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ABSTRACT

This monograph was developed as a product of two Minnesota state conferences (held on June 2, 1994 and on May 19, 1995) on transition issues facing adolescents with chronic illness and disabilities. Participants included health professionals, educators, parents, policymakers, human service providers, and young adults. Introductory remarks by Robert Wm. Blum and Colleen Wieck address issues and challenges facing adolescents with chronic illness and disability and issues and challenges facing professionals, respectively. Comments of a panel of adolescents on personal experiences with transition issues and services are summarized, as are comments of a parent, an educator, a physician, and a vocational counselor. A 1994 post-school follow-up survey of 388 young adults with disabilities in Minnesota and a national survey of about 300 transition programs are summarized. Descriptions of three exemplary programs in Minnesota are provided. Six guiding principles for improving transition services and programs are identified. Programs need to be built on youth's abilities and competencies and need to be family-centered, culturally sensitive, community-based, coordinated, and accountable. Eight recommendations focus on the need to: develop transition services and programs that foster autonomy; decrease barriers in access and utilization of services; coordinate and streamline funding and services; and improve the Individual Education Plan planning process. (DB)

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A Call to Action

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A Call to Action

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This publication is available in alternative formats upon request. To request an alternative format, contact Peggy Mann Rinehart, NCYD, University of Minnesota, Box 721, 420 Delaware St. S.E., Minneapolis, MN 55455, (612) 626-2931.

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Each conference relied on facilitators and recorders to guide small group discussion and capture the essence of these discussions. Special thanks to recorders Sara Axtell, Theora Dodd, Barb Jirik, Harriet Kohen, Bill Latimer, Bill Malcolm, Peggy Mann Rinehart, Michele Strachan, Diane Neumark-Sztainer, and to facilitators Ann Garwick, Harriet Kohen, Elizabeth Latts, Nancy Okinow and Joan Patterson.

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Transition Planning for the 21st Century

Contents

The Conferences

The National Center for Youth with Disabilities convened two state conferences, "Smoothing the Course of Transition for Adolescents with Chronic Illness and Disability" held on June 2, 1992, and "Transition Planning for the 21st Century" held on May 19, 1995, at the Minnesota Landscape Arboretum. Our goal was to develop a vision and recommendations for providing interagency services for youth with chronic illness and disabilities as they transition from adolescence to adulthood. These are the proceedings and recommendations.

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What we did...

The National Center for Youth with Disabilities convened two state conferences, "Smoothing the Course of Transition for Adolescents with Chronic Illness and Disability" held on June 2, 1994, and "Transition Planning for the 21st Century" held on May 19, 1995, at the Minnesota Landscape Arboretum.

These working conferences brought together health professionals, educators, parents, policymakers, human service providers and young adults to focus on transition issues facing adolescents with chronic illness and disability.

What we hoped to accomplish...

The purpose of these two conferences, held a year apart, was to broaden the concept of transition to include health issues and to identify strategies for improving transition services for adolescents with health-related concerns. Participants were actively involved in:

- addressing critical issues facing adolescents with chronic illness and disability as they move into adult roles;
- identifying resources and barriers in transition planning experienced by adolescents and their families;
- identifying effective transition planning strategies; and
- developing recommendations for improving transition services.

Our goal was to develop a vision and recommendations for providing interagency services for youth with chronic illness and disabilities as they transition from adolescence to adulthood. These are the proceedings and recommendations.

Transition Planning for the 21st Century

Issues & Challenges Facing Adolescents with Chronic Illness and Disability

By Robert Wm. Blum, M.D., Ph.D.

Why talk about the transition of teenagers with chronic conditions and disabilities from pediatric care to adult health care? Today, the average age of survival for youth with cystic fibrosis in the U.S. is 26 years. In Canada, Australia and Western Europe, it is 28 years. That's why we need to talk about transition.

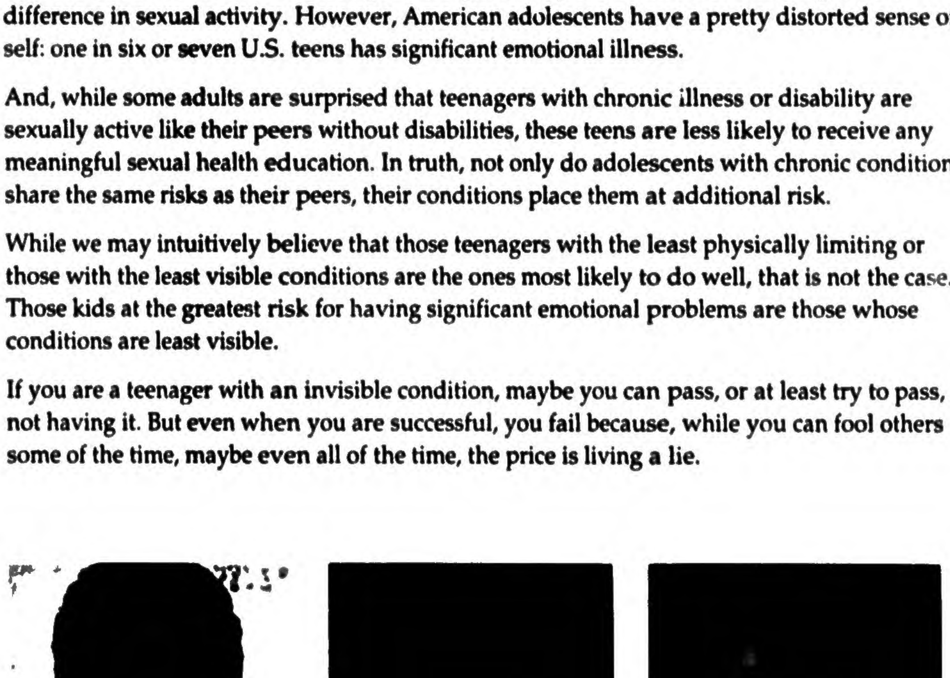
We've seen a tremendous increase in the survival in this country for youth with what were previously called "childhood" chronic illnesses and disabilities. Now, we are faced with a very significant number of young people who are maturing into young adulthood, crossing almost all conditions, that were historically fatal childhood diseases. And we, the medical, health and human service and education providers, are facing the realities of their survival: What do we do? How do we approach meeting the needs of these populations of young people? What must we do to assure, to the best of our ability, that they can lead successful adult lives?

Adolescents with chronic illness and disability, like their peers, face and deal with many of the same challenges as their peers without disabilities. Their body image is not more distorted; their emotional well-being is not significantly worse off; there is no significant difference in sexual activity. However, American adolescents have a pretty distorted sense of self: one in six or seven U.S. teens has significant emotional illness.

And, while some adults are surprised that teenagers with chronic illness or disability are sexually active like their peers without disabilities, these teens are less likely to receive any meaningful sexual health education. In truth, not only do adolescents with chronic conditions share the same risks as their peers, their conditions place them at additional risk.

While we may intuitively believe that those teenagers with the least physically limiting or those with the least visible conditions are the ones most likely to do well, that is not the case. Those kids at the greatest risk for having significant emotional problems are those whose conditions are least visible.

If you are a teenager with an invisible condition, maybe you can pass, or at least try to pass, as not having it. But even when you are successful, you fail because, while you can fool others some of the time, maybe even all of the time, the price is living a lie.



Coming to terms with one's physical condition within the context of one's life is clearly related to positive outcomes.

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The issues are different for those whose disabilities are visible. As painful as it might be to work it through, at some point, teens with visible disabilities have to face it. To face it, to come to terms with and acknowledge one's disability, —one's physical condition within the context of one's life—is clearly related to positive outcomes.

Those who live in the shadow of uncertainty are often at the greatest emotional risk and there are so many conditions that are blatantly uncertain. The young person with epilepsy can never predict what will happen. The teenager with spina bifida and latex allergies must worry that, unknowingly, he will come in contact with latex. These young people can never let down their guard. That is the reality of living with uncertainty. And for those kids, the price is exceptionally high.

Likewise, conditions that are remitting and relenting—when a condition comes and goes—seem to extract a tremendous emotional cost.

Boys with disabilities seem to have more concerns about body image than girls with disabilities. They have more concerns about their height. They have more concerns about their weight. They have more concerns about their appearance.

From a health care professional's perspective, we need to help set clear boundaries with the young person so that we do not "own" a young person's condition. Often, it's the most caring pediatricians who over-identify with the youth's condition. By assuming too much personal responsibility for a patient's condition, these well-meaning physicians limit the youth's identity and autonomy. To the extent that a physician assumes responsibility for a patient's condition, the patient is absolved of that responsibility.

We also know some of the elements that facilitate successful transition:

- Having high expectations makes a difference.
- Having clear, caring and consistent rules makes a difference.
- Believing a disability need not be a handicap makes a difference.
- Establishing developmentally expanded expectations, starting in early childhood and moving across into adulthood, makes a big difference.

When we talk about transition for youth with chronic illness and disabilities, we're talking about helping young people acquire the skills they need to become successful adults. That is the vision that we all bring into our work with young people.

Transition Planning for the 21st Century

Issues & Challenges Facing Professionals

By Colleen Wieck, Ph.D.

Transition for adolescents with chronic illness or disability translates to self-advocacy and self-determination. It means giving youth the skills they need to live, work and take their place in the community. So we come together in groups like this to try to figure out what is possible, how to find and access community resources, and how to problem-solve.

How do you actually sit down with people, listen to them, respond to them, and actually help them? Here are some things we, as professionals, must do if we are to assure, to the best of our abilities, that our youth with disabilities and chronic illness lead successful adult lives:

- First, we must help people take control of their lives and help them feel hopeful. We have learned that often people feel hopeless. Our job is to give back hope. For adults with disabilities, that often means expanding their agenda to include employment, transportation, a place to live, and a decent quality of life.
- Our training programs must help individuals move from self-doubt to belief in self. For some, that means being able to speak up for the first time. For one woman, a graduate from the Crippled Children's Hospital, it meant leaving her job and going back to school to become a secretary. "It was gaining self-esteem," she said. Giving youth the tools to move from self-doubt into belief in one's self gives them a future.
- We must move from the notion that someone "owes me a future" to helping people take responsibility and control of their own lives. So often the best advocates won't give up. They won't let their children become advocates.
- We have to move from expecting very little from people to expecting a lot. At our youth camp, we make sure everyone participates and that they choose to participate. Last year, we had 30 days of rain. And in the middle of that weather, our campers were supposed to go up a light pole, stand on one foot like karate kid, turn around, and then they are supposed to come down like Peter Pan. When one young woman did it and hit the ground, she spoke for the first time.
- We must move from the belief that people with disabilities and their families have different aspirations to the belief that everybody's aspirations are the same. In reality, it is their access to resources that are different.
- We need to move from reliance on experts to reliance on the common wealth of communities.
- We need to move from exclusion and isolation to the notion that all of us are in this together and interdependent. We must move from the belief that minority cultures are inferior to minority cultures are valuable.
- We need to move from the belief in bureaucratic norms and goals to the belief in consumer norms and goals.

Personal Experiences with Transition Issues & Services

Three young adults held a candid conversation led by Dr. Blum. Wendy Harbour, president of the Disabled Student Cultural Center at the University of Minnesota, began losing her hearing as a child. Today, she is a young deaf woman, redefining her place in both the deaf and hearing worlds. Dave S. Johnson is a personal care attendant majoring in recreational therapy at the University of Minnesota. After acquiring a spinal cord injury at age 19, he began his life as a person with a disability. Chad Pierro is a transition health specialist at the PACER Center in Minneapolis, Minnesota. He sustained a stroke shortly after birth and has cerebral palsy. Here are some of their thoughts on moving into young adulthood.

On acquiring disabilities and being born with disabilities:

Dave: The biggest thing has been support—family support, mainly. When I was disabled, most of the friends that I had no longer talked with me. They no longer wanted to do things with me, either because they were uncomfortable with me or they didn't know what to do with me. I don't know which. I don't think I had a huge personality change! ... I do have two friends now who I had before ... they are pretty cool friends!

Chad: Unlike David, I was born with my condition. I haven't known anything different. For me, it's like I didn't lose anything so I really admire what Dave's done. ...

... I had to make a choice early on about who I would associate with, and when I was younger I saw the disabled community, the community with disabilities, as something I really didn't want a part of. I didn't like the stereotypes.... But in doing that, I kind of lost part of my identity because ***I am*** a person with a disability and ***I am*** a person as well.

Robert Wm. Blum M.D., Ph.D., elicits personal experiences from several young adults.

Wendy: I guess I started losing friends because they didn't know what to do with me anymore. I didn't want to go to movies. I didn't want to go to dances. I didn't like parties that were loud. And so for my own mental health, my own well being, I lost friends. It wasn't them who severed the connection, it was me.

On the Impact of having a disability on social relationships:

Chad: I think that, for me, I see a lot of people being defined as "nonsexual" because they have a disability. It is something I had to find out on my own.

Dave: It took a while until I would ask a girl out again. I was self-conscious more than anything else. Even if she were very short, I would still look up to her. I think I stand 4'8" in my wheelchair, and going from 6'1"—that's really a difference.

Wendy: I went to private schools so I was pretty serious. I really didn't know anything about sex from anyone. ... I researched sex on my own. I remember the only person who ever said anything about being deaf and my sexual life was the person who fitted my hearing aids. She said I'd have to learn to be an aggressive flirt because, if someone started whispering sweet nothings in my ear, I wouldn't hear them!

Chad: People do not properly acknowledge the full extent of the definition of sexuality because it does not mean just intercourse. It does not mean getting what you want and just leaving. It means touching. It means feeling. It means hugging somebody. It means talking with somebody. It means intimate interactions. I didn't know that when I was younger and growing up. If I had more people when I was younger to tell me what I'm saying now, it would have helped me a lot.

Dave: It's something that they seem to talk about a lot. People tend to take on the attitude that Chad had when he was younger. Intercourse was the thing to measure a person by, whatever. I can't feel anything from here down.

Wendy: I have a different situation because I'm gay. Professionals will ask me if I'm sexually active and I say, "yes," sort of ... I need your definition .. because they are assuming all disabled people are straight. I think that the thing for me was getting involved in the Disabled Student Cultural Center and getting to know other gay disabled people.

Three young adults, David S. Johnson, Chad Pierro and Wendy Harbour share their personal experiences.

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Issues & Challenges Facing Families and Professionals

Educators, health care professionals, vocational counselors and families provide support and services that are essential in helping the adolescent with a chronic illness or disability through transition to adult life.

Each needs to attend to the psychosocial and developmental issues of adolescence. The educator must not focus only on the child's learning and cognitive development; the health care professional must not focus only on the medical concerns, and the vocational counselor must not focus only on vocational needs and goals.

Views from Different Vantage Points

Parent's View — *Karen Tommeraasen*

- Adolescents with chronic illness and disability need to receive genetic counseling.
- Families need to network with other families who have children with similar conditions.
- Rural physicians need support and updated information.

Educator's View — *David R. Johnson, Ph.D.*

- Teachers need to know how various conditions influence learning and academic achievement.
- Educational terms like "transition" and the goals to reach adult life need to be defined and measurable.
- Teachers need to facilitate the involvement of students in their own programming.

Physician's View — *Brooks Donald, M.D.*

- Health care professionals must increase their knowledge of chronic illness and disability.
- Physicians need to increase their knowledge of normal adolescent development, especially psychosocial issues.
- Physicians need to facilitate linkages with subspecialists, especially in rural areas.
- Physicians need to develop a personal relationship with their adolescent patients.

Vocational Counselor's View — *Kathryn Raymor, M.S.*

- Counselors need to develop a heightened understanding of the unique strengths and challenges that students with disabilities face.
- Secondary schools need to identify students with medical or disabling conditions who are not receiving special education services.
- Schools need to provide better systems to accommodate the needs and strengths of students.

Karen Tommeraasen is a Community Development Educator with the Minnesota Extension Service. Her grown son has juvenile diabetes and a specific learning disability. David R. Johnson, Ph.D., is Associate Director of the Institute for Community Integration in the College of Education at the University of Minnesota. Brooks Donald, M.D., is a pediatrician with Health Partners. Kathryn Raymor is a vocational counselor in the Division of Rehabilitation Services, Minnesota State Department of Vocational Services.

Transition Planning for the 21st Century:

What are Youth Saying: A Survey of Teens in Minnesota

Transition planning is supposed to help students with special health care needs live their own life: manage their own money, find their own doctor, find a place to live and get a job. Unfortunately, much of what's been called transition has been done without consulting or involving teens and young adults.

That's why PACER Center (Parent Advocacy Coalition for Education Rights) and the Minnesota Department of Health surveyed 1,641 students in Minnesota during the winter of 1995. What do young people need, they asked, in the areas of social life, independent living, college and vocational goals, medical information and job training? Clearly, the responses show that adolescents need more input from health care professionals.

For more information, please contact Ceci Shapland, PACER Center, 4826 Chicago Ave. So., Minneapolis, MN 55417, (612) 827-2966.

What's Happening In Minnesota: 1994 Minnesota Post-school Follow-up Study

The 1994 Minnesota Post-school Follow-up Study collected information on the status and experiences of 388 young adults with disabilities who received special education services while attending high school. Questions were divided into eight areas of post-school adjustment: employment, postsecondary education and training, living arrangements, social network, recreation and leisure activities.

The findings show the lives of individuals who have received the services and have improved. This study also clearly documents that young adults with disabilities continue to face many challenges moving from school to adult life.

The outlook for young adults with disabilities in Minnesota is more positive than in many other parts of the the nation and is better today than in the past. However, the collaborative work of persons with disabilities, family members, advocates, professionals, policymakers, researchers, and all others who are concerned with the lives of young adults with disabilities is far from finished.

Copies of the full report, 1994 Minnesota Post-school Follow-up Study, can be ordered. Contact: Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive S.E., Minneapolis, MN 55455, (612) 624-4512.

What's Happening Nationally: National Transition Survey

The National Center for Youth with Disabilities (NCYD) completed a national survey to identify transition programs from across the country that are designed to help adolescents with chronic illness and disability move from pediatric to adult-focused health care.

Peter Scal, M.D., Research Associate, sent out more than 1,000 inquiries to public and private health providers in a variety of settings throughout the nation asking for nominations of transition programs that incorporate any of the following health care transition elements into their programs: professional, environmental or institutional support for the concept of transition in health care; recognition and encouragement that the responsibility for decision-making and consent needs to move from the parents to the adolescent; professional sensitivity to the psychosocial issues of disability and chronic illness; primary and preventive care in addition to care for the chronic condition; and commitment to health education.

For more information, please contact: National Center for Youth with Disabilities, University of Minnesota, Box 721, 420 Delaware St. S.E., Minneapolis, MN 55455, 1-800-333-6293 or (612) 626-2825.

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More than 300 programs responded to the initial inquiry and more than 200 returned in-depth surveys. While this survey is but the first step, the information will allow us to be able to better describe actual program models, to identify elements common across these programs, and to establish a network of individuals and programs around the country with an interest in transition.

Informing the Future

Survey of Teens In Minnesota

Ceci Shapland, R.N., M.S.N.

- Fewer than half of all teens have someone to help them learn how to make their own medical decisions.
- The majority say they have no one to talk to about issues of self-esteem, risk behaviors and health promotion.
- A significant number of teens surveyed had not heard of, nor received, transition planning services.

Minnesota Post-School Follow-up Study

David R. Johnson, Ph.D.

- Eighty percent of young adults are employed; 35% have been unemployed at least once since leaving high school.
- Most young adults (62%) still live in their family home one to five years after leaving high school.
- The two most popular recreational/leisure activties were watching television or listening to music, or going out to eat.

National Transition Survey

Peter Scal, M.D.

- An overwhelming majority of those surveyed said that addressing medical and psychosocial concerns should be important goals of any transition program. More than one-half said they were key goals.
- Primary care, adolescent health concerns and social service needs were high on the list of key goals.
- While vocational issues are a major concern to young people, few of the programs include vocational counselors as part of a comprehensive program. Only 9% offer this with a clinic visit.

Comprehensive Hemophilia Center

The concept of comprehensive care has evolved over the past two decades into a sophisticated method of delivering health care in a "holistic" manner by a team of professionals who work efficiently and harmoniously to support the mental and physical health of the consumer and the family.

That's why the Comprehensive Hemophilia Center in St. Paul relies on a variety of people as they develop individual plans, including physicians, nurses, psychologists, social workers, vocational counselors, health educators, financial counselors, skilled therapists and other consultants. Since no two youth with this complicated bleeding disorder have exactly the same needs, team members work with each youth consumer and family to plan a program that best suits individual needs, and focuses on prevention.

Since almost all persons with hemophilia can become self-supporting, self-sustaining individuals, the National Hemophilia Foundation and its chapters continue to advocate for comprehensive centers.

For more information, contact: Beverly Christie, Comprehensive Hemophilia Center, Box 713 UMHC, 420 Delaware Street S.E., Minneapolis, MN 55455.

Transition Plus Services

In the St. Paul Public Schools, Transition Plus staff work in partnership with a variety of community resources and agencies, including community and technical colleges, rehabilitation services and vocational training programs to help students access programs, transportation, social services and housing facilities that promote independent living. They provide high quality, timely and individualized transition services to students with special needs so they can take advantage of existing community resources.

Using a team process, students receive individualized counseling, advising and training in home living, community participation, career and jobs training, recreation and leisure and post-secondary education—the five key areas of transition.

High school seniors receiving special education services who have met all credit requirements for graduation and need continued educational support to meet their transition goals and

For more information, contact: Karin Tomervik, Transition Plus Services, 251 Starkey St., Suite 128, St. Paul, MN 55101 (612) 293-5420.

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objectives can participate if they can travel independently or use the city bus with limited training and if they can function independently in the community with a minimum amount of supervision.

Project Launch

While transition planning occurs in the educational and vocational systems, health issues are not usually considered. Many young people with chronic illnesses are not receiving special education services. Often they have no access to transition and vocational planning.

So, the University of Minnesota's Adolescent Health Program and the National Center for Youth with Disabilities have joined with the Minnesota Department of Health, Minnesota Children with Special Health Needs; Shriners Hospital, Twin Cities Unit; and the PACER Center to start Project Launch, a transition clinic for youth with chronic illness and disability.

Project Launch: The Independent Living Clinic for Adolescents was created to assist teens and young adults and their families make successful transitions to adulthood by helping them to develop a plan that addresses issues of health, education, work, social relationships, and physical, emotional and sexual health.

For more information, contact: Betty Goodman, Social work Consultant, Minnesota Children with Special Health Needs, 717 Delaware St. SE, Minneapolis, MN 55440-9441
(612) 623-5157

Each teen and family has the opportunity to meet with a variety of professionals during the assessment. The goal, however, is to start with what the young person identifies as the most pressing needs. The clinic allows for a variety of consultations, and the opportunity for youth and families to meet together with the interdisciplinary team at the end of the day.

- A nurse or social worker can review general health care issues, discuss insurance options, and consult on issues surrounding social activities and expectations;
- A physician trained in adolescent medicine can help a young person identify medical and physiological issues, including making plans for ongoing care and the implications for healthy sexual development;
- A psychologist can discuss psychosocial issues surrounding the transition from adolescence to adulthood—gaining independence, learning styles, managing self-care, identifying adolescent health risks and their impact;
- A vocational counselor can help a teenager evaluate past work experience, explore career interests, train and assess needs, and assist in identifying strategies to meet individual goals;
- A family resource coordinator can help the young person with disabilities and the family link with community agencies, schools, physicians, and others as necessary.

Project Launch is a demonstration project available at no direct cost to families or the referring professional or agency.

Improving Transition Services for Adolescents

Experience, both anecdotal and clinical, suggests that transition services benefit young people. The incentives for developing transition services are numerous. Participants listed improved coordination of services, the ability to meet the individual physical, mental health and vocational needs of youth, and the ability to decrease duplication of services. However, barriers to programming exist. Lack of both interested and skilled personnel and reimbursement mechanisms that support transition services inhibit implementation of new models and programs.

Guiding Principles

Six guiding principles drive the recommendations for improving transition services and programs. Programs need to be built on the youth's abilities and competencies; family-centered; culturally sensitive; community based; coordinated and accountable.

Conference participants repeatedly emphasized the importance of including youth and their families in all aspects of the transition process and that providing services based on strengths promotes and fosters healthy adjustment throughout the journey from adolescence to young adulthood.

Youth with chronic illness and disabilities, their families and providers are insisting that programs fit their needs and provide quality services. Programs must:

☐ *focus on identifying and strengthening basic competencies;*

☐ *define the rights and responsibilities of consumers and providers;*

use consumer evaluations to improve services.

With these criteria, conference participants went beyond making recommendations. Rather, they developed the recommendations below with strategies that can be implemented by parents or youth with disabilities, teachers, physicians, social workers or vocational counselors. They can be implemented, regardless of agency, simply by incorporating the strategies into your everyday work plans or into the plans youth are making with their families for their productive and meaningful adult lives.

[redacted]

Recommendations & Discussion Points

1. Develop transition services and programs that foster autonomy for adolescents with chronic illness and disability.

- Provide role models by employing people with disabilities as educators, peer counselors, planners and trainers.
- Develop educational programs that help both parents and adolescents manage the transition to adulthood with autonomy.
- Develop after-school and other social programs that address the special needs of adolescents with chronic illness and disability.

2. Decrease barriers in access and utilization of services.

- Provide consistent, coordinated information that reduces barriers to finding and accessing services.
- Develop a single application form to determine eligibility for many programs and services.
- Decrease the time gap between the request for, and implementation of, services.
- Use a common language, definitions and criteria for eligibility across services.
- Develop integrated services and the opportunity for receiving services in one place.

3. Provide services and programs that are individually oriented and competency-based.

- Use functional status rather than categorical definitions as guidelines for providing services.
- Develop service plans based on individual strengths, needs and goals.
- Be sure agency mission statements, policies and models of delivery are competency-based.
- Involve consumers in developing and evaluating service plans by asking their participation on boards, in focus groups, or on planning committees.

4. Improve collaboration on transition issues among families, providers and agencies.

- Identify and train advocate-service coordinators who have knowledge of, and access to, services for adolescents in transition.
- Designate case managers to facilitate interagency and interdisciplinary collaboration.
- Establish communication strategies among public health, human service, education and vocational agencies serving youth with disabilities, i.e., through school-based clinics, interagency agreements and shared staff.
- Involve a variety of disciplines in transition planning.
- Develop and evaluate models of transition services.

5. Coordinate and streamline funding and services.

- Decrease and simplify the bureaucratic paperwork associated with accessing funds for health care services.
- Develop comprehensive plans for transition that integrate funding sources and eliminate duplication of services.
- Increase the proportion of money allocated to health care for adolescents.

6. Facilitate the move from pediatric to adult health care.

- Begin transition planning with youth, parents and providers early and proceed in a planful way.
- Provide anticipatory guidance before the age of 12 so the adolescent and family can be involved in planning.
- Provide families with the names of adult providers by the time the adolescent is 15 years old.
- Discuss health insurance coverage and alternatives with parents and youth by the time the youth is 17 years old.
- Keep in touch with the youth and family to ensure a smooth transition.

7. Increase accessible transition services in community settings.

- Develop outreach programs on transition in the school system using blended funding and staffing.
- Design and implement mentor programs in high schools for youth with disabilities so they can learn from the experiences of young adults.
- Work with community centers to insure that they are responsive and accessible to adolescents.

8. Improve the Individual Education Plan (IEP) planning process.

- Include the student at all IEP meetings at a very early age.
- Include health concerns in all planning areas.
- Provide transition services for adolescents in the juvenile court system who have IEPs.
- Focus on abilities rather than disabilities.

[redacted]

Principles for all transition programs...

Regardless of the model used, participants identified the following principles that should be applied to all transition programs.

- Transition is a process, not an event, that involves the entire family. The actual process of transition should be gradual, occurring in concert with adolescent and family development. There is no correct time for such a change; but whenever it occurs, ongoing communication among pediatric and adult providers, parents and young people themselves, is critical.
- The transition process should begin at the day of diagnosis for both providers and family members. A plan should be developed in which goals for independence and self-management are outlined on an approximate time schedule with revisions made throughout treatment. The process is characterized by explicit information-giving, recognition of the young person's increasingly greater capacity for choice and growing independence.
- The pediatrician and other child health providers must prepare themselves for transition and realize that, at some point, "letting go" is in the best interest of their patient. Both the young person and the pediatric health team may have to let go of what may be a long-term relationship.
- Different options for moving into the adult health care system should be offered to the adolescent who should be an integral part of the decision-making process. Self-empowerment and independence skills must be fostered throughout the care and treatment and, in particular, in preparation for transition. Families can be helped to understand their changing roles as the focus moves towards speaking with the adolescent alone as much as possible rather than always having parents present at consultations and appointments.
- Treatment and service plans must be individualized and tailored to the specific needs of each adolescent.
- Coordination between primary and specialty health care providers is essential as is coordination between the health care, educational, vocational and social service system.

You can be part of improving transition services in the state of Minnesota...

☑ Implement the strategies outlined here when working with youth with disabilities and their families.

☑ Reduce barriers by inviting nurses and educators, health care professionals, physicians, social workers and therapists—all who participate in planning transition services.

☑ Involve youth and families to work together.

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