

Executive Summary

Massachusetts Initiative for Youth with Disabilities Transition Project

Division of Adolescent/Young Adult Medicine Children's Hospital Boston, MA

September 2001

MIYD Transition Project Staff 1997-2001

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Supported by the Maternal and Child Health Bureau Healthy and Ready to Work Project (#H01MC00006) and the Leadership Education in Adolescent Health (LEAH) Training Program (#6T71MC00009-10).

I. Introduction and History of the Massachusetts Initiative for Youth with Disabilities (MIYD) Project at Children's Hospital Boston

The transition of patients with chronic medical conditions has become a topic of significant interest to the health care community in this country and around the world. Pediatric health care providers can expect that 10% of the patients they see will have a chronic, activity-limiting health condition. Because of earlier diagnosis and improved therapies, patients with chronic medical conditions are surviving through adolescence and into adulthood. This means that these patients will need adult medical care. Many questions remain about the best ways to structure health care and social service systems and the best methods of clinical practice that will meet the multiple needs of these patients.

The Massachusetts Initiative for Youth with Disabilities (MIYD) Transition Project at Children's Hospital Boston was funded in the spring of 1997 as part of a subcontract from the Office for Children with Special Needs, Massachusetts Department of Public Health. This project was a Maternal Child Health Bureau (MCHB) Title V initiative to increase transition and support services for youth with special health care needs by specifically examining models of care and policies within a large pediatric institution. The objective of this project was to design, pilot, and evaluate strategies to promote transition of patients with disabilities and chronic illness from a pediatric setting to adult centered care. Five clinics were selected for this project as exemplars because of the diversity of populations served, differences in degrees of physical and cognitive disability, and the varying levels of expertise for these conditions in adult hospitals. The clinics included the Sickle Cell Program, the Myelodysplasia (Spina Bifida) Program, Boston HAPPENS (Adolescent HIV Program), the Cystic Fibrosis Program, and the Adolescent Medicine Practice at Children's Hospital Boston. The project was designed to understand the process and perspectives of patients, their families, and providers regarding transitions. The project was also designed to facilitate the process of transition for specific patients and their families from Children's Hospital to an adult facility or to adult oriented care at Children's at the same time as the barriers and facilitators of effective transition were identified and solutions generated.

II. Overview of the Massachusetts Initiative for Youth with Disabilities (MIYD) Project at Children's Hospital Boston

Over the 4 _ years of the Massachusetts Initiative for Youth with Disabilities (MIYD) Transitions project, a Transition Model of care (see page 7) was developed for the specialty and primary care programs at Children's Hospital, building upon the knowledge gained from the needs assessment of providers, patients, and families; pilot testing of materials; and review of case studies. The process included the incorporation of the concept of transition into the clinics by building liaisons, the development of transition materials and timelines, the education of patients and families about transition, the actual facilitation of patients' transfer of medical care to adult facilities, and consultations within the community.

III. Barriers to Transition

Through the MIYD Project, we identified a number of barriers to successful transition common to adolescent and young adult patients who were transferring their care from Children's Hospital, regardless of type of disability or illness.

- **Family-Focused Care versus Patient-Focused Care**

The care model at Children's Hospital Boston is family-focused and offers an array of support services to families. The long-term relationships of patients and families with their doctors, nurses, and other professional staff serve as a significant source of information and support in the areas of education, financial resources (including work), transportation, psychosocial issues, and medical issues. Many of the observed differences in adult care were based on the focus of health care: patient focused rather than family-focused. The patient-centered model created obstacles for those patients transferring from one system to another. During a transition from pediatric to adult care, this change in philosophy and structure arose as a significant barrier for both patients and their family members, who had been more accustomed to a family-focused integrated model of care.

- **Attachments Between Patients and Providers**

While the process of health care transition suggests a physical transfer of care, it also may involve the loss of important attachments and relationships between patients, families, and providers. Many patients and their families often expressed fear and reluctance to "losing their doctors and nurses" at Children's Hospital. In addition, many pediatric providers reported experiencing close emotional connections with their patients and families as well.

- **Multidisciplinary Care Coordination**

One major barrier identified through this project was the lack of a coordinated service system in the adult health care system that provides the necessary supports to assist adolescents and young adults with transition. The adult care health system had limited resources for assisting patients in the coordination of care through outreach and case management.

- **Psychosocial stressors and social supports**

Patients with special health care needs, in addition to multiple psychosocial stressors, seemed to experience increased difficulty during the transition period. Complex psychosocial issues also appeared to stunt developmental readiness for some patients during the transition process and impair their ability to manage a new health care system. Patients with complex psychosocial issues, in addition to their special health care needs, required more supports and care coordination during the transition process.

- **Provider Difference of Opinions**

Through interviews and interactions with pediatric clinicians at Children's Hospital Boston, we observed that pediatric clinicians tended to have variable responses to the transition of their patients. At times, differences in knowledge and opinion among providers caused confusion around patient treatment planning.

- **Lack of Adult Care Providers for Young Adults with Special Health Care Needs**
A lack of adult care providers who have expertise in the area of childhood-onset disabilities and chronic illnesses is a significant barrier to transition. There were a limited number of adult primary care providers who have extensive experience treating patients with chronic illnesses such as spina bifida and cystic fibrosis.
- **Specialists as “Primary Care” Providers**
Many patients with chronic conditions, such as cystic fibrosis and spina bifida, view their specialists as their “primary” providers and the clinic site as their “medical home.” This places specialists in a situation in which they are responsible for primary care issues, but may not have the expertise to address these issues. As a result, primary care issues, such as preventive care, sexual activity, substance use, and mental health issues may not be fully addressed with these chronically ill patients.
- **Health Insurance Barriers**
Health insurance policies often limited options for patients wishing to transfer their care, especially when there were a limited number of providers willing to take patients with special health care needs.
- **Medical Research**
Many patients experiencing chronic illness are involved in medical research protocols within Children’s Hospital. When patients were involved in research, providers were more hesitant to promote transition and medical transfer because they wanted to continue offering patients the opportunity to participate in medical advances.

IV. Facilitators of Transition

Through the MIYD Project, several facilitators of successful transition common to adolescent and young adults with special health care needs were identified.

- **Transition Team**
The presence of a Transition Team and Transition Coordinators were significant facilitators of the process at Children's Hospital. The Transitions team consisted of physicians, nurses, and social workers. The Team raised awareness about the issue of transition to adult care providers and encouraged the referrals of those special needs patients aging out of the clinic. Their presence changed the climate of the clinic and mainstreamed the providers towards including transition into the adolescent/young adult care process.
- **Psychosocial Supports**
The Transitions Team at Children’s Hospital Boston found that those patients with more secure and supportive social networks experienced more successful transitions.
- **Provider Communication Across Pediatric and Adult Health Care Sites**
Ongoing communication between the prior pediatric providers and the new adult providers helped to ensure successful transitions.

- **Building Liaisons**
Through this project, the Transition Coordinators built liaisons and strengthened referral relationships with local hospital and community health care providers. These relationships alleviated some patient anxieties and enabled patients to feel more comfortable in the transition process.
- **Transition Planning in the Early Stages**
The Transition Team learned that the health care transition for patients with chronic illnesses and disabilities is a gradual process that needs to take place over time. In general, the more time a patient prepared for the transition, the more successful the outcome. Materials developed by the Project were extraordinarily useful in promoting independence in health care management and facilitating planning.
- **Level of Independence in Health Care Management**
A high level of independent health care management skills was viewed as a necessary component in the transition process. Patients who assumed a higher level of independence in managing their health care were more prepared to assume the responsibilities needed to organize care in the adult health system.

V. Conclusion and Recommendations

Many issues challenge adolescents and young adults with special health care needs and chronic illness as they begin transition to the adult health care system. Other transitions are occurring at the same time including work, school, relationships, living arrangements, and increased independence. A number of recommendations and conclusions can be drawn from the Transition Project conducted at Children's Hospital Boston:

- **Transition should be viewed as both patient and family centered.**
Transition needs to proceed with direction from the young person and involved family members, taking into account their comfort with the process, feedback, and individual timeline. The Transition Team needs to work closely with the patient and family.
- **The Transition process is gradual and needs to start early, with adolescents taking increasing responsibility for their health care.**
Adolescents and young adults with special health care needs should be encouraged to begin discussing medical transition with their providers and families between the ages of 13-15 years to optimize the outcome. Medical transition should also be incorporated into and coordinated with a young person's Individuals with Disabilities Education Act (IDEA) educational plan.
- **A structured Transition Model, printed and web-based materials, and communication tools facilitate Transition.**
Transition curricula and resources are essential to educate adolescents and families about the various aspects of the Transition process. Similarly, curricula and resources for providers can be used to educate physicians, nurses, social workers, and others about the issues that patients and families experience during the transition process.

- A Transition Coordinator is essential for successful transition of adolescents and young adults with special health care needs.

The creation of a Transition Team, with a Transition Coordinator, helps to ensure that patients, families, and providers work together to incorporate the process of Transition into the health care plan. The Transition Coordinator is ideally a MSW or RN with extensive experience in health care and chronic care who can assess psychosocial issues, provide supportive care and case management, work collaboratively across disciplines and across institutions, identify barriers and facilitators to transition, and provide follow-up care.

- Collaboration between pediatric and adult care institutions is critical for successful transitions.

Strengthened institutional collaboration between pediatric and adult health care facilities allows providers to work with families across the transition continuum. As adult and pediatric providers work together, families will feel more supported throughout the transition process.

- Advocacy for adequate insurance coverage and availability of case management are needed to improve outcomes for young adults with chronic illness.

Transition teams need to work together with public health professionals and advocates familiar with current health care insurance policies to ensure that transition is incorporated into all services provided to adolescent and young adults with special health care needs. Case management is an essential component of pediatric and adult-centered care.

Transition from pediatric care to adult centered care and transfer of care for youth with disabilities and chronic illness are challenging life changes. Psychosocial, interpersonal, and medical concerns need to be addressed in the health care site. Collaboration between the two care settings, building on the strength of each, is extremely important. Education of patients, families and providers helps to ensure that transition is successful. Working with advocates can help to ensure that insurance issues are addressed over time so that the HMOs and Medicaid can also help to support this process. The pace of transition needs to be one that is comfortable for the patient, family, and providers. A Transition Team, with an experienced Transition Coordinator, is essential to provide youth with disabilities the support and resources to make transition to adult-oriented care successful.

VI. Materials developed or adapted for the Transition project

Materials that were developed or adapted by this project and by the Institute for Community Inclusion for providers included: Transition Planning for Adolescent with Special Health Care Needs and Disabilities: A Guide for Health Care Providers, “The Transition Intake Form” and “Health Care Skills Checklist.” Materials for patients included: “Transitions: A Guide to Getting Older at Children's Hospital” (also available at www.youngwomenshealth.org), “Transitioning? A Guide to Finding a Primary Health Care Provider,” “Managing Your Health Care,” “Medical Wallet Card,” “Transition Role-Plays,” “Communication with Doctors and Other Health Care providers,” and “Taking Charge of Your Health Care.” Materials for families included: “Parent Tips,” “Family Sheet” “Resources on the Web,” and “Massachusetts State Resources.” In

addition, a new guideline for Children's Hospital Nursing, "Children's Hospital Nursing Guideline: Transition Planning for Youth with Special Health Care Needs" was adopted.

VII. Acknowledgements

Over the past four years, numerous people have been involved in the Massachusetts Initiative for Youth with Disabilities project at Children's Hospital Boston. The MIYD Transition Project staff would like to thank the physicians, nurses, social workers, and staff of the Adolescent Medicine Practice, Myelodysplasia Program, Boston HAPPENS HIV Program, Sickle Cell Program, Cystic Fibrosis Program, and the Institute for Community Inclusion at Children's Hospital for their commitment and dedication to this initiative. The staff would also like to thank Nicole Roos, MBA, and Deborah Allen, ScD, of the Massachusetts Department of Public Health for their help and guidance throughout the project. Lastly, we would like to acknowledge the support of the Maternal and Child Health Bureau Healthy and Ready to Work Project (#H01MC00006) and the Leadership Education in Adolescent Health (LEAH) Training Program (#6T71MC00009-10).