

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, M.D.**  
**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 counselling 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 counselling 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 counselling, 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 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 spina 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 adjuncts 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 counselling 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 counselling 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 2.2/1,000 (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 non-rheumatologic 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 spina 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 longterm 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 ensurance.

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.

**Table I**  
**The Chronically Ill or Disabled Adolescent and the Dutch Health Care System**

<b><u>First level:</u></b>	general practitioner
<b><u>Second level:</u></b>	local pediatrician
<b><u>Third level:</u></b>	(university) pediatric centers
-	other health care
facilities:	- Physical Therapy
	- Home Care: Cross organization
	- Psychosocial care: RIAGG (institute for ambulatory mental health care)
	- Special Institutes: <ul style="list-style-type: none"> <li>- revalidation centers</li> <li>- institutes for handicapped children</li> <li>- institutes for blind children</li> <li>- institutes for mentally handicapped children</li> </ul>
-	"special" schools, e.g. for deaf children, children with learning disabilities
-	special facilities, e.g. home adjustments (elevator, bath, etc.)

**Table II**  
**Levels of Care and Their Benefits**

<b><u>First level:</u></b>	General practitioner: -	"generalist"
		- knowledge of child/family
		- knowledge of local circumstances
<b><u>Second level:</u></b>	Local pediatrician: -	specialized
		- direct contact with first level
		- in the neighborhood of the patient
<b><u>Third level:</u></b>	(University) pediatric center: -	knowledge of rare pediatric disorders
		- multidisciplinary care

**Table III**  
**Current Deficiencies in Dutch Health Care**

General practitioner:	delay in diagnosis
Local pediatrician:	delay in diagnosis
	delay in adequate treatment
University center:	distance
	expensive medical care
	deficient cooperation with level I and II

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;
- 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 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 (1. 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're 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 longterm 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 counselling 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 individuals' 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 non-medical 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 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.

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