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Moving into Adulthood for Youth with Disabilities and Serious Health Concerns

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For families with youth who have disabling conditions, the end of high school coincides with a number of changes for which they may be unprepared: school to work, home to independent living, pediatric to adult health care, among others. In their chapters in *On Your Own without a Net: The Transition to Adulthood for Vulnerable Populations*, edited by D. Wayne Osgood, E. Michael Foster, Constance Flanagan, and Gretchen Ruth (forthcoming, University of Chicago Press), Robert Blum, and Patience Haydock White and Leslie Galloway examine the needs of youth with disabilities and other serious health issues as they leave childhood for adulthood. This brief summarizes those findings.

A generation ago, most young people with chronic or disabling conditions died before they reached adulthood. Today, more than 90% will survive into adulthood. As Blum reports in his chapter, although the exact prevalence rates of youth with disabilities depend on the definitions used, several patterns are clear. Prevalence rates of disabilities among young people have increased significantly since 1975. Prevalence rates increase with age. Ethnic minorities sustain more disability with more limitations than white youth, and poor families with less-educated parents or single parents are more likely to have children with disabling conditions.

Five Principles to Guide the Transition to Adulthood

Leaving high school is often associated with the greatest disruption for youth with disabling conditions because it marks the end of a structured schedule and is accompanied by rising expectations for work and independent living. As White and Galloway suggest in their chapter, several general principles should guide the transition to adulthood for this group of youth.

First, the transition should be a process, not an event, and should involve the entire family as a support system. It should also begin early, even as early as diagnosis, ensuring that by young adulthood, youth are fully prepared to assume more responsibility for their lives. A survey of 1,300 youth with disabilities aged 14–25 by the Pacer Center revealed that fewer than one-half of the respondents had received any guidance about making medical decisions, nor had they ever been asked about their work plans.¹ Another study of youth with sickle cell disease found that one of the youths' main concerns was that the transition planning had not begun soon enough.²

Health care providers and family members must recognize that “letting go” is in the best interest of the youth. Often, families take the approach of “why change if the current approach is working?” This approach, unfortunately, can create a crisis when the young adult is forced by age, insurance, or life plans to move to another facility or provider. Making changes when the youth is comparatively healthy and involved in the choice is often the better approach for all involved.

¹ B. Wright, “Teens Say Job Training Their Top Need,” *Point of Departure*, vol. 2, no 2 (2001), p. 8.

² J. Telfair et al., “Transfer as a Component of Transition of Adolescents with Sickle Cell Disease to Adult Care,” *Journal of Adolescent Health*, vol. 15 (1994), pp. 558–65.

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Youth, White and Gallay report, should also be prepared for the change from a pediatric health care provider to an adult provider. The latter typically approaches illness and disability from a very different perspective than to what the youth may be accustomed. Pediatric providers often use a team approach, for example, while adult health care providers must acknowledge the privacy rights of individuals. As a result, the youth themselves should be prepared to be their own advocates. Three elements that might make the transition to adult health care providers smoother include an explicit policy on when the young person is required to move to adult medical care; a period of preparation before moving, including gaining an understanding of the treatment rationale, the source of symptoms, signs of deterioration, and how to seek and get help; and a coordinated transfer process, including a detailed written plan, pretransfer visits to the adult clinic, and meeting with the designated provider.³

In a related note, the attitudes of physicians toward physical disability or chronic illness are often at odds with the youth's view of his or her condition. Physicians are trained to fix a problem, yet young people with a disability may not want to be "fixed." Likewise, framing the disability as a deficiency or abnormality is often counter to how youth view themselves.

Teenagers with disabilities offered several suggestions for improving the transition to adult medical services, including having an attentive health care provider, being allowed to make decisions related to health care, ensure that providers explain the transition process, have a doctor of the same gender, introduce the youth to the doctor at around age 14 or 15, and be given options of care with a rationale for each option.⁴

Finally, coordinating health care, education, vocational, and social service systems is essential. Many youth, for example, drop out of college for health reasons. Given that education is such an integral factor in employment, keeping youth engaged is essential.

Findings from a Minnesota Transition Center study in 1999, White and Gallay report, identified 126 programs that offered transition services for those with special health needs. Most programs focused on disease management and did not address other relevant issues, such as independence, continuing education, or job training. Job training, in fact, is often the most pressing issue for young adults. In the Pacer study, all those interviewed placed job training as their most important need, followed closely by independent living skills and vocational guidance. These concerns may be warranted. According to a Finnish study reported by Blum in his chapter, about one-fourth of young adults with disabilities had received no vocational training. In the United States, while about 79% of those aged 18–30 were in the labor force, only 72% with mild disabilities were working, and only 39% of those with severe disabilities were working.⁵

Factors that Affect the Outcomes of the Transition

As Blum reports, the level of independence a young adult with a disability is capable of achieving is ultimately determined by a combination of factors, including individual factors, the extent of the disability, his or her family, and the environment in which the youth lives.

The type and severity of the disability clearly affects the way youth will transition. Those with mental retardation or multiple physical impairments, for example, are more likely to remain dependent compared with those with other disabilities. Youth with sensory impairments are more likely than those with learning disabilities to pursue higher education, and youth with multiple impairments are the least likely to seek higher education, Blum reports. Employment outcomes are similarly imbalanced. Although about 79% of young adults aged 18–30 were in the labor force between 1994 and 1995, 72% of those with mild disabilities were working, and only 39% of those with severe disabilities were working. Often, Blum reports, employers believe that those with disabilities will have more

³ R. Viner, "Transition from Paediatric to Adult Care: Bridging the Gaps or Passing the Buck? Archives of Disease Control in Childhood, vol. 81 (1999), pp. 271–75.

⁴ D. Patterson and C. Lanier, "Adolescent Health Transitions: Focus Group Study of Teens and Young Adults with Special Health Care Needs," *Family Community Health*, vol. 22 (1999), pp. 42–58.

⁵ P. Scal et al., "Young Adults with Childhood Onset Disability Making their Way into Adulthood," *Pediatric Research*, vol. 53 (2003).

The Research Network on Transitions to Adulthood and Public Policy examines the changing nature of early adulthood, and the policies, programs, and institutions that support young people as they move into adulthood. Significant cultural, economic, and demographic changes have occurred in the span of a few generations, and these changes are challenging youth's psychological and social development. Some are adapting well, but many others are floundering as they prepare to leave home, finish school, find jobs, and start families. The network is both documenting these cultural and social shifts, and exploring how families, government, and social institutions are shaping the course of young adults' development. The Network is funded by the MacArthur Foundation and chaired by University of Pennsylvania sociologist Frank Furstenberg.

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absences, when in fact, the opposite is true. Employers also often assume that necessary accommodations will engender resentment among nondisabled workers.

Regardless of their pursuits, those with mild incapacity or “invisible” conditions often have the most difficulty adjusting emotionally. As one young person with spina bifida and only a mild gait disturbance said, “I am rejected by those with spina bifida and cerebral palsy, and I am rejected by those who are able-bodied. I live in no-man’s land.”

Beyond the condition itself, individual factors influence outcomes. The individual’s perception of how others respond to him or her is important to success. In addition, social skills are also important to success, Blum reports. Unfortunately, many young adults with disabilities have had fewer opportunities to develop social skills. Coupled with the effects of stigma, time demands, and constraints imposed by their condition, young adults with disabilities are often socially isolated, and social isolation is the foundation of depression. In addition, social isolation impedes the important informal supports that arise from friends, coworkers, and others who can help youth manage the transition to adulthood.

Conclusion

Medical advances have made tremendous strides in prolonging the lives of youth with disabilities. Where we have been less successful is in normalizing their lives. Transitional planning for youth with disabilities or serious medical conditions should be a critical component of their lives. Such planning should start early, involve the youth, include vocational programs, and build a strong support system for the youth that includes the medical community, family, friends, peers, and the larger community in which they live.

Based on Robert Blum, “Adolescents with Disabilities in Transition to Adulthood” (chapter 12) and Patience H. White and Leslie Gallay, “Youth with Special Health Care Needs and Disabilities in Transition to Adulthood” (chapter 13). In On Your Own without a Net: The Transitions to Adulthood for Vulnerable Populations, edited by D. Wayne Osgood, E. Michael Foster, Constance Flanagan, and Gretchen Ruth. University of Chicago Press, forthcoming fall 2005.

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