with required 10 to 15 years of constant attention to ensure a maximal habilitation of the infant becoming a toddler, becoming a child, becoming an adolescent. I molded those youngsters as best I could into the best they could be -- my interest was very proprietary. I was aware of the situation and tried to maintain a reasonable balance. How much more difficult for the reluctant physician!

Because our society is so mobile, new patients are sometimes referred mid-stream; in these instances, I found it hard to feel the same degree of interest in an inherited case as I had in one I had cared for since birth. It must have been the same for my patients whom I transferred elsewhere.

My point is -- if these feelings exist within pediatrics -- how much more stressful might this be when transferring to adult care.

Even today, former patients still beat their way through the bureaucracy to ask one to intervene when barriers have become insurmountable. Frequently, these barriers stem from faulty communication or unreasonable attitudes.

There are other points to be made and addressed:

- Existing knowledge gaps must be filled concerning techniques, community resources, experience of others, and achievable goals.
- The range of care delivery models must be assessed and documented.
- Methods of coordination with other services must be explored.
- The financing of care must be regarded as an immediate priority.

We are talking about labor-intensive care, increasingly expensive, and the reimbursement systems which have not caught up with these facts.

Children with special needs entering the adult system are not overly welcomed because:

- They should many times overstay their DRG norm.
- They may not be covered -- any longer -- by their parents' insurance.
- If employed -- even part time -- they may be part of the working poor -- uninsured but not destitute enough to be on welfare or even eligible for Medicaid.

For the rest of this century, everything we discuss in reference to medicine, health care delivery or policy will merely be symptomatic of the overarching tension between our aspirations for health care and our resources to pay for them.

The two populations at greatest risk of medical neglect are the elderly and children. We will have to fight harder than ever for the funds to care for special needs children and young people.

It is unlikely that any administration or any Congress will address this issue on the clear merits of the situation -- in spite of the nation's affluence and prosperity. But the day will come when the business community will exert much greater pressure than at present for a more realistic method of funding health care. We must be prepared for that day so our special needs children are not shortchanged as the health care delivery system is rebuilt. We must be certain that there is adequate documentation of the essential range of health services so that implementation may take place without delay as soon as resources are made available.

These are the issues we ask you to discuss with us over the next two days -- along with any additional ones from your experience you would like to bring forth.

Let us clearly identify the problems and plan concrete efforts which each of you can pursue within your own organization. Let us then outline some efforts we can jointly pursue to knock down the barriers currently preventing our young people from living their lives to the fullest.

### **A Background Issue Brief**

Suzanne M. Bronheim, PhD.  
National Center for Networking Community Based Services  
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Over the past 20 years, there has been a dramatic improvement in mortality rates for many chronic "childhood"

conditions due, in large part, to advances in medical and surgical care. Survival rates for disorders such as spine bifida and leukemia have increased by almost 200 percent. The average age of survival for young people with cystic fibrosis is pushing well into the twenties with one third living into their thirties. It has been estimated that, overall, some 84 percent of children with chronic conditions survive into adulthood.

Unfortunately, in many cases, the medical care system has not changed in response to its own successes. Large numbers of these "survivors" continue to receive their medical care in pediatric settings. It is not uncommon to see patients in their late twenties receiving inpatient care on pediatric wards and in children's hospitals. Others are simply lost to ongoing follow-up once they "outgrow" pediatric services, since no specialty services addressing their condition exist in the adult medical system.

This situation has a negative impact on these young people in several ways. While the pediatric caregivers who have provided specialty care throughout their childhood are typically indisputably expert in treating their special conditions, they may not have the expertise to address the medical needs of adults. Issues related to gynecology and obstetrics for young women and other disorders of adulthood which may be unrelated to the young person's special health care needs may not be addressed as well as they would be in the adult health care system. In addition, other pediatric subspecialists providing consults may also lack experience with "adult" disorders or the manifestations of a given problem in the adult population.

Another way in which receiving medical care in pediatric settings may have a negative impact on young adults is in relation to their own psychosocial development. Pediatric caregivers may have a difficult time switching from dealing with the parents as the responsible parties to dealing with the young adult. It is hard to accept that the child one has cared for is now an adult and pediatric caregivers may collude with parents in "overprotecting" the young patient. Issues such as sexuality, reproduction, vocational concerns or even the financial aspects of care decisions are often not discussed with the patient, as they would be in the adult health care sector. Even the best efforts at education in these areas by pediatric caregivers may be ineffective if the patient feels that his/her parents make the decisions about care. Remaining in pediatric care settings becomes one more factor impeding the development of adult independence in young people with special health care needs. Finally, there is a very insidious, negative message in keeping these young adults in pediatric care. It is an understandable by-product of the history of the mortality of many of these "childhood" disorders, but it is devastating. The failure to develop a capacity to care for these young adults in the adult care system suggests that we believe that they are living on "borrowed time". It gives the message that working to make the difficult transition to adulthood may not be worth the effort, because it may be a greatly shortened span of time!

Young people who do not have special health care needs seem to make the transition to adult health care with little fanfare. Why does there seem to be this bottleneck in the progression for youth with special health care needs? A number of factors seem to play a role in the problem. These include: attitudinal barriers (on the part of pediatric and adult caregivers, families and patients) knowledge gaps; care delivery models typical in adult health care; financing of adult health care services and coordination of health care services with other needed services. Each issue must be addressed in order to insure that youth with special health care needs can grow up and find appropriate medical care.

### **Attitudinal Issues**

Those who have attempted to facilitate the transition of young adults to the adult health care system have quickly discovered that the issue arouses very strong feelings. Parents are often quite reluctant to leave the pediatric caregivers who they often view as having kept their child alive, in order to seek care in untested waters. These feelings are particularly acute when their child's disorder is one that is not familiar to the adult caregivers. Parents may have close personal ties with the pediatric caregivers forged during moments of crisis and shared worry. The clinic and hospital staff are often a major part of the family's support system. Parents who experience the move to adult health care settings have a hard time adjusting to the focus on the young adult as the responsible party. They complain of feeling shut out and ignored when the adult caregivers consult with them as a courtesy with the permission of the young adult patient. Thus parental resistance to the move can be quite strong. Many young people share their parents' fears about the change as well, although most express very positive feelings about being "treated as an adult."

The caregivers' attitudes also make the transition problematic. Pediatric caregivers also have strong ties to the families and the patients – it is very hard to see them leave. They have a difficult time really believing that the child they may have cared for from birth is truly an adult (or should at least be treated as one.) They feel that no one in the adult system has the expertise to deal with the patients' medical problems and, more importantly, that adult caregivers are cold and uninterested in these patients' many psychosocial needs. On the other side of the care system, adult care providers may feel that these patients are immature and their families too involved and demanding. If they do not have experience with a young person's special condition, the caregivers may feel defensive or threatened about seeking consultation or supervision from pediatric caregivers who specialize in the treatment of the disorder. Certainly there is no incentive to pursue the treatment of a group of patients if one does not have the knowledge and experience to do so.

These attitudes must be addressed in any efforts to change the system of care. When the problems and setbacks that attend any change come along, it is too easy for any or all of the parties involved to feel that "it isn't worth the trouble" or to be too quick to see any problem as proof that their worst fears have been realized.

### **Knowledge Gaps**

One very real barrier to a smooth transition to adult health care for youth with special health care needs is the lack of knowledge and expertise in the adult care system to deal with their special problems. Some of the disorders involved have been historically thought of as "pediatric conditions", many of which are cared for in special centers or units. As a result, physicians and other caregivers in the adult system may have little knowledge and no experience caring for these disorders. Some form of training and expanding knowledge is needed to make the transition from pediatric settings, where the staff have had years of experience with a particular disorder, to the adult settings.

While these young adults with special health care needs should be treated as adults, many have had delays in both the physical and psychosocial aspects of adolescence. Thus many in their twenties are more like mid-adolescents in their development. Their families are also often still unresolved about letting go and making the move to becoming the parents of an adult child. A large proportion of adult specialists may not have had training in the issues of adolescent development and may be perplexed and frustrated in caring for this population. This lack of knowledge can easily undermine the success of the transition.

### **Care Delivery Models**

Over the years, the pediatric system of care has recognized that interdisciplinary team care is the most effective model for serving children with special health care needs and their families. Many of the disorders treated need the input of multiple professionals, all of whom must have a familiarity with the special aspects of the care of a particular condition. While the interdisciplinary team approach to care has made an appearance in the adult health care system (e.g. cardiac care clinics, diabetes centers, etc ), it is not the model available in most specialty departments. Many physicians in the adult care system are unfamiliar with or even uncomfortable with this model of care. It is important that in seeking to find medical services in the adult sector, young people with special health care needs do not have to give up the model of care that is critical for appropriate treatment of their chronic health conditions.

### **Financing Care**

The financing of care for young adults with special health care needs is a problem that has an overriding importance for the issue of growing up and finding medical care. There are issues for caregivers, institutions and consumers. Caregivers may find that caring for these young people is more time consuming than usual, yet reimbursement systems may not adequately recognize this factor. In addition, team care is very costly and again, reimbursement systems may not provide adequately for the many kinds of services needed. Inpatient hospital care in adult institutions, where DRG's have been applied, may be problematic. Because of the complex nature of their medical problems, these young patients may be seen as a drain on resources, when DRG's do not

recognize their real need for prolonged hospital stays. Even in states where there are public programs to help pay for care of specific conditions after the age of twenty-one, the agencies administering them are child oriented and may relate only to pediatric institutions or caregivers. Finally, a very serious issue is the fact that these young people typically find themselves without any health insurance coverage. Once they reach the age of twenty-two or leave home and school, they are no longer covered under their parents' policies. If they are gainfully employed, they may not qualify for public sources of medical coverage. Often they also find that they cannot secure full time employment, because they are a risk that employers do not want to insure. Thus, incentives to become productive, independent adults may be undermined in order to deal with financing health care needs.

### **Coordination With Other Services**

Young people with special health care needs often have many other associated needs. They may need a variety of special therapies, special equipment, extra training to help with vocational fulfillment, special diets, and special accommodations in the environment. During childhood the educational system and the medical system may coordinate many of the services for the child and family. The adult care system, not having dealt with these particular needs, may lack knowledge of resources and ties to the resources needed. Development of these ties within the adult care system will be needed to insure appropriate care for these young adults. On the positive side, the adult caregivers are much more familiar with many types of services that will aid in the growing independence of these young people in the areas such as vocational development.

This paper is certainly not meant to be an exhaustive discussion of the issues related to transition to adult health care for youth with special health care needs. These are, however, the key issues that will need serious consideration throughout the system. Clearly, members of the pediatric and adult health care systems, families and young adult consumers must all become actively engaged in the process if positive change is to be effected. Many of the statements are generalizations and there are specific instances when youth with special health care needs can access appropriate adult health care services. There is, however, much work to be done.

## **Section I**

### **Overview and Scope of Problem**

In order to present the concept of adolescent transition from more than one perspective, papers were requested from professionals who were known to have a special viewpoint based on their own life experience or special interest.

We have an introduction through the highly personal experience of a young woman who felt deeply the emotional discomfort of leaving the protective warmth of Pediatrics for the cooler clinical atmosphere of an adult service. However, unlike others, she was able to make a personal adjustment, and to survive with distinction.

A pediatrician speaks for professional health staff when they are faced with implementation of a transition program. The increased life expectancy of children who have cystic fibrosis made it necessary to develop a bridging program between a Children's Hospital and an adult pulmonary unit. From this paper, we learn about the importance of preparing young people for this transfer and to choose the optimal time for the event. The benefits of an interdisciplinary care team are described. The difficulties experienced in developing a strong link between these two programs are not minimized, and we have a realistic picture of the reluctance and rewards associated with the growth of such cooperation. We see these events occurring through the eyes of the responsible health care providers.

A health care financing expert addresses the universal burden carried by disabled adolescents and their families. She has given a succinct account of the financial dilemma faced by nearly all individuals in this category when eligibility for medical insurance benefits is curtailed by age, and they fail to qualify for coverage through state or private schemes. The points are made through discussion of an imaginary young adult - and specifying the available options and alternatives available for obtaining payment for essential medical care.

The paper on training emphasizes the importance of an appropriate orientation for professional staff, patients, and their families when improvement of the transition process becomes a priority. Staff in both pediatrics and adult health services should work together and share relevant information; this should be a continuous process before and after transition. The technical aspects of managing rare medical conditions with which the adult physician may be unfamiliar, must be included in the curriculum. Attitudes and communication skills are central to the successful shaping of new relationships between staff and young patients.

## **Learning to be an Adult Patient: When the Rules Change**

### **Margaret Stineman, M.D.**

My own medical treatments, most of which were surgical, began at age three and continued into my adult years. I do not want to talk a great deal about the specifics of my medical condition or surgery. Briefly, I had procedures on my eyes, my musculoskeletal system, and my internal organs.

When I was a child, I would always bring my guitar to the hospital. I named the guitar. Its name was "Friend." I was in the hospital often, so the staff came to welcome me and "Friend." I would make up songs - sing for the other children, for the nursing staff, the doctors, and the orderlies. Everybody was interested in my guitar and my musical gifts. Sometimes the nurses from the adult wards would borrow me to cheer up their patients. The older folk would marvel at my "courage," and feel inspired by the songs saying things like "Poor little thing, in spite of all her problems she can smile." I treasured these times, since by lifting the spirits of those around me, I forgot the hurt. One man who, looking back, must have had laryngeal cancer sent me a book of Emily Dickinson's poetry. In the cover was inscribed "Dear little Margaret, I can not use my voice anymore. Your songs are my words."

The guitar was a way that I could feel comfortable and accepted within an environment that inflicted physical pain on me, and left me frightened and set apart from my peers. It was a way of reaching out to other people. In letting me play my guitar the pediatricians, the surgeons, the nurses, and all the people in the hospital let me show them that I was a human being who just happened to be physically different. After a spinal fusion, I learned to play the guitar lying flat on the bed without moving. It would draw people to me. I would not feel so alone. So different.

I made my own transition from pediatric into adult health care on schedule quite abruptly when I was 16. I can recall sitting on starched white sheets in my semi-private room, taking Friend out of its case and quietly beginning to pluck out a melody. No one marveled at my courage. My songs inspired no one. No one saw my gifts. Nobody was drawn to listen. In fact, I suddenly blushed realizing that playing my guitar within the sterile walls of this hospital room was disquieting to the nurses, the doctors, and the patients. In fact, it was down right infantile. I sent my guitar home with my parents. I had to face the fact that appealing crippled children on posters grow up to be uninspiring physically deformed adults. The adult medical milieu was no nonsense. It was interested in one thing - the expedient treatment of disease - the cutting - the curing. It appreciated the privacy of the individual at the expense of personal sharing and expression. The doctors and the nurses had little time or inclination to know the patient. In my own medical internship, I would need to confront this tragic fact made vivid by my past experiences. When suffering from post call sleep deprivation, or when struggling to save lives one can not always see or hear the patient. So to survive, I was forced to adopt the methods of those who had cared for me, even though I knew this approach was imperfect. The guitar for me as a child was a calling out of who I was. As an adult I had to close myself, and just become a patient. The care of disabled children is holistic and team driven. The young child is seen as developing within the context of family. Disabilities are noted, but more importantly abilities are seen and encouraged. An attempt is made to view illness within the context of a life. I found this less so bc the case as an adult. There is a supportive aspect of pediatric care which is lost in the transition into adult care. The care of the adult is disease oriented, less holistically supportive. This was one of the most difficult aspects of my transition into adult care. One minute I was in a nurturing environment that attempted to see me as the individual that happened to be physically unusual. The next moment I was in a

attempted to see me as an individual that happened to be physically unusual. The next moment, I was in a medical milieu that did not care to look beyond my physiological impairments.

As a child the many procedures, diagnostic tests, and surgeries were done on me as a passive participant. The doctors, the nurses, the therapists had some special knowledge. Children are not good at tolerating pain. The physicians seemed to feel that reasoning about the necessity of drawing blood is going to fall on deaf ears. In fact, I put up gracefully with the various procedures I had in my early years because I felt there was no alternative. The doctors knew everything. I had no right to question. It all ran by magic law. Each time, I was rolled into the OR I thought I would roll out normal. If I didn't it just meant I needed more surgery. Decisions were made by my doctors, my parents, not by me.

At age 18, I was absolutely dumbfounded when a resident turned up in my hospital room with a consent form for surgery. This doctor was telling me there were risks that I could die, and that I personally would have to accept this possibility. I saw death about me in the hospital as a child but had not connected it to myself. Where were my magical pediatric illusions? The doctors in pediatrics were so magical. They could cut and fix my body. They had never told me I could die. Now I sat in a foreign land. A different hospital. A different health care system. I was supposed to become part of the decision making process. I could take control, but I did not know how. Did I even want to take control? How could I ask questions? How could I make a decision about a medical procedure or the need for surgery? For 16 years the decisions were made for me. Although, at 18, I signed the consent form, I neither read nor comprehended it. I signed it, not because I wanted the surgery, but because I had always done what had been asked of me. The results of the surgery would direct the remaining years of my life.

As a disabled child I was an infant. As an adolescent I was a child. In my adult years, I would finally pass through adolescence. Prolonged infancy encouraged dependency. This made the acceptance of personal responsibility difficult. As an adult aged patient I felt cast into a foreign sea. My boat had oars, but I did not know how to use them. In broad terms the adult seeks care, the child receives care. The developmentally immature adult in the adult system of care is a victim since he or she is assumed to be autonomous.

Please realize many of the children we will be thinking about today have far greater physical problems than I do. And few have the remarkable family support I have. Many might feel differently about their transitions into adult care. Others may never even make it, forever remaining children in adult bodies, and still others may make it but in the confusion become lost to the health care system entirely. I was lucky. I am an example of what should, and can be, but what rarely is. Only with my present vision can I make sense of my past experiences. There were four primary differences in the two systems of care that led to difficulty in my transition. First, was the change in both type and level of support. Second, was the change in the decision making and consent process. Third was a marked reduction in the acceptance of family participation. Fourth, was a reduced tolerance and sensitivity to the psychosocial issues of disability.

We have a magnificent system of health care in this country. The fact that I can stand here before you today is attributable to that fact. Now I am proud to take my place in it as a physician. Through our medical advances, we are giving life to children who in the past died. These children are now entering adult care. They bring new problems to a system that is unfamiliar with childhood disabilities and developmental problems. I believe that our ability to care for the person has fallen short of our capacity to care for the disease. Neither the pediatric nor adult care specialties are at fault. Each needs to adapt, and form collaborative bridges to and from the other. The briefings I read in preparation for this conference are an excellent beginning. They imply a sharing of expertise, and a coordinated transition plan. It was primarily the stark contrast between the two systems of care and abrupt transition that seemed problematic.

**Growing Up and Getting Medical Care:  
Youth With Special Health Care Needs  
Obstacles to Transition from Pediatric to Adult Health Care Systems**

**Daniel V. Schidlow, MD.**



**The Family.** For successful transition to occur, it is very important to include the family in the equation. To a great extent, transition is a family affair and its success depends on the cooperation of those people who constitute the support systems for the individual. Transition truly starts at birth and should continue throughout adolescence into adulthood. Parents should try to endow their children with the necessary tools to achieve independence and self reliance. Emotional dependency on the part of the parents, excessive need for control of the child's behavior and activities, and parental psychopathology mitigates against successful transition. The perception of the disease process as lethal at an early age (even when this is not necessarily accurate) or the perception of the patient as unduly healthy or unduly sick, will hamper efforts to achieve transfer of care effectively. Mistrust in caregivers is also a serious obstacle.

**The Pediatric Caregiver.** This area is one of the most important and essential to successful transition. Many pediatricians who have invested their careers in the care of these patients, see with some apprehension their transfer to a new source of services. They may see it as a serious blow to their economic or programmatic base, their ability to support their health teams and their research and educational activities. Some will allege a "poor return on the investment" of having to help train adult specialists unfamiliar with the disease. They may have no confidence in the ability of their adult colleagues' care for these patients. Some may feel that they have the skills necessary to deal with all aspects of care of a particular disease regardless of the age of the individual. Others may hide a subconscious feeling that the patients indeed have a short life span and change of caregiver is traumatic and unnecessary, or that the adult patients can be comfortably and appropriately cared for in pediatric institutions by pediatric health care teams. The overriding concerns seem to be the economics of losing patient base and the strong emotional bonds between pediatric care givers and patients and their families.

**The receiving end: the adult caregiver.** The adult health care system has not been ready, by and large, to care for these patients. Lack of knowledge of specific disease entities, heightened perceptions of the demands of care, and economic concerns stand in the way of a more receptive attitude. Health care administrators worry about the potential negative impact of undersupported chronic disease programs.

Adult caregivers have insufficient understanding of the nature of congenital diseases and may have a rather "catastrophic" view of their clinical course. It is of interest, however, that the transfer of care from pediatric to adult systems occurs naturally for certain conditions such as diabetes or end-stage renal disease. This fact is possibly related to the degree of expertise already present in these areas in Internal Medicine. This is not, in general, the case with conditions such as congenital heart disease, cystic fibrosis or spina bifida.

The process of transfer from pediatric to adult health care systems is by no means easy and requires effort by all parties. The initiative and leadership must originate, in my view, from the pediatric caregivers and be strongly supported by interested caregivers in the adult health care community. Parallel systems at the tertiary care level as well as in the community need to be structured with the participation of a variety of professionals. Some of the necessary conditions for transition from Pediatric to Adult care are:

- A Pediatric team leader,
- An Adult team Leader,
- Ongoing collaboration and sharing of responsibility,
- Patient and family preparation (coordination of needs with attitudes),
- Team building and communication,
- Administrative and economic planning,
- Interagency collaboration.

For the adult caregiver unfamiliar with the care of chronically ill children and adolescents, but who is interested in helping establish the transitional bridge, this process presents opportunities for professional fulfillment, prestige, research opportunities, career advancement, use of innovative approaches to health care, emotional rewards, and in most cases adequate reimbursement.

It would be naive to expect this process to be simple. On the contrary, it is fraught with difficulties. Emotional and financial issues are closely intertwined and may easily weaken efforts to meet the goals previously described, if not dealt with promptly. Economic support for multidisciplinary care, widespread education and

support of health care activities is still insufficient and more is needed. Insurance coverage for chronically ill individuals attempting to leave the parental home is difficult to get and presents a grave concern. Some states have expanded through their Crippled Children's programs or line items in state budgets to these specific adult programs. The budgets and numbers of these programs are insufficient at this time to cover all the needs of these individuals.

The future brings new challenges and issues of concern. These issues must be faced not only by health caregivers but by the community as a whole, including government, private industry and consumers. Issues for the future include the following:

- Methods to increase the number of transition programs,
- Ways to achieve interagency collaboration,
- Definition of the scope of "over 21 state programs",
- Medical insurance for the young disabled adult,
- Home and community based care,
- Role of state Crippled Children's programs.

Our program at Temple University School of Medicine in Philadelphia, Pennsylvania will be described by Dr. Stanley Fiel later in this meeting. Our experience and that of others indicates that transition is not an impossible task. It is our firm conviction that transition from pediatric to adult health care systems for chronically ill youth is desirable, feasible, and rewarding.

## **Adolescents and Young Adults with Special Health Care Needs: The Challenge for Financing**

**Peggy McManus**

Introduction

Obtaining major medical health insurance -- either private coverage or Medicaid -- for young adults with special health care needs is a very serious problem. It makes the insurance problems of pregnant women, adolescents and chronically ill children look minor.

Today, more than 20% of disabled young adults, ages 19-24, are without any form of health insurance protection at all. Thousands more are insured but without adequate coverage for the services they require. I don't know how many of you have actually attempted to find coverage for someone who is uninsured and has a pre-existing condition. Let me assure you it is not easy. And, unfortunately, in many instances it is impossible, unless the young adult moves to another state, or lands a job with insurance benefits, or becomes more disabled, or pregnant. Still, I believe there are many real financing options that we can take better advantage of now in our own communities and at the federal and state levels.

I am honored to be here to present new findings from our study on adolescent health insurance coverage funded by the Bureau of Maternal and Child health. Briefly, a year and a half ago, Paul Newacheck of the Institute of Health Policy Studies at UCSF, Harriette Fox and I received a three year grant from the Bureau of MCH to analyze the health insurance needs and options for adolescents and young adults.

I will begin my presentation with a few facts on adolescents and young adults who have special health care needs. Next, I will discuss the hypothetical case of Susan, aged 18, with juvenile diabetes -- not unlike the case of John in our agenda materials -- and play out a probable scenario if she were privately insured, publicly insured or uninsured. I will use this case example to show what short and long-term financing improvements might be attempted.

Although there is much to discuss in financing, I am going to limit my presentation to ways in which Susan and John may retain insurance coverage after they lose their "dependent umbrella" under their parents' plans, and also how to get the uninsured Susans and Johns of this world some insurance benefits. I will not be addressing ways to improve benefit plans or reimbursement – two very critical issues.

The major themes I would like to leave you with are these:

We have a serious insurance crisis for young adults with special health care needs and one that cannot be simply solved with what is available today. The major problems are that their access to private or public health insurance plans is very limited - in fact, many refer to this group as medically uninsurable; their premium costs and other cost-sharing requirements are unaffordable considering a typical young adult's income; and finally, once insured, their plans are often woefully inadequate. Consequently, I believe significant reforms in both the private and public sectors will be required to have a significant effect on these problems.

The second theme is that the sooner disabled adolescents and young adults and their families are counseled about their financial options, the better the results will be. The best time is when these young persons are ages 17 or 18, not 20 or 21.

## **Facts**

Who are the disabled adolescents and young adults about whom I will speak? According to the 1984 National Health Interview Survey, they are the 6% of all noninstitutionalized adolescents or nearly 2 million 10-18 year olds (1), and 5% of all young adults or almost 1 1/2 million 19-24 year olds (2) who suffer from chronic conditions that limit their ability to engage in school, extracurricular activities or work. In general, I am speaking about a relatively small population with significant needs for major medical insurance protection.

The leading causes of disability among adolescents, ages 10- 18, according to Paul Newacheck (3) are mental disorders, diseases of the respiratory system, diseases of the musculoskeletal system and connective tissue, diseases of the nervous system, and diseases of the ear and mastoid process (see Table 1). Taken together, these five chronic conditions represented 3/4ths of all disability among noninstitutionalized adolescents in 1984.

Preliminary data on disabled young adults from the 1984 National Health Interview Survey show that diseases of the musculoskeletal system and connective tissue are the leading cause of disability followed by mental disorders, diseases of the respiratory system, nervous system, ear and mastoid process.

What is the insurance status of adolescents and young adults with these chronic disabling conditions? You can see from Table 2 that 14% of disabled adolescents or 270 thousand adolescents and 21% of disabled young adults or 300 thousand young adults are uninsured. Taken together, this represents a little more than 1/2 million young persons without any form of health insurance protection.

Let us look more closely at the population of disabled young adults, on whom we are concentrating today. How do they compare to disabled adolescents? According to Table 2, young adults are 50% more likely to be uninsured. Only 57% are privately insured - 16% fewer than disabled adolescents, and 28% are publicly insured - 27% more than disabled adolescents.

How do disabled young adults compare to nondisabled young adults? They are four times as likely to be publicly insured as their nondisabled counterparts, as shown in Table 2. Notwithstanding, over half of disabled young adults are still privately insured.

What difference does health insurance make for disabled young adults' access to primary care? According to Paul Newacheck (1): "Disabled adolescents without health insurance were almost three times as likely to have delayed seeing a doctor for 2 or more years compared to disabled children with insurance coverage."

## Case Study

Turning from national facts to a real life case example with which we can all identify; Susan is aged 18 and has juvenile diabetes. Looking at Susan in some different financing scenarios, we can review her benefits and predict how financial counseling might be helpful. The choice for Susan who is aged 18, not John who is 21, is intentional because the sooner the young adult and his or her family are counseled, the better the chance of reasonable insurance coverage. Susan is privately insured by her father's group health insurance plan and she will be completing school in June. Her health insurance options will depend upon whether she stays in school, works, gets married, lives at home, or lives on her own.

1. First and foremost: Susan's parents should find out at what age she will lose coverage under her father's plan. In most major medical plans, the magic age is 18 unless the individual is regularly attending school. Susan's parents should also be informed that many employers are even lowering the age of qualified dependents regularly attending school – down from 22 or 23 to 18 or 19.

2. Whether or not Susan goes on to college, her parents have at least one option for keeping her on their plan. It is called the COBRA continuation policy. If Susan's father works for a company with more than 20 employees, he needs to notify his employer within 60 days after Susan's 18th birthday that she will no longer qualify as a dependent and that he wants to purchase the company's group plan for her. Of course, Susan's parents or Susan will have to pay the full cost of the plan – which might come to about \$2,000 per year. This COBRA continuation policy is available for three years. While expensive, no pre-existing condition exclusions can be used and they must offer the same plan as previously available. Moreover such a group plan would be less expensive than a comparable non-group plan.

3. Another option for continuation is as follows: Again, before Susan turns 18, her parents should call their state health insurance commissioner's office or local advocacy group to find out if they reside in a state that has mandated a law which requires that handicapped and financially dependent young adults can remain on their parent's policy. According to a recent Blue Cross survey, 34 states have such a mandate. Under this rule, Susan's parents must notify their employer within 31 days of her loss of dependent coverage or their application will be unsuccessful. This mandate does not apply to employers who self insure, and over 50% are in this category. As you can see, the age of 18 is a very important time for financial counseling for adolescents with special health care needs.

4. If Susan is going to college, even on a part-time basis, she should be encouraged to purchase a student health insurance plan if it is offered, and if she qualifies. In our 1988 college health insurance survey, almost half of all plans had a pre-existing condition exclusion, and another third imposed a waiting period for pre-existing conditions. The rules for preexisting conditions vary. Typically, coverage for treatment of the pre-existing condition is excluded but other ongoing health needs are covered. In addition, many plans have a pre-existing condition waiting period for various lengths of time, commonly 1 year, after which time, coverage will be available. In other words, Susan may need to purchase the insurance for one year so that she can have subsequent coverage. Note: Student health insurance plans are distinct from the student health center services available at most colleges. Student insurance premiums are very inexpensive - about \$250 per year in 1988 (4). As might be anticipated, student health insurance plans vary dramatically in their quality, with state universities and larger colleges offering better plans in general.

5. If Susan is not going to school, she should be encouraged, if at all possible to seek employment on a full-time basis in a medium to large firm. Otherwise, she may be totally incapable of gaining employment based insurance.

6. If Susan cannot continue with her parent's plan, cannot get student health insurance, cannot get employer-sponsored health insurance, then she is in serious difficulty... This, of course, is exactly where our financing system disintegrates for Susan and all the other young adults with special needs in this country. In this instance, she should be advised to contact Blue Cross for information about their open enrollment period, and also contact other large federally qualified HMOs for information about any open enrollment period. This happens only rarely -

at best once a year- and it is not advertised, for obvious reasons.

7. At this point, Susan and her family must begin to develop new investigative skills. Does the state offer a high risk pool? Presumably she would qualify if she can show proof of being rejected from insurance twice. Does the local advocacy group have any other suggestions?

8. As you can see, we have met a very serious private insurance roadblock.

**Let us now put Susan in a different family, one in which she is covered under her mother's Medicaid plan.**

1. If Susan does not go onto college or vocational training she will automatically be dropped from Medicaid as a dependent at the end of her 18th birthday, unless:

-- the state she lives in adopted the Medicaid option to cover adolescents to ages 19, 20, or 21.

2. Even if Susan goes onto college, she will automatically be dropped at age 19 under Medicaid, unless again:

-- the state she lives in adopted the option to cover adolescents to ages 20 or 21.

3. If Susan does not go onto college and works and stays at home or lives on her own, she can attempt to qualify for AFDC or SSI or general assistance under Medicaid. Unless she is pregnant or disabled enough to meet the stringent SSI requirements though, she will not qualify for Medicaid.

4. As you can see, we have met a very serious public insurance roadblock.

**Finally, let us put Susan in another family who is uninsured.**

1. Susan and her family can attempt to qualify for Title V. However, as you know, the financial and diagnostic eligibility criteria are limited. She can also contact her state health department to see if there are any indigent care programs for which she might qualify

2. In the end, Susan must rely on the availability and capacity of publicly funded health services and free care from doctors and hospitals and other community agencies.

3. As you can see, we have met a very serious uninsured roadblock.

**Strategies:**

To address this nettlesome issue of financing strategies at any depth would take an entire conference but briefly, there is no question that we must start counseling disabled young adults and their families no later than age 18 or we all will suffer the consequences.

See Table 3 on insurance strategies. On the private sector side, we must take greater advantage of continuation policies. In addition, it is important to develop high risk pools in every state for the medically uninsurable, as suggested by Harriet Fox (5). Beyond that basic floor, it is evident that some very significant reforms are needed. Suffice it to say we need to have at least one major medical insurance plan that is available to young adults with special health care needs. To assure that such a product is affordable, we can encourage more premium subsidy programs.

In the public sector, our challenges are just as great. Unless we can expand Medicaid to include more than those who currently qualify for AFDC and SSI, we will continue to have a public financing system that does not

serve the needs of disabled young adults, particularly those who are single and living at home. As shown under Table 3, I have listed several possibilities for reform:

- Increasing financial eligibility
- Increasing optional groups
- Mandating for the medically needy
- Targeting general assistance funds
- Expanding SSI

## **FINANCING STRATEGIES FOR DISABLED YOUNG ADULTS**

### Private Sector

1. Encourage greater use of continuation and conversion policies.

-- COBRA: all employers with more than 20 employees

-- State mandate for financially dependent individuals who are mentally or physically handicapped (in 34 states)

2. Offer high risk pools in every state (available in 15 states).

3. Offer premium subsidy programs. (Model: Caring Program sponsored by Blue Cross in Western Pennsylvania)

### Public Sector

4. Expand Medicaid eligibility:

- by increasing the financial eligibility standards,
- by covering additional optional groups (e.g., all children under 21 living in poverty)
- by adopting medically needy coverage in the 14 states without it,
- by targeting general assistance funds for disabled young adults who do not qualify for SSI or AFDC
- by revising SSI disability and financial eligibility criteria (e.g., by eliminating the 209B option, improving the disability listings, amending the resource requirements)

5 Subsidize the purchase of Medicaid for the poor, near poor, small businesses and the uninsurable. (Model: Arizona)

6. Increase support for Title V services to include young adults up to age 25.

As with the premium subsidy programs described under the private sector, it would be most beneficial to allow near-poor families, and families and young adults with high medical expenditures the option of "buying into" Medicaid. Finally, in conjunction with other traditional insurance reforms, it may also be wise to consider expanding Title V's mandate and funding to include young adults with special needs.

Both Susan and John need an insurance plan. Today over 20% of our Susan's and John's do not have any and the likelihood that they could qualify for public or private insurance in the U.S. is minimal. This is something that must be corrected soon in order to increase their chances of a reasonable transition to adulthood.

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## **Staff Training for Transition**

### **Hilary E.C. Millar**

In order that adolescents with special needs may achieve a smooth transition from a Pediatric care setting to an Adult health facility it is essential that plans for staff training should be included in the process. This educational component could be considered in part as a reorientation of existing skills rather than a venture into completely new territory.

From the days of the Children's Bureau, the Maternal and Child Health Program has supported new health initiatives through Title V and related legislation by promoting staff training in all the professional disciplines. The resulting benefits have had wide recognition.

Today, we are a group composed mainly of physicians who have shown concern over the graduation of disabled teens from a children's milieu to an adult health care environment, thus underlining another developmental milestone. It is expected that physicians should take the initiative for planning a logical sequence of events for the implementation of this new focus.

However, it should not be overlooked that much of the success of Pediatric programs for children with disabilities has stemmed from the interdisciplinary team approach adopted in this setting. This inclusion of all staff members has been advantageous for patients, families and staff themselves. A core curriculum shared by trainees of all disciplines provides a solid foundation, and in no way precludes study of special areas of expertise which are best addressed within the single discipline.

### **Who should be trained?**

The Pediatric staff both in the hospital and the community must be willing to relinquish patients with whom they have had a long and eventful association. The briefing format of Internists and other colleagues should be studied so that the history of each young person's medical condition is understood and the current management and medical regime is clear. A willingness to continue support after transition, if this should be needed, requires thinking through before acceptance of this collaborative approach. Also, the preparation of families for this change should be made well in advance of transfer.

Those physicians who will take on the care of the adolescent as an adult will also need

Those physicians who will take on the care of the adolescent as an adult will also need preparation. These will include the principal Internist at the tertiary level who is responsible for the continued planning and assessment for the young person's medical condition. This training should be extended to the wide range of sub-specialists

who may be called upon for special problems. The non-medical health professionals particularly nurses, social workers, psychologists, nutritionists, and therapists for speech and occupation and physical rehabilitation should be included. The staff in the Emergency Room should at least have some briefing about this group of patients who may arrive in a critical condition.

Primary care Providers must be included; these physicians and others may be hospital based, working in community clinics, or active in private practice.

### **What is the content of the training?**

#### **Knowledge**

Internists are likely to be faced with rare disease entities with which they are unfamiliar, as patients with these conditions have in the past rarely emerged beyond the confines of Pediatrics. The inclusion of adolescent health in medical school curricula has been slow, and some senior staff members may not be aware of the accumulated body of knowledge relevant to all teenagers whether disabled or not.

An appropriate core curriculum might be expanded from the following headings:

**Characteristics of Adolescents** - with special emphasis on those factors which affect the uptake of medical care.

**Growth and Development in the Teen Years** - showing the sequence of events and the inappropriateness of chronological distinctions.

**Effect of Teenage Lifestyle** - the possible effects of substance abuse, risk taking, inadequate nutrition, sexuality issues, unsatisfactory family relationships.

**Disease Related Limitations**- particularly in relation to sports, automobile driving, alcohol use, dating, employment, genetic implications.

**Complications of Disease Process** - onset of degenerative processes - physical, mental, and emotional changes.

**Legal Implications** for the care of minors; to include the rights of minors, informed consent, and privacy issues.

**Financial planning.**

**Ability to discuss what teenagers want to know** and not to be limited to traditional areas of health education.

#### **Skills and Methods**

These are directed towards the provision of comprehensive and continuous health care

**Preventive Services** - these should be provided in addition to the monitoring services for the principal illness or condition. This periodic screening might include the following: vision and hearing testings, dental assessment, a full physical evaluation, review of dietary habits, weight-pattern, exercise tolerance and gynecological assessment.

**Health Education** - particularly with reference to the characteristics of the disease - as previously, parents may have been the main recipients of this information. The structure of the health care system, especially the availability of community agencies and facilities. and an overview of the sources of financial support for the

young adult are important topics for the new order.

**Counseling** - this is not necessarily limited to medical matters, as the caregiver should be available to discuss various areas of need, or to make a useful referral to a more knowledgeable resource if more appropriate.

### **Attitudes**

Some physicians cannot tolerate their own perception of teenagers - these individuals might well be helped to examine the cause of their aversion. When young people are thought to be consistently too time consuming, challenging, unappreciative or non-compliant as patients, it is possible that the physician is still working through his/her own adolescent difficulties. On the other hand, the older physician may be experiencing problems with his own children and the patient's behavior may be an unpleasant reminder of what takes place in his own home.

Professional attitudes may be conveyed during any interaction with young patients through verbal communication or general manner. It may be necessary to discuss areas which are highly sensitive; previously these issues may have been shared with the parents alone, excluding the adolescent. It is important to listen and not to appear to control the dialogue. An assessment of a young person's powers of comprehension will help to eliminate misunderstanding, and in any case use of technical terms and jargon is best limited to a minimum. It is desirable to avoid behavior which suggests a condescending or patronizing attitude, and at the same time it is usually helpful to retain a measure of professional identity.

### **Inclusion of Parents and Family**

Parents may reflect their long association with the health care system and feel they know a great deal about their son's or daughter's condition. Provided that the young person agrees, parents should continue to be included in discussions of new information and further decision making. They may be paying medical bills, and providing board, lodging and tuition as well as giving highly valuable general support. Even when relationships within the family are poor or missing altogether, this bond is of central importance to the young disabled person - the family is usually the main source of emotional and economic support. Parents have lived through many crises in raising a child with a disability; these have occurred at birth, at school entrance, and at puberty in addition to the periods of stress when active surgery or other treatments were needed. Now the child's assumption of responsibility for his own medical care may be seen as threatening, and a development for which there has been little preparation.

### **Methodology**

The successful implementation of a training program depends upon the answers to the following questions:

1. What is the objective of the training?
2. Has the process of transition and subsequent services been agreed and documented?
3. Who will provide the training?
4. Will there be joint sessions to include the Internists, Pediatricians, and other involved groups?
5. What is the curriculum?
6. Will there be study days, short courses or continuous in-service training?
7. Will training be conducted in their institution, community based, statewide, or at a regional level?
8. Will the training program be evaluated?

## **Conclusion**

The time has come to implement the process of transition. There will be various models and approaches to meet the needs of existing programs. Training of staff should be discussed and developed early so that staff who participate in this transfer of care are fully prepared.

## **Section II**

Growing Up and Getting Medical Care:  
Youth with Special Health Care Needs

Case Study and Response

### **Case Study.**

To illustrate the issues related to growing up with special health care needs, this case study was prepared. It is a composite of many young people and many conditions. The medical condition is left unspecified, since the issues cut across diagnosis and symptomatology.

John is a twenty one year old male who has suffered from a chronic medical condition since he was two years old. At that time, he had an acute onset, requiring prolonged hospitalization. In the intervening years, he has needed numerous special treatments that have interfered with school attendance and the normal childhood business of playing, joining sports teams, and exploring the world. He has had several surgeries that have left large, visible scars. John has also had some mild learning problems in school and has always been viewed as impulsive and immature by his parents and teachers.

John's adolescent years have been difficult for him. While he has been relatively healthy, considering his condition, he still has been constantly reminded of his problem by regular visits to the local tertiary hospital specialty clinic. He has no primary care physician and has not since his problems began. In addition, he must take medication daily and cannot engage in vigorous contact sports. Like many young people with chronic medical conditions, John's condition and the drugs used to treat it have delayed the onset of puberty. In junior high and high school he was much smaller than the other boys and undeveloped. This resulted in suffering a lot of physical intimidation from his peers (being stuffed in his locker, etc.) embarrassment in gym class and social ostracism. Girls were also not interested in dating a "little boy." His depression, impulsivity and immaturity affected his behavior so that he was further ostracized. John particularly hated when peers noticed his scars and asked about them. Sometimes he told them he got them in a knife fight to make himself seem less vulnerable. John was actively involved in scouting, at his father's insistence. He achieved the rank of Eagle Scout in order to please his father.

His parents continued to attend his doctors appointments. His caregivers felt that he was immature and irresponsible and looked to his parents to make decisions and to ensure that he followed their recommendations. In addition, afraid that he would not take his medicine, his mother either made him take it in front of her or counted the pills left in the bottles. John never asked to have the medications refilled, but his mother kept track and went to the pharmacy. John's father felt stuck in his job, but did not change, because that would have left the family, and thus John, uninsured for preexisting conditions for a nine month period. John's mother, after years of devoting herself to his care, returned to work during his adolescence. She only worked part time however, because he needed her help with school homework. John learned to drive and got his license, but wasn't allowed to go to many of the places his younger sister went, because his mother told him he would get lost going someplace new. This was also the reason he was not allowed to drive to his medical appointments alone.

John graduated from high school and entered a state college. He had never been away from home alone before, since in all his scouting activities his father had come along. He still looked like a thirteen or fourteen year old. John's roommate turned out to be a good looking, athletic boy who was very popular with the girls and had drinking parties in their room late into the night. John needed more sleep than most people his age and this was hard on him. John was determined to be socially accepted at college. He thus began to drink heavily and party every night. He also began smoking cigarettes and briefly experimented with drugs. He was unable to organize his work and was taking his medication sporadically. In part this was due to his disorganization; in part, to his belief that he was a special case that did not need this medicine. Two months later he had to go home, severely depressed and suicidal.

Currently, John is living with his parents. There is serious conflict among them and he longs to move out. He is working 30 to 40 hours a week at a fast food restaurant and going to the local junior college. His grades are poor and he feels that he needs time off from school to get clear about his goals. John is looking for a job with good health insurance benefits, because if he leaves home and quits school he will lose his parents' insurance coverage. He does not even focus on whether he will like the job. Unfortunately, he has not been able to keep a job long enough to qualify for benefits. In one case, he was fired for suspicious reasons shortly before he was to go onto the benefit package of the company.

In the past two years, John has begun to grow and looks more his age. This has led to more success with girls and he is dating someone special right now. He worries that he will not be able to support her and that she may not want a long term involvement with someone with his health problems. John looks forward to having a family of his own. He has no idea if his condition can be inherited, since the physicians figured he was too young to worry about that issue.

Recently John has had an exacerbation of his condition. Because the hospital clinic had decided he should go to the adult clinic now that he was twenty-one, John met with the adult specialist. He became quite upset when the physician told him that he would shortly need more intense medical intervention. He was confused about what had happened and did not understand many of the terms the physician used to explain it to him. When he asked for clarification, his physician became angry, saying he was "playing games." John went home and asked his mother to explain it all to him, since he hadn't really paid attention in these past few years to what the doctors had been saying. He then felt very depressed, realizing that his failure to take responsibility for his care and his not taking his medicine to "get back" at his mother had been very self-destructive.

John represents the challenges to us all in making growing up with special health care needs less painful. While John and his family have many needs, the health care system can help a great deal by rethinking how we serve these young people and their families.

## **Responses To The Case Study**

Panel Members:

Merle McPherson, MD.

Kenneth Whittington, M.D.

Arthur Elster, M.D.

Hilary Millar, M.D.

This case study presents many of the problems experienced by adolescents and their families at the time of transition. John's small stature, delayed puberty, and immature behavior represent difficulties above and beyond

his primary medical condition. In addition to these adverse characteristics, John was probably acutely conscious of his inability to fit into the social scene with his contemporaries. In their efforts to be supportive, the parents had become unduly controlling of all of John's activities, including his medical care, and were thus delaying his assumption of adult responsibilities even further. The health care system had failed to provide appropriate counseling to John or his parents.

The panel were unanimous in their response to John's predicament. They felt that in spite of continuous monitoring at the tertiary level, John and his family lacked the presence of a primary care physician. Dr. Whittington commented, "The family physician should be the quarterback of the team — working with the entire family, while giving the appropriate treatment or helping the family find the expertise needed: then guiding the process so that medical problems do not 'fall in the crack' of one physician thinking the other is providing certain services." Dr. Whittington expanded the role of the primary care physician to one who fulfills critical needs such as teaching, instruction, and listening.

The absence of appropriate orientation and training of health care professionals involved was evident throughout. There was no clear plan for John's transfer from the pediatric service to adult care and in the event movement was fragmented and disorganized. There is no record of discussions and advice about unacceptable behavior. Decisions about John's further education and employment appear haphazard and not part of the overall agenda for John's future. It appears that everyone talked around John and not to him. Dr. Whittington of the American Academy of Family Physicians remarked: "It only takes a moment of reflection to see how divisive this is for everyone involved. I start directing my conversation to young patients, rather than to whomever brought them, much earlier in my practice."

The lack of early and timely financial counseling compounded this family's numerous difficulties. Dr. McPherson of Maternal and Child Health outlined the services which should have been provided for John and paid for through an ideal insurance scheme:

- Team care to cover counseling, health education, and financial advice.
- Case management with periodic review.
- Coordination of services.
- Medical supplies and adaptive equipment.
- Primary care.
- Therapies for rehabilitation.
- Coverage for excessive costs of a pre-existing condition, major medical expenses, and catastrophic complications.

Dr. McPherson stressed the point that these essential services must be available within the health system, and individual young people must be protected through solid insurance plans which are guaranteed to cover the service components which are deemed necessary. Only when the services are accessible, and there is an adequate provision for payment, will we have a program for young disabled people of which we can be proud.

From the information provided it appears that staff had not been exposed to local or national post-graduate training efforts about transition of care. There is evidence that communication between pediatrician and internist was sketchy and incomplete.

Dr. Arthur B. Elster of the American Medical Association summed up the medical deficiencies portrayed in this case history in these words:

"The passage through adolescence is fraught with medical and social hazards. Physicians are trained to deal with the former issues, but usually not the latter. Because of the often co-occurrence of both medical and social disorders, physicians have been increasingly asked by educators and society to assume a greater role in assisting adolescents with the myriad of issues they face. Key to the management of adolescent health therefore, is having the knowledge and ability to both deliver primary care, and to help organize care among various types of health, social service and educational systems.

"Adolescents who have a disability present even a greater challenge for the primary care physician. This is especially true when the disability is one that has required intensive management by a tertiary care specialist. These young people not only often remain under the medical supervision of that specialist, but they and their parents form strong emotional ties to him and the hospital care unit. Providing primary care and organizing for the broad health needs of young adults in this situation can be difficult.

"The transfer of care from a pediatric to an adult medicine setting can only work when all involved parties cooperate. The youth, their parents, the pediatric and adult services, primary care providers and specialists must all play a role in the transition process. This process should work best if the complex medical, emotional and social needs of youth have been properly addressed prior to the transition."

### **Section III**

#### Description of Models of Programs Where Successful Transition Has Taken Place

There are many obstacles to be overcome in the provision of painless transition of adolescents from pediatric units or children's hospitals to an adult health service. Care in a unit which caters only to children tends to be holistic in approach, to depend upon an interdisciplinary team, and to emphasize developmental progress. Adult-focused units have traditionally been oriented toward the management of the medical condition. Although there has always been an interest in keeping patients out of hospital and active in the work force, knowledge of the psychosocial and domestic background of the patient population has been less of a priority. It is necessary for young people to learn to manage their lives and their medical conditions with less automatic support, but this change should come gradually and with due preparation. Young patients must not feel abandoned; they should know that when a crisis arises, and this is not often a life threatening occasion, there are staff around who can and will help. It is not only the pediatric staff who can respond to phases of depression, family disputes or other practical and theoretical problems which from time to time confront all of us. There are several programs around the country which have taken successful steps to make an interface between the two patient populations - these are adults and children, defined at present in chronological forms.

In Philadelphia, patients with cystic fibrosis have been able to move from the Children's Hospital chest clinic to the pulmonary disease section at Temple University Hospital without loss of confidence in the process. Dr. Stanley Fiel describes how this coordination of care has been achieved.

Another method of sequencing pediatric and adult services was initiated in New York City, and has been functioning well for over a decade. Cornell University Hospital and Mount Sinai Medical Center both concentrate on the comprehensive care of hemophiliacs in their departments of hematology. The life span for hemophiliacs, as with those who have cystic fibrosis has been extended to a remarkable extent. This has led to a need to graduate teenage patients to an adult setting to make time and space for the younger new enrollees. The desirability of greater autonomy for teenage hemophiliacs makes care in an adult setting a logical goal. Dr. Louis Aledort has provided an account of how these two programs attained this desired result.

Dr. Patience White presented a description of the evolution of programs for children and young people who have rheumatoid arthritis. This new field is likely to have a shortage of medical specialists for some time to come. Studies of this population have shown that adolescents with Juvenile Rheumatoid Arthritis are at risk for underemployment and do not, as a rule, receive adequate pre-vocational guidance.

It was fortuitous that two colleagues from the Netherlands were visiting the United States at this time, and were able to accept an invitation to speak at this conference. Their paper made a valuable addition to the program, and served to broaden the horizon to include international developments. Both Dr. Kuis and Dr. Sinnema have had considerable experience in the provision of care for adolescents with long term medical conditions. Their paper emphasizes the importance of support and encouragement in every aspect of life, and describes the

standard services to promote independent living, continuing education, and vocational training. A short account of the Dutch health care system is included to brief the audience about available medical services and the prevailing medical insurance legislation

Two brief case histories are cited to illustrate some of the difficulties of transition. The similarity between these problems in the Netherlands and those in the U.S.A. points out the universality of the issues regardless of the country or continent involved.

We were left with the certainty that health professionals in the Netherlands have made a firm commitment to support disabled young people through transition. Their strategies include social, educational, and vocational preparation to ensure that this group of young people will be able to function according to their maximal potential in an adult society. These efforts in the Netherlands form a part of the legislative framework for a coherent policy on the rehabilitation and social integration of disabled people as formulated by the Council of Europe in 1988.

## **Transitioning of Patients from Pediatric to Adult Care**

### **Stanley Fiel, M.D.**

As a result of improvements in medical technology, many patients with chronic pediatric conditions are now living well into adulthood. The adult health-care system, however, has not been ready or, in many instances, willing to take on these patients because of a lack of knowledge of the diseases. Patients themselves have been reluctant to move to the adult health-care system because it would mean giving up the familiar atmosphere of the pediatric setting and the multiplicity of services that have typified pediatric care. Nonetheless, remaining in the pediatric setting may rob these patients of their developing independence as well as deprive them of appropriate subspecialty care by those familiar with adult medical issues.

In our project, cystic fibrosis was the prototype disease for the transition from pediatric to adult care. Cystic fibrosis is the most lethal genetic disease of the Caucasian population, with a genetic rate of about 1 in 2,000 and approximately 35,000 patients in the United States. Our program is based at a university hospital with a pediatric affiliate. Our total CF population is 350 patients; almost one-third of these patients are 18 or older.

The magnitude of the transition problem can be seen from the current survival data. The median survival today is 26 years; about one-third of all patients in CF centers are adults (i.e., older than 18). Many internists and other adult-care practitioners are not knowledgeable in the disease, nor do they necessarily feel an obligation to care for these patients. By choice or default, pediatricians often remain responsible for the care of CF patients who are moving into adulthood. Yet the pediatric health-care system by definition is not equipped to deal with the medical or psychosocial issues involved.

Following is a distillation of our practical experience in developing a transition program for a group of CF pediatric patients who were ready and willing, with the proper support, to take on adult independence and relative self-sufficiency.

In developing a transition program, a few preliminary steps are crucial. The hospital administration must first agree to the concept of admitting these patients to the adult hospital. Sufficient faculty backup must be assured, and agreement of the department chairmen must be secured so that allocation of physician time may be planned. Finally, a transition team must be recruited and trained.

The critical elements in making the transition work are these: (1) There must be a practicable fiscal policy geared to admitting these patients. (2) There must be a strong nurse coordinator who can bridge the gap from the pediatric to the adult side. (3) There must be adequate training of the team members, since most of the adult team will have little knowledge of the pediatric disease. (4) The pediatricians must be properly oriented to the transition: if the pediatric side is not completely in agreement with the program, they can undermine it by not

transition, if the pediatric side is not completely in agreement with the program, they can undermine it by not preparing their patients properly for the transition.

In our project the adult team concept was a success. The patients' attitudes have been excellent, and there have been essentially no problems in transfer of care to an adult institution. We presently see all patients at the adult hospital. At intervals the adult team confers with the pediatricians on those patients who are 16-18 and are getting ready for transition. Pediatricians and internists have privileges at each other's institutions, and there is ready communication about patient-care issues.

Not all has been smooth sailing, however. Among the more considerable difficulties has been the recruitment and training of a team whose members are willing to do a particular job for a small proportion of their overall time. We have dealt with this problem by buying time from our team's respective disciplines. Another major hurdle has been the financing of the project. In Pennsylvania, if it were not for a state-supported "over 21" program as well as an MCH SPRANS grant to help support our team, we would not have been able to get our project off the ground. The hospital administration continually forces us to demonstrate that these patients are not depriving the hospital of revenue; because a DRG-based system is used in adult hospitals, patients with chronic disabilities give poor payer returns

There is an additional aspect to the economic problem, and that is the pediatricians themselves. There is a general feeling among them that relinquishing the care of adult patients will result in an unacceptable economic loss.

When beginning a transition program, then, the financial questions to be considered may be summarized as follows: Is there a state program of support for chronically ill patients over 21? What is the payer mix of the population at hand? What is the DRG for the disease? What is the length of stay and resource allocation for this patient population? Notwithstanding the payer mix that exists in the overall group, if the payer mix for hospitalizations (for a one-year period) and use of resources is weighted toward the uninsured, the program may fail.

One of our goals was to evaluate the generalizability of our demonstration project. We are hopeful that transition programs for patients with other diseases such as chronic heart disease, chronic renal disease, sickle cell anemia, hemophilia, and spine bifida -- will benefit from the example of our model and the lessons we have learned.

One of these lessons I have saved for last. It is no doubt the most important one. Simply put, it is that a transition program can have everything in place -- the financial resources, the institutional commitment, the interinstitutional cooperation -- and still not work if the team fails to earn the confidence of the patients. Our own success in doing so, not without struggle, has been a source of gratification and pride.

## **The Hemophilia Model**

### **Louis Aledort, M.D.**

Hemophilia is a life-long, genetic, congenital disease of low density incidence. It is characterized by bleeding which may be external or internal and may occur spontaneously or following trauma.

As early as the 1960's there was recognition that the provision of comprehensive care for hemophiliacs required the services of a multidisciplinary team. The ultimate goal for the team effort remains the education of the patient for self advocacy.

At this time, several other events took place concomitantly; the discovery of cryoprecipitate was followed rapidly by the availability of Lyophilized forms of Factor VIII and IX. The doses of these life-saving blood clotting

adjutants were available in a much smaller volume than for the whole blood or plasma used previously; which enabled patients to use self-infusion methods at home.

The team centered around the hematologist but included colleagues from other medical disciplines, perhaps most frequently the oral surgeon, the orthopedist, the neurologist and the general surgeon. Support from the non-medical disciplines included nursing staff, social workers, and physiotherapists. Vocational rehabilitation was increasingly necessary as life expectancy extended. Financial counseling became a vital resource as frequently the ability to pay for care was overtaken by the high cost of product usage to control hemorrhage.

Initially, care for hemophiliacs was provided on a voluntary basis. There was little or no support from the established centers, and the provision of the new blood products ran at a loss. Once the blood products were fully available, underwriting by third party payers (with open enrollment) or through state funding became a reasonable possibility.

The Hemophilia Act of 1975 formulated a National Blood Policy. The Act required that a network of interrelated centers be developed which would emphasize outreach methods, transportation where catchment areas covered long distances, communication with primary physicians, and utilization of community resources.

In New York City a consortium was funded. To optimize staff and be cost effective it was decided that Cornell would serve mainly children, and Mount Sinai would focus, as previously, mainly on the adult hemophiliacs. This cooperative effort has worked well and served as a model. In addition, at both centers, adult and pediatric patients are seen at the same place and by the same staff team.

Additional progress has taken place in the last decade which includes:

- Blood products can now be purchased by the Region which represents a cut in cost for the Public Health Service and Third Party Payers.
- Increased research efforts in areas such as "Family Intervention" are being carried out by NHLBI.
- Attempts to strengthen the program in underserved areas.
- Additional staff training is taking place nationally and outside the United States.

When the AIDS epidemic was recognized, hemophiliacs were at high risk for becoming HIV positive and in some cases developing the clinical findings of the disease. It has been found that 70% of Factor VIII deficient patients, 50% of Factor IX patients, and 20% of single donor products have positive blood tests for AIDS. The hemophilia centers were well poised to handle this major complication. The medical, psychosocial, educational and sexual needs and concerns of patients were already receiving regular review by trained and empathetic staff. Therefore the mechanism for counseling patients about this new health threat was already in place and functioning well.

The low density distribution of hemophilia has led to regionalization and development of pockets of expertise. These centers have provided care and the means to support that care. However, a series of events has occurred which threatens the existence of these programs.

a) The out-of-pocket expenses caused by the cost of the new safer blood products have increased

b) The goal of chronic disease is to concentrate services into regionalized clusters. However, this system may bring its own problems within the regional institutions. Attention should be refocused on ways to reinforce hospital commitment.

i) Major Medical lifetime caps for those who have them will be reached in 10-15 years. Current Medicaid payments do not recognize these new products, and the 20% uncovered portion reaches \$12-14,000 per year. The catastrophic coverage, soon to be implemented, does not cover in-patient medications.

ii) Institutions previously committed to large numbers of hemophilia patients are rethinking their position. DRGS do not take into account large clusters of high cost patients in a given hospital, and the phenomenon has occurred with the regionalization process. Losses on blood products for in-patients can be as high as \$100,000 per patient for a given DRG even without an increased length of stay.

iii) The challenge to the team of managing the previously emancipated adolescent, now isolated because of HIV infection, plus a burgeoning sexuality is far from met, and if solved will serve as a model not only for other chronic diseases, but to all concerned with HIV transmission.

## **Young People With Rheumatoid Arthritis**

### **Patience White, M.D.**

Juvenile Rheumatoid Arthritis is a difficult disease to diagnose and the diagnosis is made by excluding other causes of arthritis in a child with swollen joints for longer than six weeks. The prevalence of arthritis is 2.211,000 (1) in the U.S., but many other conditions have arthritis as a component of the illness so the prevalence of Juvenile Rheumatoid Arthritis in the U.S. is estimated to be between 135,000 to 200,000 children. The prognosis of JRA depends on the severity of the disease. The course of the disease for the majority of cases is one of disease activity interwoven with periods of remission and approximately 10% go on to serious functional deterioration. Mortality is rare and almost all children survive into adulthood. Until the early 1980's, the majority of children with JRA were cared for by adult rheumatologists, pediatricians, or nonrheumatologic pediatric specialists, few of which offered a team care approach. In 1976, there were 27 pediatric rheumatologists with only 17 of 128 US medical schools employing a pediatric rheumatologist (2).

In the early 1980's, the Bureau of Maternal and Child Health under the leadership of Dr. Merle McPherson established at least ten Pediatric Rheumatology Comprehensive Care Centers. By 1986, there were 103 pediatric rheumatologists with 57 medical schools employing a pediatric rheumatologist. The establishment of these centers increased the number of children correctly diagnosed, and improved the availability of comprehensive care from a team of health care providers. During six weeks in 1986 the seven MCH funded centers completed a database on over 1100 visits to their main and outreach clinics (3). At this time, comparisons were made between prior diagnosis, and diagnosis at the Rheumatology Center; 20% of the children were given a definite rheumatic diagnosis for the first time, and a further 20% of children were found to be unaffected by connective tissue disease. Thus, over 40% of the population had a changed diagnosis after review by a pediatric rheumatologist. Similarly, the rate of referral among this population to occupational and physical therapists and social workers increased by 35% after assessment at a pediatric Rheumatology center. Despite this improved care, there are not enough pediatric rheumatologists to cover the US and its medical schools. Large areas of the US do not have a pediatric rheumatologist and due to the small number of training programs, it would take over 10 years to train enough pediatric rheumatologists to have one in each medical school (4). Thus, these comprehensive centers must continue to educate pediatricians, internists, family practitioners and adult rheumatologists to improve the care of children with arthritis. Better communication about diagnosis and comprehensive management through family centered team care must be achieved since many children will be cared for by a non-pediatric rheumatologist in the next decade.

One lesson I have learned from young adolescents with juvenile arthritis came in the area of vocational readiness. As both an internist and a pediatrician, I travel back and forth between the adult and pediatric hospitals. In the adult clinic I would ask what jobs people were doing and in the pediatric clinic how school was progressing. I noted that many of the young adults with arthritis who had graduated into my adult clinic from the pediatric clinic did not have a job and a few had had a summer job experience. This observation led me to discover that 50 to 75% of young adults with disabilities are jobless. Of those not working, sixty-seven percent wanted to work and of those working seventy-five percent were working part-time which often resulted in poor health care benefits. In the United States, the availability of prevocational programs is the responsibility of the Special Education Department; however, further investigation revealed the following information:

1. Only 21% of 300,000 students leaving special education programs become fully employed.
2. Only 31% of those in special education have vocational planning as part of their individual education plan.
3. The high school dropout rate of those in special education is five times greater than those in regular education.
4. Most federally funded vocational rehabilitation programs Will not provide services to young people under 18 years of age.
5. Most children with disabilities are not in special education and therefore receive no vocational counseling. Often these children are away from school seeing their physicians during vocational or home economics classes so they will not miss any major classes such as math or English.

Thus through funding by the Division of Maternal and Child health, an Adolescent Employment Readiness Center at Children's Hospital National Medical Center in Washington, D.C. was developed where prevocational counseling is offered within a tertiary pediatric hospital to all children with a chronic physical disability. The program offers job exploration, job readiness sessions, and help in obtaining summer job experiences. Educational sessions are offered such as a Parent and Adolescent Vocational Day and an advocacy training course for parents. There is a research component of the study which is evaluating the efficacy of the program. As part of the research over 60 chronically disabled adolescents have completed the nationally normed, age-matched, Career Maturity Inventory (5) which categorizes attitudes about work. To date children with neurologic conditions such as spine bifida and epilepsy have mean scores in the 30th percentile, those with non-neurologic conditions such as juvenile arthritis and cystic fibrosis have mean scores in the 40th percentile, both were below the national norm of the 50th percentile. These two groups, the neurologic and non neurologic, were similar in age, sex, socioeconomic and functional status and work experience. A very surprising difference was the age at which the parents felt their children would be ready to work; for the neurologic group - age 17, for the non neurologic group - age 14. Thus parental expectations may play a major role in the career maturity of children with chronic physical disabilities (6).

There are many lessons to be learned from the development of the new field of pediatric rheumatology: foremost the shortage of specialists in this field necessitates a high level of collaboration between pediatricians, adult rheumatologists and other specialists at least during the next decade; also, a new area of career immaturity has been identified, and this will require careful consideration by all who care for young people with chronic disabilities if they are to be productive contributors to society.

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## **Issues of Adolescent Transition in the Netherlands**

**Wietse Kuis, M.D.**  
**Gerben Sinnema, Ph.D.**

In the Dutch Health Care System, the general practitioner (GP) plays an essential role. Every Dutch resident has his/her own GP and referrals to the second or third level of health care can only be made by the GP. In Table 1 an overview of health care facilities is presented, as well as a list of special schools and facilities like home adjustments. Table 2 shows the three levels of care and their benefits. In the ideal health care system there exists a perfect coordination between these three levels of care. For chronic diseases, referrals to the second or third level should not be delayed and for rare diseases multidisciplinary teams in university (children's) hospitals deliver comprehensive care for these children with long-term medical conditions. However, in the Dutch health care system the coordination between the different levels of care is often deficient (Table 3).

A crucial issue is the financing of the health care system. The costs of health care are about 8.6% of the gross national product. As a principle everybody is ensured. Employees with an income below \$20,000 are ensured under the Sickness Benefits Act (1964) and are entitled to get prescriptions, treatment and nursing in a hospital, a stay in a rehabilitation center or other medical institution for a maximum period of 52 weeks. Included also are special services like physical therapy, speech and hearing therapy. Persons with an income over \$20,000 need a private insurance.

Besides the Sickness Benefits Funds and the private insurances, all residents in the Netherlands, regardless of their age or social status, are covered by the Exceptional Medical Expenses Insurance Act. Payments are made under the act in cases where lengthy, costly, intensive or other special treatment, or nursing care are necessary for long-term patients, disabled persons, mentally disturbed persons, elderly individuals who are physically or mentally ill and persons with chronic diseases like cancer, rheumatism, etc. This act, together with another act - the General Disablement Benefits Act- has stimulated advances in medical and social rehabilitation of the disabled.

## **Difficulties in the Transition of Chronically Ill Youth to Adult Health Care**

Mortality rates for many chronic pediatric conditions have decreased because of improved care. As a result, many patients with chronic pediatric conditions are now living into adulthood. For many of these chronic diseases multidisciplinary (highly specialized) teams have been formed in (university) pediatric centers. The transition of patients from this type of care to the adult health care system is frequently problematic. To illustrate this, two examples are given.

Patient I, Frans, a boy born 03-23-71 has a crippling form of Juvenile Chronic Arthritis since 18 months of age and was referred to our hospital at the age of 14 years. He was completely wheelchair-dependent and there was still a persistent, polyarticular arthritis. A multidisciplinary team consisting of pediatricians, physical therapists, an orthopedic surgeon and a clinical psychologist developed a treatment plan. Drug treatment, physical therapy and orthopedic operations including total hip replacement, were necessary to improve his condition. In the beginning, he was very depressed and needed a lot of support to undergo the necessary operations and the physical therapy thereafter. He is now seventeen and usually of an even temperament. Although his clinical condition is much better (ability to walk), he still has to undergo some major surgical procedures. He remains a rather dependent boy and has not yet finished his schooling. In the near future he will continue to need much support.

The decision to refer him to an adult rheumatologist is difficult to make because:

- there is a strong emotional bond between the boy (as well as his parents) and the Pediatric multidisciplinary team.
- he still needs psychosocial support and even in the very developed adult centers there is a paucity of caregivers.
- he has not finished his schooling; in adult centers there are no school facilities.

So, we still hesitate to refer this boy to an adult center although in some aspects he has grown up and no longer fits into a pediatric setting.

Patient II, Jacqueline, a girl born 12-31-68, has a seropositive polyarticular juvenile chronic arthritis. At the age of fourteen, she was completely wheelchair-dependent and after very intensive treatment for years we succeeded in getting her in a rather favorable clinical condition. One of the problems with this girl was that she and her family were strongly focused on her physical well-being. There was hardly any time and energy for her development of independence and for her educational career. Her emotional status, however, improved considerably: from a socially isolated and extremely depressed girl with a low self-esteem and a negative body image, she developed into a teenager with a re-established trust in people, with quite a lot of fighting spirit and an improved body image. She is volunteering at a kindergarten now, and preparing herself for adult education. However, these developmental gains are rather unstable. Jacqueline strongly feels she still cannot cope without the support of the members of the pediatric team.

Although in this case there are no plans for major surgical interventions in the near future, she still needs a lot of psychosocial support. One of the possibilities for this girl is to place her in one of the special vocational training centers for adolescents with chronic diseases or disabilities and, with regard to the medical care, refer her to an adult center. However, until now she has refused transition to adult health care.

For young people like Frans and Jacqueline a successful transition from adolescence to adulthood implies that they "will take as active a part as possible...in every sphere of life...and will achieve full development within their possibilities" (Council of Europe, 1988, (1)). This broad objective is based on the idea that disabled people are part of the community and must be recognized and accepted as full members. It is a fundamental issue in the Dutch federal policy that disabled people must be enabled to use as much as possible the general facilities and arrangements open to the entire public. In addition, however, special facilities and services have been created in order to meet the needs of disabled youth and young adults who face the difficult task of getting "a start in society". These facilities and services focus on independent living, education, vocational training, employment, and social integration.

**Independent living.** Some 30 years ago - on a one night TV charity show - the Dutch people raised the money to build a village in the woods where physically handicapped people could live on their own - together, but apart from the community of "healthy people". Nowadays, the philosophy has fundamentally changed: a physical handicap as such may never be an impediment to live in the community of one's own choice. Dwelling adaptation on an individual basis is financially supported by local or federal authorities. Administrative regulations are sometimes complicated and time-consuming, but in the end the money will always be provided. In addition to the possibility of individual dwelling adaptation, there are specific housing projects for (young) people with serious physical handicaps. Such a project ("cluster") consists of 12 to 15 houses with an assistance unit in the immediate vicinity. Assistance is supplied for daily functions, such as provision of meals, bathing, and dressing. In June 1987, 27 cluster projects were in operation and 10 projects were still under construction.

**Education.** In general, chronically ill or handicapped adolescents are supported to stay in the mainstream of regular education as long as possible. Secondary schools for special education are divided into fourteen different types, according to the nature of the disabilities. Special education is supplied for:

- deaf youngsters;
- adolescents who are hard-of-hearing;
- adolescents with serious speech troubles;

- adolescents with serious speech troubles;
- blind youngsters;
- adolescents with poor eyesight;
- physically disabled youngsters;
- adolescents who are in a hospital for a period longer than two weeks;
- youngsters with chronic diseases;
- slow learning adolescents;
- adolescents with normal intelligence who have learning difficulties and behavioral problems;
- adolescents with severe behavioral problems;
- multiply disabled children
- adolescents who are residents of specific institutes.

Local authorities are obliged to take care of transport of pupils to school. Before admittance to a special school, a thorough physical, psychological, social and educational assessment is made. However, there are no (official) specific services for long-term educational counseling. The privately funded Foundation for Education and Disability fills in a part of this gap.

**Vocational training.** Schools for special education generally try to prepare their pupils for a place in society. Often, however, this turns out to be insufficient: the individual development of independence may be delayed, and the labour market is not awaiting youngsters with special health care needs. There are several facilities for support:

1. Rehabilitation centers and hospitals frequently have social services to serve specific vocational training opportunities.
2. The privately funded Organization for Chronically Sick Children and Young People gives personal guidance and informs schools or employers about the potentials and constraints of the young people in question.
3. Regular employment offices have special placement consultants who can negotiate between the handicapped young adult and a possible employer.
4. In institutes for vocational training and rehabilitation young people can live for one to two years to acquire special skills. In "Hoensbroeck" 150 trainees, aged 18-40 years, can choose between courses on fine metal, electronics, technical design and administration. In "Werkenrode" 30 trainees, aged 16-25 years, can choose between printing trade administration and horticulture. Of course, physical and psychosocial treatment is supplied as an integral part of the vocational training.

**Employment.** Rates of unemployment are regrettably high in the Netherlands. In the total population of young adults aged 19-23 years 26% are unemployed. For young adults with a disability the estimates are as high as 65-80%. Counseling by a special placement consultant proves to be effective, as 46% of the young adults can be provided a job. After vocational training in a center like "Hoensbroeck" or "Werkenrode", even 67-72% of the young adults get employed.

Because of the extreme difficulties facing disabled (young) people to conquer or to keep a place on the labour market, politicians are now discussing the moral or legal obligation for employers to have a fixed percentage of disabled people in their organizations. Government, employers and trade-unions try to reach "gentlemen's agreements" as they fear that employment enforced by law would not work out. Well-to-do companies might prefer to pay the penalties for non compliance. For the different branches of industry and government services, specific regulations about quota (3-7%) and about financial compensations are under way now.

**Social rehabilitation and integration.** In the realm of social integration the role of lay organizations, such as associations for people with a particular disease or handicap, is becoming more and more important. These associations offer information to patients, parents, schools, employers and the public in general, and often provide networks of social support. Some patient organizations are quite successful as political pressure-groups. Basic issues in the process of social integration are autonomy and independence, mobility, accessibility of

Basic issues in the process of social integration are autonomy and independence, mobility, accessibility of public buildings, means of transport and communication facilities, and opportunities for leisure activities and holidays.

In the last few years, young people (ages 15-30 years) with a visible or an invisible handicap have their own association ("Jopla") to fight jointly for their legitimate rights.

**A European strategy.** The Netherlands are a part of the European Community. The Council of Europe (the European parliament) established on May 5th 1949, has today twenty-one member states. Until now, thirteen states have agreed upon a legislative framework for a coherent policy on the rehabilitation and social integration of disabled people (I. Council of Europe, 1988) These states are Austria, Belgium, Cyprus, France, Federal Republic of Germany, Italy, Luxembourg, the Netherlands, Portugal, United Kingdom of Great Britain and Northern Ireland, Spain Sweden and Switzerland. There is still a long way to go and surely the process is going on often too slowly, but the forces to join hands in giving disabled young people the place in society they are entitled to, can never be stopped.

## **Reference**

1. Council of Europe. Legislation on the rehabilitation of disabled people in thirteen member states of the Council of Europe. Strasbourg, 1988.

## **Section IV**

### **Conference Actions**

Discussion groups organized within the conference structure were unanimous that further progress should relate to the following issues:

1. The development of generic guidelines for the transition of adolescents from pediatric to adult care.
2. The improvement and refinement of existing models of care.
3. The extension and upgrading of financial support systems for medical care for disabled youth.
4. The strengthening of family empowerment and promotion of liaisons between self-help groups and organized medicine.
5. Training and medical education for staff, adolescents' families, and others.
6. Research to identify information about adolescent development and how this may be applied to the provision of health care at the time of transition.

### **Development of Generic Guidelines for Transition**

The purpose of developing national guidelines for the medical care of adolescents during transition is to improve the quality of individual care at this critical time and for the future. These guidelines will be drafted collaboratively by a small group of attendees from the Jekyll Island Conference. The material will be collated by members of the National Center for Networking Community Based Services at Georgetown University Child Development Center and reviewed subsequently by a wider group of experts. The publication will be distributed nationwide to relevant agencies, organizations, and individuals. It is anticipated that this process will take at least one calendar year.

The substance of the guidelines will include the following:

1. To describe the range and scope of services to be available through each program.
2. To provide an outline for a summary of past events and a clear method for identification of current problems in all aspects of medical and psychosocial well-being.
3. To suggest an individual plan for future medical care.
4. To offer guidance for the assessment of and readiness for transition based on the interpretation of developmental problems.
5. To emphasize the importance of coordinated care and provide specific suggestions of effective methods.
6. To present the available options for financing services and to outline a systematic approach for exploring all possible alternatives.
7. To describe the health care team giving their role and function, for the benefit of families and trainees.

It is anticipated that the guidelines would serve an important purpose in general situations beyond direct patient care and programmatic expansion. These would include:

1. Briefing patients, families, and the community about services.
2. Providing a baseline data for reimbursement.
3. Training health professionals and others.
4. Addressing research in areas where there is a lack of knowledge or an inadequate interpretation of existing data.
5. Producing new checklists, forms, and records to improve clinical documentation.
6. Forming a springboard for a textbook on transition.
7. Subsequent development of guidelines for specific medical conditions

There is general concern about the inadequacy of the present reimbursement system for young people with long-term medical conditions. There will be three main approaches to this major issue:

#### A. Benefit Design

At present there is no satisfactory definition of need. This definition will be formulated from the generic guidelines. Benefits should be expanded to include multiple providers, both specialist services and care from members of a core team. All components of broadly prescribed treatment should be covered financially possibly through a consensus methodology.

A paper will be requested to elaborate upon this theme.

#### B. Access to Financial Support

This is a national problem which will eventually require a national solution. The present mandate is to request each state to articulate a plan for all individuals in need of special services. Also, each state will analyze its state plan to know the numbers of the special needs and uninsured populations. Resources to provide individual financial counseling for the special needs population would fill a wide gap. All states will be asked to work towards open enrollment without exclusion of those with pre-existing conditions.

Specifically, a pamphlet designed for families that describes the optional routes for acquiring medical insurance for disabled adolescents will be commissioned.

### C. Development of a Financing Coalition

This group will be convened by the Surgeon General to focus on funding initiatives for programs dealing with transition and the continued care of young people. Directions for funding will be in keeping with emerging fiscal structures.

The group will be composed of representatives from a wide range of professional and commercial organizations. The selection of members will be made on the basis of their interest in adolescents and their expertise in the financing of medical care.

### Family Empowerment

In order to promote a stronger family voice on behalf of young people with handicaps it has been recommended that family centered care should become a more prominent focus. MCH has been asked to work closely with the self-help groups' consortium to develop teaching resources for young patients and their families.

### Training and Medical Education

To raise the level of consciousness at all levels, conference attendees are asked directly to provide information about transition through professional newsletters and journals, and the public media. Groups to be approached include:

- all medical specialties
- colleagues in education, social services and rehabilitation
- self help organizations
- patients and their families

More detailed information is to be conveyed through continued medical information programs, by the presentation of papers and the organization of workshops at the meetings of professional societies.

Professional education programs should be encouraged to include sessions devoted to the health care delivery system and legislative issues and to encourage providers to consider a more comprehensive approach to health care. Although the medical school curriculum has become congested with competing priorities, residents would benefit from an exposure to all issues of transition. Attendees at the conference are asked to negotiate these arrangements with their local hospital or university.

### Research

Although considerable information is available, much data has not been fully analyzed or made applicable for use in existing situations. Universities will be asked to undertake further work to make existing studies of greater practical value.

New areas for investigation include the following:

- To design a tool for measuring functional disabilities.
- To develop models to define disability in a socioeconomic context.
- To initiate an information bank defined by disease entity.
- To study the effect of several disabilities on growth and development.
- To study the assessment process in relation to readiness for transition.

The four discussion groups reported their recommendations for action with marked unanimity. The development of national guidelines for transition and subsequent care was considered to be of prime importance for the planning and implementation of improved medical care for disabled adolescents. Restructuring of the financial support system will be based on the range and scope of services as described in the guidelines. Promotion of the medical needs of young people, and their families, should be encouraged so that awareness of the possible gaps in services is heightened among health professionals, social agencies, and in the community. Relevant training for caregivers in Pediatrics and in Adult Health Care must include the issues of transition. Research is to be stimulated particularly in areas relating to the timing of transition and the effect of a disabling condition upon an individual's psychosocial development. The groups convened were in agreement that these topics should be addressed first, but there was no intent to exclude other areas of concern and interest.

### **Surgeon General's Closing Remarks**

The Surgeon General's workshops have been the mechanisms that I have used for the past eight years to sort out problems, to initiate or expand programs, and also to make policy. That policy is sometimes made by suasion, sometimes by public demand, and sometimes by alerting the people responsible. This workshop is different. First of all, I think some of you came here unaware or at least unconvinced about the problem we have been discussing. You can imagine how true that must be in the health care system at large. Another nice thing about this meeting is that very few, if any, of you came with a personal agenda to promote.

We are only beginning to be in a position to advise other people about the mechanism and management of transition, although we have been providing programs for the comprehensive health care of special needs children for several decades.

One of the happy things that I see in the future is that the Center for Disease Control, which has previously confined its activities to acute illness, has now established a division of surveillance of chronic disease, so that I suspect, although they cannot accumulate those data immediately, in a few years time much more solid information will be available about the young disabled population.

In the Fall of 1987, when on the campus of UCLA, I conducted a Surgeon General's Workshop on self-help and mutual aid. This movement arose because of the dissatisfaction of parents over certain aspects of health care delivery. This became a public movement arising from a perceived deficiency; but this was followed by unresolved turf problems between those who are engaged in self-help and those who deliver health care in a traditional way. The self-help groups tend to be somewhat hostile toward organized medicine, and doctors, particularly, appear to be suspicious of the more informal support groups. In spite of these attitudes, self-help groups have grown extensively and are also able to be very effective. I refer to groups such as Alcoholics Anonymous, mastectomy support groups, Dieters Anonymous, Gamblers Anonymous, My Sister's Place, among many others. Fortunately, for purposes of our concern, there is a self-help group for most diagnoses that we consider part of our purview. Conditions include Spina Bifida, Cerebral Palsy, Epilepsy, and some of the learning disabilities to name a few from the lengthy list and organizations. There are potential dangers associated with the self-help group; this form of care could become a hiding place for quacks and charlatans, and this could keep some people away from the mainstream of conventional health care. However, having worked with these groups now for more than three years, I think that eventually self-help will be the "other" health system in this country and that it will accept the burden of disease prevention and of health promotion in the United States. If a partnership between the self-help groups and the doctors could be engineered, and the present hostility and suspicion allowed to dissipate, the result would be an outstanding combination of supportive and preventive care

with diagnostic and therapeutic management. I believe there is a very important role for self help in the management of transitional care. I will direct appropriate individuals in my department to be a liaison between the Maternal and Child Health Office and the self-help leadership, and will keep you informed about developments.

You were invited here because of your perceived expertise and we interpret your presence as a commitment to future interest in this concern. Therefore, I suggest that you take the findings and the discussion from this conference back with you; that you report your participation to the newsletter or newspaper of whatever organization you represent; that you start some thinking at home by perhaps doing ward rounds, having interdisciplinary and bi-lateral conferences, presenting a paper on the plenary session of your national and/or state society meetings, and making opportunities for local promotion of the concept of transition. I would also suggest that you introduce transition services and concerns on your society's and your hospital's continuing education programs as applicable to appropriate specialties, but particularly to associated nonmedical groups, which are sometimes left out of these deliberations. As your information improves, and you have data on which you can rely, I would hope that you would write and that you would publish.

It would be well, I think, to recall the remarks of Dr. Whittington yesterday: "You will succeed, I am convinced, faster and better if you abandon all thoughts of teaching a new subject." His alternative approach was "start off by complimenting the audience on their expertise, and then suggest a slight change in their focus to meet this particular set of circumstances."

Training was mentioned; my experience has been that it is extraordinarily difficult to enter the curriculum of any school. For many students, I think discussion of transition from pediatric to adult care will appear abstruse. Therefore, I believe that this subject is best included in the education of house officers and as a part of the continuing education of graduate physicians.

Several references have been made to family issues. I believe that there is a clear need for strategies to develop family coalitions and to teach families to be managers of the care of their own children. I suggest that first we explore the self-help connections to which reference has already been made. Secondly, I would like to ask Maternal and Child Health to consult with the Association for Care of Children's Health to explore the family coalition concept with a possible focus on transition. And then, depending on how those two approaches develop - coalition and exploration - Maternal and Child Health might consider convening a small group of participants of this meeting and plan further.

The need for guidelines has been mentioned from the very beginning of this meeting. I will address two areas - those covering care and services and the financial guidelines. I think that you have reached a rather broad consensus on this topic and I would like to ask the organizers of this meeting if they would implement the following tasks. Initially, they should develop a plan and a timetable for the publication of a document containing generic guidelines for transition; this would include a clarification of the issues enunciated here, a plan for individual services, an outline of the programmatic scope and an assessment tool to gauge developmental readiness for transition from pediatric to adult care. There should be a description of professional functions and the parts to be played by the patient, his family, and the community. Alternative methods for coordination of all of the above will be suggested. Such a document should be used in a variety of ways, including informational purposes, training, and for the future development of diagnostic specific guidance. Certainly, the document should be used to change the basis of reimbursement and it would be helpful to anybody designing a research project in this field. The task would amount to a year's work involving many who attend this meeting, and other specialists, and experts for review purposes.

Peggy McManus showed us with great clarity the barrier-ridden process of entering a financial system to provide care for special needs children, especially at this transitional time. In this regard, I would like to ask that Maternal and Child Health work with her and others to establish guidance for parents and professionals, in chart form, that should trigger a financial review by families at critical times in the life of their child, determined chronologically, developmentally, or by events in the medical history. There should be an evaluation of alternatives pointing out the pitfalls, the Catch-22 situations, and the prospect for success so that we do not raise expectations unrealistically. I would suggest that MCH appoint a task force to address such changes and to propose an ideal model to be used as a guide for financing the care of special needs children. The health care

to propose an ideal model to be used as a guide for financing the care of special needs children. The health care system is due for an overhaul. This is unlikely to happen immediately but I do think that piecemeal benefits should not be rejected but grasped and considered as stepping stones for the future.

When these two sets of guidelines have been prepared it will be time to reconvene a group such as this where triumphs and failures may be shared, leading to regrouping and further progress. Most importantly, out of these experiences will come a clarification of resources needed in terms of personnel, services, programs, money, and research.

Turning now, almost in conclusion, to research. New initiatives must be devised. We need reliable methods for the comparison of service models; we must be able to evaluate the level of satisfaction for staff and patients; and we should seek new data on cost-effectiveness. The trend of medical costs must be under constant review. Legislators are more likely to respond if they can see a goal and are given some projections about numbers under consideration and dollars involved.

A suggestion was made to get universities more involved in this type of research: data analysis, gathering of disability information, finding functional definitions for disability, developing a diagnostic-oriented information bank, and also a national program directory. Those are all very important suggestions and I think the university involvement must be stimulated by knowledgeable individuals - such as yourselves. The people that you convert to your way of thinking will also be important allies in the future. One of the best ways to involve university programs is to approach interested individuals who are on the staffs of university affiliated children's hospitals.

An additional area of needed research lies in the field of human development. We have not determined landmarks for all phases of human development, and we don't know how these milestones are altered by the presence of a chronic illness. I will convey your concerns to the Director of the National Institute of Child Health and Human Development and discuss possibilities for inviting proposals to address these developmental issues, from which usable data would become available.

And then, finally, there is the action that we will take after we leave this conference. I will distribute, with appropriate covering letters, the proceedings of this workshop to appropriate individuals and groups. This list is not at all complete but I will start with the Secretary of HHS, the Undersecretary of the same Cabinet Department, the Assistant Secretary for Health, the Administrator of the Health Care Financing Administration, and the Commissioner of the Social Security Administration. I will see that the chief executive offices of appropriate companies involved in the health insurance industry get this packet, as well as members of the House and Senate who are involved with committees that deal with health and health appropriations. The proceedings should go to the directors of adolescent services in the states and to the chief executive offices of the many advocacy groups around the country, known for their interest in the disabled.

In conclusion, let me say that my response to your discussions and comments merely highlights some of your findings. We will review all you have said, especially the call for action. We will amplify this response where necessary and where possible. Most importantly, we will keep you informed, but we also want you to keep us informed. We would like copies of your publications and information about your presentations to professional and other groups. If we have this material, we will see that it is circulated widely.

The staff from Maternal and Child Health and Georgetown University join with us to express our thanks and appreciation for your presence here. It has been a good workshop, and we appear to be off to a good start. I am hopeful that in about two years time, we shall be impressed by the accomplishments that have been achieved, and the progress made will show tangible results of our conference here in the Spring of 1989.

#### **Participant List**

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## **Planning Committee**

**Growing Up and Getting Medical Care:  
Youth with Special Health Care Needs**

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**GROWING UP AND GETTING MEDICAL CARE:  
YOUTH WITH SPECIAL HEALTH CARE NEEDS**

**AGENDA**

**March 13- 15, 1989**

**The Jekyll Island Club, Jekyll Island, Georgia**

**Monday, March 13th**

7:00pm- 9:00pm  
*Aspinwall and Pulitzer Rooms* Reception, Registration

**Tuesday, March 14th**

8:00am- 9:00am  
*DuBignon Room* Breakfast

9:00am - 9:45am  
*DuBignon Room* Introduction and Welcome  
Vince Hutchins, M.D.

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Growing Up and Getting Medical Care: The Challenge for Youth with Special Health Care Needs

C. Everett Koop, MD., D.Sc.

9:45am- 10:45am Overview and Scope of the Problem

*Chairperson:* Robert Blum, M D.

*Presenters:* Margaret Stineman, MD.

Daniel Schidlow, M D.

Margaret McManus

11:00am - 12:30pm

*Pulitzer, Alexander, Morgan and FR Rooms Strategy Task Groups*

A - Robert Blum, M D.

B - Phyllis R. Magrab, Ph.D.

C- Suzanne M. Bronheim, Ph.D.

D - Merle McPherson, M.D.

12:30pm - 1:30pm

*RF Veranda Lunch*

1:30pm - 3.30pm

*DuBignon Room Critical Issues in Providing Appropriate Health Care to Youth with Special Health Care Needs:*

*Case Study Responses*

*Chairperson:* James Nuckolls, M.D.

*Presenters:*

Financing - Merle McPherson, MD.

Organization of Services - Arthur Elster, M.D.

Practice Issues - Kenneth Whittington, M.D.

Training - Hilary Millar, M.D.

3:30pm - 5:30pm

*Pulitzer, Alexander, Morgan and FR Rooms Strategy Task Groups*

(same groups)

6:30pm

*DuBignon Room Dinner*

**Wednesday, March 15th**

7:30am- 8:30am

*DuBignon Room Breakfast*

8:30am- 10:30am

*DuBignon Room Successful Models of Care: Lessons Learned*

*Chairperson:* Merle McPherson, MD.

*Presenters:*

Hemophilia Example: Louis Alcdort, M D.

Juvenile Arthritis Example: Patience White,

M.D. Cystic Fibrosis Example: Stanley Fiel, M

D. European Example: Wietse Kuis, M.D.

Gerben Sinnema, Ph.D.

10:45am - 11:45am Call To Action

10:45am - 11:45am Call to Action  
*Facilitator:* Phyllis R. Magrab, Ph.D.

11:45am - 12:30pm U.S. Surgeon General Response  
C. Everett Koop, M.D., D.Sc.

12:30pm  
*RF Veranda Working Lunch*

## **Briefing Paper**

### **Growing Up and Getting Medical Care: Youth with Special Health Care Needs**

#### **What Are the Issues?**

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Over the past 20 years, there has been a dramatic improvement in mortality rates for many chronic "childhood" conditions due, in large part, to advances in medical and surgical care. Survival rates for disorders such as spine bifida and leukemia have increased by almost 200 percent. The average age of survival for young people with cystic fibrosis is pushing well into the twenties with one third living into their thirties. It has been estimated that, overall, some 84 percent of children with chronic conditions survive into adulthood.

Unfortunately, in many cases, the medical care system has not changed in response to its own successes. Large numbers of these "survivors" continue to receive their medical care in pediatric settings. It is not uncommon to see patients in their late twenties receiving inpatient care on pediatric wards and in children's hospitals. Others are simply lost to ongoing follow-up once they "outgrow" pediatric services, since no specialty services addressing their condition exist in the adult medical system.

This situation has a negative impact on these young people in several ways. While the pediatric caregivers who have provided specialty care throughout their childhood are typically indisputably expert in treating their special conditions, they may not have the expertise to address the medical needs of adults. Issues related to gynecology and obstetrics for the young women and other disorders of adulthood which may be unrelated to the young person's special health care needs may not be addressed as well as they would be in the adult health care system. In addition, other pediatric sub-specialists providing consults may also lack experience with "adult" disorders or the manifestations of a given problem in the adult population.

Another way in which receiving medical care in pediatric settings may have a negative impact on young adults is in relation to their own psychosocial development. Pediatric caregivers may have a difficult time switching from dealing with the parents as the responsible parties to dealing with the young adult. It is hard to accept that the child one has cared for is now an adult and pediatric caregivers may collude with parents in "overprotecting" the young patient. Issues such as sexuality, reproduction, vocational concerns or even the financial aspects of care decisions are often not discussed with the patient, as they would be in the adult health care sector. Even the best efforts at education in these areas by pediatric caregivers may be ineffective if the patient feels that his/her parents make the decisions about care. Remaining in pediatric care settings becomes one more factor impeding the development of adult independence in young people with special health care needs. Finally, there is a very insidious, negative message in keeping these young adults in pediatric care. The failure to develop a capacity to care for these young adults in the adult care system, suggests that we believe that they are living on "borrowed

time". It gives the message that working to make the difficult transition to adulthood may not be worth the effort, because there may be a greatly shortened life span!

Young people who do not have special health care needs seem to make the transition to adult health care with little fanfare. Why does there seem to be this bottleneck in the progression for youth with special health care needs? A number of factors seem to play a role in the problem.

These include:

- attitudinal barriers (on the part of pediatric and adult caregivers, families and patients)
- knowledge gaps care delivery models typical in adult health care
- financing of adult health care services
- coordination of health care services with other needed services

Each issue must be addressed in order to insure that youth with special health care needs can grow up and find appropriate medical care.

### **Attitudinal Issues**

Those who have attempted to facilitate the transition of young adults to the adult health care system have quickly discovered that the issue arouses very strong feelings. Parents are often quite reluctant to leave the pediatric caregivers whom they often view as having kept their child alive, in order to seek care in untested waters. These feelings are particularly acute when their child's disorder is one that is not familiar to the adult caregivers. Parents may have close personal ties with the pediatric caregivers forged during moments of crisis and shared worry. The clinic and hospital staff are often a major part of the family's support system. Parents who experience the move to adult health care settings have a hard time adjusting to the focus on the young adult as the responsible party. They complain of feeling shut out and ignored when the adult caregivers consult with them as a courtesy with the permission of the young adult patient. Thus parental resistance to the move can be quite strong. Many young people share their parents' fears about the change as well, although most express very positive feelings about being "treated as an adult."

The caregivers attitudes also make the transition problematic. Pediatric caregivers often have strong ties to the families and the patients- -- it is very hard to see them leave. They have a difficult time really believing that the child they may have cared for from birth is truly an adult (or should at least be treated as one:) They feel that no one in the adult system has the expertise to deal with these patients' medical problems and, more importantly, that adult caregivers are cold and uninterested in these patients' many psychosocial needs. On the other side of the care system, adult care providers may feel that these patients are immature and their families too involved and demanding. If they do not have experience with a young person's special condition, the caregivers may feel defensive or threatened about seeking consultation or supervision from pediatric caregivers who specialize in the treatment of the disorder. Certainly there is no incentive to pursue the treatment of a group of patients if one does not have the knowledge and experience to do so.

These attitudes must be addressed in any efforts to change the system of care. When the problems and setbacks that attend any change come along, it is too easy for any or all of the parties involved to feel that "it isn't worth the trouble" or to be too quick to see any problem as proof that their worst fears have been realized.

### **Knowledge Gaps**

One very real barrier to a smooth transition to adult health care for youth with special health care needs is the lack of knowledge and expertise in the adult care system to deal with their special problems. The disorders involved have been historically thought of as "pediatric conditions", many of which are cared for in special centers or units. As a result physicians and other caregivers in the adult system may have little knowledge and no experience caring for these disorders. Some form of training and expanding knowledge is needed to make the transition from pediatric settings, where the staff have had years of experience with a particular disorder, to the

adult settings.

While these young adults with special health care needs should be treated as adults, many have had delays in both the physical and psychosocial aspects of adolescence. Thus many in their twenties are more like mid-adolescents in their development. Their families are also often still unresolved about letting go and making the move to becoming the parents of an adult child. A large proportion of adult specialists may not have had training in the issues of adolescent development and may be perplexed and frustrated in caring for this population. This lack of knowledge can easily undermine the success of the transition.

### **Care Delivery Models**

Over the years, the pediatric system of care has recognized that interdisciplinary team care is the most effective model for serving children with special health care needs and their families. Many of the disorders treated need the input of multiple professionals, all of whom must have a familiarity with the special aspects of the care of a particular condition. While the interdisciplinary team approach to care has made an appearance in the adult health care system (e.g. cardiac care clinics, diabetes centers, etc.), it is not the model available in most specialty departments. Many physicians in the adult care system are unfamiliar with or even uncomfortable with this model of care. It is important that in seeking to find medical services in the adult sector, young people with special health care needs not have to give up the model of care that is critical for appropriate treatment of their chronic health conditions.

### **Financing Care**

The financing of care for young adults with special health care needs is a problem that has an overriding importance for the issue of growing up and finding medical care. There are issues for caregivers, institutions and consumers. Caregivers may find that caring for these young people is more time consuming than usual; yet, reimbursement systems may not adequately recognize this factor. In addition, team care is very costly and again, reimbursement systems may not provide adequately for the many kinds of services needed.

Inpatient hospital care in adult institutions, where DRG's have been applied, may be problematic. Because of the complex nature of their medical problems, these young patients may be seen as a drain on resources, when DRG's do not recognize their real need for prolonged hospital stays. Even in states where there are public programs to help pay for care of specific conditions after the age of twenty-one, the agencies administering them are child oriented and may relate only to pediatric institutions or caregivers.

Finally, a very serious issue is the fact that these young people typically find themselves without any health insurance coverage. Once they reach the age of twenty-two or leave home and school, they are no longer covered under their parents' policies. If they are gainfully employed, they may not qualify for public sources of medical coverage. Often they also find that they cannot secure full-time employment, because they are a risk that employers do not want to insure. Thus, incentives to become productive, independent adults may be undermined in order to deal with financing health care needs.

### **Coordination With Other Services**

Young people with special health care needs often have many other associated needs. They may need a variety of special therapies, special equipment, extra training to help with vocational fulfillment, special diets, and special accommodations in the environment. During childhood the educational system and the medical system may coordinate many of the services for the child and family. The adult care system, not having dealt with these particular needs, may lack knowledge of resources and ties to the resources needed. Development of these ties within the adult care system will be needed to insure appropriate care for these young adults. On the positive side, the adult caregivers are much more familiar with many types of services that will aid in the growing independence of these young people in areas such as vocational development.

This paper is certainly not meant to be an exhaustive discussion of the issues related to transition to adult

health care for youth with special health care needs. These are, however, the key issues that will need serious consideration throughout the system. Clearly, members of the pediatric and adult health care systems, families and young adult consumers must all become actively engaged in the process if positive change is to be effected. Many of the statements are generalizations and there are specific instances when youth with special health care needs can access appropriate adult health care services. There is, however, much work to be done.

## **Case Study**

### **Growing Up and Getting Medical Care:**

#### **Youth with Special Health Care Needs**

## **Case Study**

To illustrate the issues related to growing up with special health care needs, this case study was prepared. It is a composite of many young people and many conditions. The medical condition is left unspecified, since the issues cut across diagnosis and symptomatology.

John is a twenty one year old male who has suffered from a chronic medical condition since he was two years old. At that time, he had an acute onset, requiring prolonged hospitalization. His initial care was in a children's hospital. but when the specialist he saw moved to a nearby university hospital, his family followed. There he was seen by a team of physicians, a social worker, a psychologist and nurses. Three times during his elementary school years, John and his parents received psychotherapeutic input to deal with school problems, and his reactions to surgery. In the intervening years, he received numerous special treatments that have interfered with school attendance and the normal childhood business of playing, joining sports teams, and exploring the world. He has also had several surgeries that have left large, visible scars. John has also had some mild learning problems in school and has always be viewed as impulsive and immature by his parents and teachers.

John's adolescent years had been difficult for him. While he was relatively healthy, considering his condition, he still had been constantly reminded of his problem by regular visits to the local tertiary hospital specialty clinic. In addition, he had to take medication daily and could not engage in vigorous contact sports. He had no primary care physician and has not since his problems began. He always returned to the tertiary care clinic for all his medical care. Because the focus was on his special health care needs, issues such as sexuality, education about drugs and alcohol, etc. were never broached.

Like many young people with chronic medical conditions, John's condition and the drugs used to treat it de eyed the onset of puberty. In junior high and high school he was much smaller than the other boys and undeveloped. This resulted in suffering a lot of physical intimidation from his peers (being stuffed in his locker, etc.) embarrassment in gym class and social ostracism. Girls were also not interested in dating a "little boy." His depression, impulsivity and immaturity affected his behavior so that he was further ostracized. John particularly hated when peers noticed his scars and asked about them. Sometimes he told them he got them in a knife fight to make himself seem less vulnerable. John was actively involved in scouting, at his father's insistence. He achieved the rank of Eagle Scout in order to please his father.

Through his adolescence his parents continued to attend his doctors appointments. His caregivers felt that he was immature and irresponsible and looked to his parents to make decisions and to ensure that he followed their recommendations. In addition, afraid that he would not take his medicine, his mother either made him take it in front of her or counted the pills left in the bottles. John never asked to have the medications refilled, but his mother kept track and went to the pharmacy.

John's father felt stuck in his job, but did not change, because that would have left the family, and thus John, uninsured for preexisting conditions for a nine month period. John's mother after years of devoting herself to his care returned to work during his adolescence. She only worked part time, however, because he needed her help with school homework. John learned to drive and got his license. but wasn't allowed to go manv places his

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younger sister was, because his mother believed he would get lost going someplace new. This was also the reason he was not allowed to drive to his medical appointments alone.

As John approached the end of high school, there was some discussion about his receiving his care from adult care specialists. This was not done, however, because of John's many psychosocial problems. The adult care physician did not have a team and the psychiatrist from the medical liaison service only had experience with adults. In addition, John was then receiving a new type of treatment just developed in a collaborative effort by the special centers that treated his disorder. The adult care specialist stated that he/she did not know of that treatment and considered it highly experimental. John and his family did not make the change.

John graduated from high school and entered a state college. He had never been away from home alone before, since in all his scouting activities his father had come along. He still looked like a

thirteen or fourteen year old. John's roommate turned out to be a good looking, athletic boy who was very popular with the girls and had drinking parties in their room late into the night. John needed more sleep than most people his age and this was hard on him. John was determined to be socially accepted at college. He thus began to drink heavily and party every night. He also began smoking cigarettes and briefly experimented with drugs. He was unable to organize his work and was taking his medication sporadically. In part this was due to his disorganization, in part to his belief that he was a special case that did not need this medicine. Two months later he returned home, severely depressed and suicidal.

Currently, John, now age 21, is living with his parents. There is serious conflict among them and he longs to move out. He is working 30 to 40 hours a week at a fast food restaurant and going to the local junior college. His grades are poor and he feels that he needs time off from school to get clear about his goals. John is looking for a job with good health insurance benefits, because if he leaves home and quits school he will lose his parents insurance coverage. He does not even focus on whether he will like the job. Unfortunately, he has not been able to keep a job long enough to qualify for benefits. In one case, he was fired for suspicious reasons shortly before he was to go onto the benefit package of the company.

In the past two years, John has begun to grow and looks more his age. He has had more success with girls and he is dating someone special right now. He worries that he will not be able to support her and that she may not a long term involvement with someone with his health problems. John looks forward to having a family of his own. He has no idea if his condition can be inherited, since the physicians figured he was too young to worry about that issue.

Recently John has had an exacerbation of his condition. Because the hospital clinic had decided he should go to the adult clinic now that he was twenty-one, John met with the adult specialist. He became quite upset when the physician told him that he would shortly need more intense medical intervention. He was confused about what had happened and did not understand many of the terms the physician used to explain it to him. When he asked for clarification, his physician became angry, saying he was "playing games." John went home and asked his mother to explain it all to him, since he hadn't really paid attention in these past few years to what the doctors had been saying. He then felt very depressed, realizing that his failure to take responsibility for his care and his not taking his medicine to "get back" at his mother had been very self-destructive.

John represents the challenges to us all in making growing up with special health care needs less painful. While John and his family have many needs, the health care system can help a great deal by rethinking how we serve these young people and their families.