

POSITION PAPER

Transition to Adult Health Care for Adolescents and Young Adults With Chronic Conditions

Position Paper of the Society for Adolescent Medicine

Facilitating a smoother transition for adolescents with chronic health conditions from the child to the adult health care system has been a topic of numerous expert panels, conferences, and policy statements [1–7]. As stated in the original 1993 Society for Adolescent Medicine's (SAM's) position paper, "systemic inertia, fueled by insufficient information about transition options and outcomes, helps maintain an outdated status quo" [4].

The goals of an organized, coordinated transition to adult health care for young people with chronic conditions are: to optimize health and to facilitate each young person's attaining his or her maximum potential. Proactive transition to the adult health care system encourages young people to be successfully integrated into a comprehensive care system to meet their complex needs. The transition must include primary, secondary, and tertiary care with a careful delineation of a financing system that will support a comprehensive care program.

There remain numerous questions about many of the basic transition mechanisms. For example, who most needs a deliberate transition plan, at what age should transition planning begin, how should the transfer of medical care occur, what preparation is required, and in what manner should the actual transfer of care take place? One of the most basic questions remains: What are the effective strategies to engage the adult health care system in the care of these young people? Although transition principles have been described and a variety of models have been proposed and implemented, outcome data are still lacking, especially those that would support one model over another. Without a definitive model, the best approach at this time is to advocate for certain principles that would facilitate an effective transition to the adult health care system.

Principles of Successful Transition

Despite the paucity of meaningful data, there are several fundamental principles of transition that have achieved nearly universal endorsement:

- In whatever health care setting it is delivered, services need to be appropriate for both chronological age and developmental attainment.
- Adolescents and young adults with chronic conditions share many of the same health issues and concerns as their peers. Thus, transitional health programs should be prepared to address common concerns of young people, including growth and development, sexuality, mood and other mental health disorders, substance use, and other health-promoting and damaging behaviors.
- Many adolescents with chronic conditions are at higher risk than peers for unnecessary dependency, developmental difficulties, and psychosocial delay. A successful transition to adult health care may help prevent this by enhancing autonomy, increasing a sense of personal responsibility, and facilitating self-reliance.
- Transition programs should be flexible enough to meet the needs of a wide range of young people, health conditions, and circumstances. The actual transfer of care should be individualized to meet the specific needs of young people and their families.
- Health care transition is most successful when there is a designated professional who, together with the patient and family, takes responsibility for the process. Each patient and family should have a coordinator and advocate who helps to facilitate and streamline their transition experience.

National Consensus Conference

In 2001, a consensus conference on improving transition was jointly convened by the American Academy of Pediatrics and the Health Resources and Services Administration of the Department of Health and Human Services. The aim of the conference was to craft a consensus policy statement on health care transition for adolescents and young adults with chronic health conditions that would enjoy widespread support. The resulting policy statement has been endorsed by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine [8]. The consensus statement articulated six "critical first steps" to ensuring the successful transition to adult-oriented care:

1. Ensuring that all young people with special health care needs have a health care provider who takes specific responsibility for transition in the broader context of care coordination and health care planning.
 2. Identification of the core competencies required by health care providers to render developmentally appropriate health care and health care transition, and ensuring that these skills are taught to primary care providers and are an integral component of their certification requirements.
 3. Development of a portable, accessible, medical summary to facilitate the smooth collaboration and transfer of care among and between health care professionals.
 4. Development of up-to-date detailed written transition plans, in collaboration with young people and their families.
 5. Ensuring that the same standards for primary and preventive health care are applied to young people with chronic conditions as to their peers.
 6. Ensuring that affordable, comprehensive, continuous health insurance is available to young people with chronic health conditions throughout adolescence and into adulthood.
1. For young people with special health needs, the primary care provider or principle caregiver, in partnership with the patient and family, must take responsibility for coordinating primary health care, specialty health care, and ancillary health services. Psychosocial development and health, educational and vocational progress, and overall wellness must also be addressed.
 2. Ongoing education for patients, families, and providers, to highlight the importance and value of a developmentally appropriate and coordinated transition. Consumer and advocacy groups can be helpful in supporting the transition experience.
 3. That adults, including those with childhood-acquired chronic conditions, should receive adult-oriented *primary* health care from appropriately trained and certified providers, in adult health care settings.
 4. That further efforts should be made to engage the adult health care sector to make adult-oriented health services more widely available to adolescents and young adults with chronic health conditions. Minimally, this must include adequate training of adult health care providers, attention to financial and administrative barriers, and ensuring appropriate services (e.g., educational and vocational support) to meet the unique needs of this population.
 5. That collaborative development of "best practices" for the specific management of adults with diseases of childhood should continue to be developed (e.g., [9,10]). Apart from raising the overall standard of care (regardless of where care is delivered), such guidelines would be especially useful for adult-oriented subspecialty providers and hospitals with less experience managing these conditions.
 6. The elimination of protocols, policies, and restrictions by hospitals, third-party payers, and others that impede the timely transition to adult services for young people with special health needs.
 7. That further research is required to address a number of unanswered questions. Research that would examine health outcomes, functional and long-term outcomes, and cost-benefit issues is especially needed.

Recommendations

The Society for Adolescent Medicine joins the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine in endorsing the national Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs. In addition, the Society for Adolescent Medicine recommends:

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