HELPING ADOLESCENTS WHO HAVE DISABILITIES NEGOTIATE TRANSITIONS TO ADULTHOOD

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Adolescents who have disabilities face unique challenges as they progress through the transitions necessary to achieve optimum functioning in adulthood. These youths often need professional assistance to successfully negotiate these important transitions. Our article describes processes for collaborating with these adolescents, their families, and other professionals to facilitate successful transitions to a more healthy, productive, and satisfying adulthood.

Children who have chronic conditions and developmental disabilities now have increased survival and longevity because of advances in medical knowledge and technology. Today in the United States, 90% of those born with a disability will live to at least age 20 (Blum, 1995). In 1994, 12.6 million children under the age of 18 had chronic health conditions that mandated use of health and related services beyond those generally required by children (Newacheck et al., 1998). Recently, new public policies support the inclusion of individuals with developmental disabilities within mainstream culture (Goldberg, Gardner, & Gibson, 1994). Federal legislation, such as the Individuals with Disabilities Education Act (IDEA) and Americans with Disabilities Act (ADA), mandates free public education in an inclusive environment; access to facilities such as public transportation, stores, and recreational facilities; independent living within the community; and equal opportunity for employment with necessary accommodations for individuals who have disabilities.

Despite these policy supports, many youths who have disabilities fail to participate fully in society once they become young adults. High school graduation rates are lower than for adolescents without disabilities, and

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of those who do graduate, fewer go on to college. In a comparative survey of nondisabled and disabled young people age 16–24, labor force participation rates were lower, unemployment rates higher, and mean earnings for disabled youths were lower (Newacheck, 1989). Fully 21% of those with disabilities had only public health insurance such as Medicaid, compared with only 6% of those without disabilities. Poorer health care outcomes also have been reported for individuals with disabilities. In one survey, young adults with disabilities contacted health care providers an average of 11 times per year compared with 4 times for young adults who did not have disabilities. In addition, they had an average of 2,200 hospital days per 1,000 person-years compared with 408 for those without disabilities. (McManus, Newacheck, & Greaney, 1990).

Adolescents who have chronic health conditions, like their healthy peers, need to successfully negotiate the transitions from school to work, from home to community, and from child-centered pediatric to adult-oriented health care. The first two transitions are more important but require stable, optimum health for success. Making these transitions requires more than fulfilling a checklist of activities; it requires changes in attitudes, of both the adolescents and their families and of members of the adult society into which they must be integrated. Our article examines key issues in the transition to adult living for youths with chronic illnesses or disabilities and recommends actions that they, their families, health care providers, and others can take to help them successfully negotiate these transitions.

THEORETICAL FRAMEWORK

A combination of theoretical frameworks and constructs provides insight into this complex topic. Erikson’s psychosocial developmental theory (Erikson, 1959), Rutter’s construct of “chains of adversity” (Rutter, 1989), and stress and coping, family systems, and self-efficacy theory (Bandura, 1977) all provide a useful foundation for understanding adolescents’ transition challenges and for developing strategies for assisting them and their families.

Erikson (1959) defined “identity versus role diffusion” as the psychosocial stage with which the ego must contend during adolescence. To achieve a sense of personal identity, adolescents use role models and peer groups to experiment with different identities and roles. Unfortunately, youths with disabilities have fewer positive role models in popular American media such as movies, television, and periodicals. Because youths who have chronic conditions often look different and may know few individuals who have the same disability, peer identification is more difficult. Moreover, physical and cognitive impairments may have imposed
barriers to successfully meeting earlier psychosocial developmental challenges. Since these impairments remain life-long realities, typical identity development is especially difficult and may be impossible for some adolescents who have disabilities.

Erikson (1959) also includes gaining independence from the family as important in developing identity. However, individuals who have disabilities may have to live with their families longer than others because of financial and other reasons, further impairing their developing independent identity. Also during this stage, adolescents must re-address earlier developmental challenges such as trust, autonomy, initiative, and industry, all of which may have been less than successfully met in earlier years.

Immediately after adolescence, suggested Erikson (1959), young people face the psychosocial challenge of “intimacy versus isolation.” Most individuals who have disabilities, even those with significant cognitive limitations, have many strengths and hope to achieve typical adult interpersonal relationships. If individuals who have disabilities cannot develop a sense of identity, cannot achieve independence from their families of origin, and have difficulty finding a peer group, their sense of isolation may be deepened. Developing a sense of intimacy with another individual may therefore be more difficult. Moreover, specific aspects of certain disabilities that affect social interaction, such as the difficulty with speech articulation or voice volume that often accompanies cerebral palsy, may be further barriers. Conditions that impair physical sexual functioning such as severe mobility impairment or loss of enervation to the sexual organs, also can impair developing intimacy. And because cultural norms of beauty usually do not include individuals with disabilities, these adolescents may have more difficulty identifying someone who recognizes their intrinsic worth and who desires an intimate relationship with them.

The chains of adversity framework provided by Rutter (1989) is helpful to understand the challenges of transition faced by adolescents who have disabilities. For youths who have chronic illness or disability, chains of adversity occur when the individual’s physical impairments initiate a sequence of outcomes that are disadvantageous. For example, an individual with cerebral palsy who has difficulty with verbal communication, who requires assistance with activities of daily living, and who needs frequent health care interventions is likely to have poorer school attendance and peer relationships. This results in less school success and may lead to early departure from school. The adolescent thus may lack scholastic qualifications for optimum employment, leading to unemployment or “underemployment” in unskilled work. The result is a poor employment record that adversely affects the individual’s ability to cope
with stress and fulfill typical adult roles such as independent provider, spouse or other family member, or parent. Such chains of adversity help explain the relationship between certain characteristics, such as low socioeconomic status, and poorer functional developmental outcomes for youths who have disabilities. Interventions that break chains of adversity promote more positive outcomes.

Self-efficacy theory supports adolescents’ participation in decision-making in developmentally appropriate ways. Pediatric health care providers and family members should include children in discussions about their health care and encourage them to participate, helping them to manage their own care in whatever ways they can from the earliest possible age. Doing so promotes clients gaining knowledge and confidence that supports independence in many life spheres; lack of participation keeps them in dependent relationships with a sense that they cannot alter or have control over their environment.

Adolescents who have disabilities may be viewed as immature by their parents, friends, and professionals. Many disabilities require treatments and programs for managing hygiene and activities of daily living that place great demands on parents and individuals. Activities such as catheterizing their child, ensuring that medications are taken in a timely fashion, and ensuring that numerous visits to health care providers are attended create dependency relationships between parents and their children not typically found with children who are not disabled. Thus, parents of children who have disabilities may have more difficulty “letting go.” This difficulty, compounded by a desire to protect children who have disabilities (a desire also common in pediatric health care professionals [Strax, 1991]), can be a pervasive barrier to successful transition.

Adolescents with chronic conditions or disabilities may have more difficulty gaining cognitive developmental readiness for transition to adult independence. In some conditions, such as Down Syndrome, cognitive development proceeds more slowly and plateaus at a lower level, making it more difficult for school personnel, family members, and others to adequately prepare these youths for adulthood. Conditions like cerebral palsy and autism are frequently compounded by mental retardation. Other conditions, such as spina bifida and Turner’s Syndrome, are associated with learning disabilities rather than mental retardation, but these also hinder the development of readiness.

PROMOTING SUCCESSFUL TRANSITION

Findings from several investigations suggest that a number of factors may enhance successful transition for adolescents who have disabilities
(Kokkonen, Saukkonen, Timonen, Serlo, & Kinnunen, 1991; Nazr, Campbell, & Howarr, 1992; Wysocki, Hough, Ward, & Green, 1992). These include:

- High self-esteem.
- Positive social orientation.
- Warm and cohesive family in which parents are supportive but not overprotective.
- Adequate social supports including a network of friends with and without disabilities.
- Sense of contributing at home through carrying out various chores and responsibilities.
- Previous success coping with stressful experiences.

To be most helpful in promoting successful transitions, the practitioner needs to complete certain assessments and then assist the adolescent to plan transitions based on his or her unique strengths and areas of need. Practitioners also need to be aware of the extreme complexity of this process and to work for each adolescent with others in various health care and school- and community-based agencies to prepare a transition program that is individualized, comprehensive, and coordinated.

**ASSESSMENT**

Evaluating the adolescent’s ability to negotiate the transitions from adolescence to adulthood includes assessing the child and his or her family, as well as the larger environment, in terms of potential barriers and facilitators for the transition. Assessments of different areas by several members of an interprofessional team to identify both strengths and needs and commitment to continuing assessment over time is most effective. Table 1 presents arenas for assessment, with topics that need special consideration.

The first phase is to assess the individual, the family, and the larger environment for potential barriers and facilitators for the transition. The first step is to evaluate the child’s developmental readiness, with reliance on developmental theory (such as Erikson’s psychosocial theory and Piaget’s theory of cognitive development) for guidance as to what should be expected of youth at different ages. This assessment may be done formally or informally. For example, Cappelli, MacDonald, and McGrath (1989) developed a questionnaire to evaluate the readiness for transition to adulthood of adolescents with cystic fibrosis. This questionnaire included items regarding knowledge about cystic fibrosis as well as behaviors associated with its management. They found that the behavioral items were
more highly correlated with later successful transition than were the informational items. These behavioral items included being able to identify the names of medications, taking medications without reminder, taking initiative in contacting health care providers, and actively participating in procedures such as pulmonary physical therapy. Similar instruments could be developed to formally assess developmental readiness of youths who have other conditions, such as spina bifida or congenital heart disease.

The second step is to evaluate the youth’s and family’s structures, social supports, and goals. Information obtained from the family on daily activities, relationships, rights, and responsibilities can help identify the current family structure. Stressors, coping mechanisms, and social supports should be identified. The importance of social supports has been underscored by the work of Werner & Smith (1992), who found that, in a population of adults with chronic conditions, successful adult functioning at age 33 years was correlated with having had a relationship with a supportive adult as a young person. Identifying both the adolescent’s and the family’s goals for future independent living, work, and health care helps determine how much consideration they have given to transition and how realistic the goals are.

The third step is to evaluate the environment outside the family. The best planning should begin long before the child becomes an adolescent,
and certainly before he or she leaves school. Because children not only gain knowledge, but also social prowess and skills in problem-solving and decision-making while in school, the school is one of the most critical environments to evaluate.

Many social programs are now available to support meeting the needs of children who have disabilities (Burns & Thorman, 1993). All students who have disabilities are protected under Section 504 of the Rehabilitation Act of 1973 (PL 93-12) that prohibits discrimination on the basis of disability in federally funded or assisted education and employment programs. These children have the right to receive education with reasonable accommodations, including specialized education and related aids and services. All schools should have a Section 504 plan that outlines the procedures for developing an accommodation plan and providing necessary services for such students. Under IDEA, the individual education program for children who have cognitive disabilities must include plans for transition by the time the child is 15 years old. Some states mandate a transitional plan even before this age.

Other aspects of the environment to be evaluated include programs that can assist individuals with finding affordable and accessible housing and suitable employment. Information about model programs and technical assistance for those interested in helping youths with these issues is available through the National Information Center for Children and Youth with Disabilities (NICHCY) at 1-800-695-0285.

Adolescents with disabilities and their families need to address questions such as How will the youth gain income, e.g., through employment, public assistance, or reliance on family or friends? What kind of continuing education will be pursued after high school, if any? Where will the youth live, and what types of supports will be needed for optimal independence, autonomy, safety, and privacy? How will these supports (such as personal care aide or homemaker services) be obtained? How will continuing health care needs be met and paid for? Can the youth drive or use public transportation? If not, how will transportation needs be met? Does the adolescent have strong peer supports and good mental health or will special supports be needed? Can he or she make appropriate judgments and choices or is help with advocacy needed? How will long-term future needs be met? Parents are often especially worried about what will happen to their child after they can no longer provide direct assistance.

**PLANNING**

Intervention to help with transitions must be planned carefully to meet several goals:
- To maximize the developmental potential.
- To optimize the health of the adolescent or young adult.
- To identify and break any adverse chains.
- To promote relief of stress and positive coping patterns in the adolescent and the family.
- To promote positive family functioning in support of the adolescent’s increasing independence.
- To support development of self-efficacy in the adolescent.

To achieve these goals, the plan should be in place early in the youth’s secondary educational experience. It should include strategies to help the youth understand and appreciate his or her strengths and abilities in light of a realistic appraisal of his or her disabilities; be an effective self-advocate; develop optimum knowledge of his or her chronic condition and its management; attain optimum independence and assumption of responsibility for self care; and articulate goals and make realistic plans for future living, work, and socialization.

**IMPLEMENTATION**

All the following activities are designed to promote progress through Erikson’s stage of identity versus role diffusion, to break chains of adversity, and to increase independence and self-efficacy for the adolescent during the process of transition. Table 2 summarizes these suggestions.

**Identify Care Coordinator**

The role of the care coordinator, with the adolescent as the central player, is to determine the needs of the adolescent and family, plan comprehensive care, and facilitate, coordinate, and monitor care to ensure that all needed services are being received. Being a care coordinator means being knowledgeable about the adolescent and family as well as about community resources available to meet the individual’s needs. In some cases, the adolescent, with appropriate assistance from parents or another adult, can assume this role. This is the ideal situation for promoting future independence, but it may not be feasible for adolescents or families with removable barriers such as cognitive limitations or very high levels of stress and chaos in daily life.

Adolescents who have cognitive disabilities may be eligible for care coordination services through their state developmental disabilities services organization. Unfortunately, however, care coordination services may be difficult to obtain because the current health care financing system includes limited opportunities for providers to be appropriately paid.
for time spent in indirect care activities. In this case, the primary care pediatrician or nurse practitioner may assume this role and absorb the cost, or the parents and adolescent may become the care coordinators by default instead of by choice and will need assistance to accomplish this difficult but most important task.

**Plan Transition**

Assistance in planning the transition process with the patient, care coordinator, family, school, and other involved community agency personnel, and the future provider of adult health care is essential. The developing plan should be assessed continually for its feasibility and acceptability to the adolescent and family, and for the ways in which it empowers them. The best plan will fail if the client and family are not motivated to implement it or if they lack the resources it requires.

**Provide Health Maintenance**

Health maintenance and preventive care with emphasis on nutrition, physical fitness, sexuality, substance abuse prevention, personal safety, and

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<tr>
<th>Table 2. Suggested elements of a transition implementation plan</th>
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<td>Adolescent assumes central role on transition team</td>
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<tr>
<td>Care coordinator identified and active</td>
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<tr>
<td>Transition plan goals, objectives, and time frames agreed upon</td>
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<tr>
<td>Comprehensive transition plan developed, involving:</td>
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<tr>
<td>Adolescent</td>
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<tr>
<td>Family</td>
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<tr>
<td>School</td>
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<tr>
<td>Present and future health care providers</td>
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<tr>
<td>Community-based support</td>
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<tr>
<td>Health care transition integrated</td>
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<td>Health status optimized</td>
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<tr>
<td>Adolescent self-care and advocacy skills developed</td>
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<td>Providers of adult health care identified</td>
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<td>Bridges to effective adult care created</td>
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<td>Financing for future health care ensured</td>
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<td>Progress toward goals and objectives regularly evaluated</td>
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<tr>
<td>Transition plan revised as needed</td>
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<td>Successes celebrated</td>
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<td>Difficulties used positively</td>
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emotional health are important. Unlike the care of younger children, with its strong focus on health promotion and anticipatory guidance, adolescent health care visits often occur in conjunction with health crises. These crises are more frequent among youths who have disabilities, diverting attention from health promotion and prevention to medical problems that are often managed in the specialist’s office. Therefore, emphasizing health maintenance and preventive issues is even more essential.

**Teach Self-Care**

Instruction in self-care that promotes health maintenance and prevention of health problems, especially secondary conditions is needed. For example, youths who have mobility impairments need to learn how to prevent skin breakdown, obesity, chronic constipation, and joint contractures. Those who have learning disabilities or mental retardation need environmental structures and cues to remember to carry out health maintenance routines faithfully. All these youths need to learn how to stay fit physically and attend to their emotional health. Preventing secondary conditions is especially important to maintaining employment.

**Move to Adult Providers**

When the adolescent is ready to change to adult care providers, pediatric providers must support the building of a trust-based relationship with the new provider. Demonstration programs have found that joint visits including the old pediatric and new adult providers of care is beneficial (Schidlow & Fiel, 1990; Strax, 1991). Including family members in these visits should be at the discretion of the adolescent. If they do attend, family members should be coached on how to provide assistance from a distance and to support the adolescent in making his or her own decisions and in becoming self-efficacious.

**Share Information**

Inform the new care providers about the adolescent’s condition, current management of the condition, and about the client’s strengths, needs, and goals. Information regarding the adolescent’s condition is necessary because many chronic conditions of adolescents have been previously considered to be “pediatric.” Therefore, these conditions and their care may be unfamiliar to adult care providers. But, due to increased longevity, these are now conditions of adults. This information should be transferred in a written, detailed health care summary, and the adolescent should have a copy. Self-efficacy in the adolescent can be supported by building the
summary document about the condition over time and by always including input from the adolescent and family as documents are written and communicated to other providers of care. Community resources that assist with adult services should be identified for the new caregivers, since adult providers may not have used these agencies previously.

**Continue Liaison Between Pediatric and Adult Care**

Pediatric health care professionals and educators who are knowledgeable about conditions that are unfamiliar to many adult care providers, such as spina bifida, cystic fibrosis, and congenital heart conditions, should participate in preservice and continuing education for professionals who care for adults. Studies have shown transitions have been more successful for clients who have conditions such as diabetes that are more familiar to internists (Schidlow & Fiel, 1990). Transfer of care to providers trained in family medicine or physicians who completed a medical-pediatrics residency, who see both children and adults, may help bridge the gaps between the two cultures of pediatric and adult medical care (Rosen, 1995).

**Ensure Future Financing**

Health care and social service needs require payment. For example, assist the youth to obtain all assistance for which she or he may be entitled, such as Social Security Disability Income, and to obtain employment that offers comprehensive health insurance as a benefit option. If rights or entitlements are being denied, the local advocacy center should be contacted.

**Encourage Expression of Feelings**

Encourage the adolescent to ventilate feelings throughout the process, and assist him or her to become informed regarding all health care options and to make his or her own decisions about future care. Open expression of feelings is facilitated when care providers are truly interested in the client, are good listeners, and have developed a long trusting relationship with the adolescent. Added value results when the adolescent has realized positive outcomes from sharing feelings in the past.

**DOCUMENTATION**

To help a family and adolescent identify personal goals related to developing independence, a checklist or a questionnaire should be provided
that covers the main areas of importance in transition planning including social skills and support, plans for school or work, financial support, health care, and long-term planning. A formal checklist is available from Sample, Spencer, & Bean (1990). Also, Kennedy et al. (1998) have developed questionnaires that assist both parents and adolescents to identify medical and nonmedical needs. For some adolescents, social skills training may be of benefit for gaining further self-efficacy; others may need family counseling to bring the family structure back into order and to break chains of adversity.

During routine health care visits, the health care provider can perform an interpretive interview and teaching physical examination (Hassler & Hostler, 1986; Willson & Hostler, 1986). During the interview, the concerns of the family and adolescent are attended to, and they are provided with relevant information for each concern. Medical and rehabilitative interventions are discussed, and plans made for future care. During the teaching physical examination, the youth’s abilities and disabilities are reviewed system by system. After the examination, more specific health education can be provided either by the primary health care provider or a health education specialist. Reinforcing this teaching at home and at school assists the youth to feel more competent, to enhance self-efficacy, and to possibly break such adverse chains as the school failure in our earlier example.

Some health care providers help adolescents create their own personal medical summary—basically a condensed version of the medical record compiled by the client. Such a summary provides emergency information; lists of medical problems; long-term medications; service providers; daily routines; equipment such as adaptive devices; information on positioning, therapeutic goals, toileting, meals, and communication mechanisms; and brief summaries of health care visits and laboratory tests and x-rays. This document is intended to improve communication with health care providers as well as to encourage the individual with disabilities to be more aware of his or her care. Developing this document over time in collaboration with the adolescent enhances its effectiveness and may enhance self-efficacy.

In 1992, at least 10 programs in the United States focused on assisting youths who have chronic illness or disabilities with transition (Carlin, 1992). The National Center for Youth with Disabilities* is specifically designed to offer information and resources focusing on transition for youths with chronic health conditions. This center has many available resources on transition care. Its personnel welcome contacts and provide

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*National Center for Youth with Disabilities, University of Minnesota, Box 721, 420 Delaware St. SE, Minneapolis, MN 55455, (612) 626-2825.
valuable documents and other resources at low cost. Betz (1998) lists other valuable resources in a helpful review of this topic.

EVALUATION AND FOLLOW-UP

Whenever adolescents who have disabilities are assisted with transitions, the process and outcomes of interventions should have a fourfold evaluation:

1. Measuring whether or not the intended interventions actually are taking place (e.g., is the clinically depressed adolescent receiving appropriate counseling and medications and responding to them?)
2. Determining the level of satisfaction of the adolescent and family with the interventions.
3. Monitoring process and progress toward intermediate objectives (e.g., have adult-oriented care providers been identified and educated about the adolescent’s condition?).
4. Measuring success in meeting identified outcome objectives (e.g., was the young adult able to find and hold a meaningful job or have secondary disabilities been prevented?).

When variances from the planned course of action are identified or objectives are not being met, analysis needs to determine whether the variance is related to provider, system, or patient-related variables. Then the plan can be modified accordingly, thus increasing the probability of its success.

CONCLUSION

Transition from adolescence to adulthood is a complex and challenging process, even for typically developing youths. Moreover, despite progress through the ADA, IDEA, and inclusion of individuals with disabilities in mainstream society, most individuals still generally view people with disabilities negatively. They see them as different from the norm rather than as valuable people who are more like themselves than not. Therefore, adolescents with disabilities face additional transition challenges related to their disabling conditions and society’s attitudes toward them.

Pediatric health care providers, who know the strengths and potential contributions of young people with disabilities and who understand their disabling conditions, must assume responsibility for helping to create the bridges they need to be fully included and optimally valued in adult society. Effectively assisting individual adolescents to become healthy, competent, contributing adults meets an immediate need. It is equally
important that we advocate for systems and policy changes that support the development of a new society in which all people are fully valued. The end result, a society that benefits from the contributions of all its members, will be well worth the effort.

REFERENCES


