

## Quality Health Care for Adolescents with Special Health-Care Needs: Issues and Clinical Implications

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### **Abstract:**

Assuring quality health care for the diverse U.S. adolescent population is a subject of growing concern among health-care providers and policy makers. Health-care services and policies must appreciate that experiences of adolescents with special health-care needs include challenges that stretch beyond those unique to their conditions to include relationships with family, friends, and professionals as well as their ability to function in school, clinics, and other settings. This review explores those issues while building upon the six core outcomes delineated in the draft 10-year action plan offered as an accompaniment to the U.S. Department of Health and Human Services' Healthy People 2010 guidelines.

### **Article:**

The experiences of adolescents with chronic illnesses and disabilities or special health-care needs, henceforth adolescents with special health-care needs (ASHCNs), embody not only the complexities of being an adolescent, including relationships with family, friends, and professionals as well as their ability to function in school, clinics, and other settings, but also challenges unique to their conditions. In a recent *Journal of Adolescent Health* (2002) volume devoted to adolescent risk and vulnerability, Nightingale and Fischhoff (2002) described the special health-care needs that ASHCN face as having the potential to engender "daunting challenges and even panic." These potential challenges and uncertainty are shared among ASHCN, their families, and those who develop policies and provide services for them.

The U.S. Department of Health and Human Services' (DHHS) Healthy People 2010 guidelines highlight the elimination of disparities for vulnerable and at-risk populations including ASHCN, with a special emphasis on access to health-care services. As an accompaniment to Healthy People 2010, a 10-year action plan (U.S. DHHS, 2001a) developed under the leadership of the Maternal and Child Health Bureau (MCHB) lists six core expectations or outcomes of the pursuit of achieving community-based systems of services for children and youth with special health-care needs (Health Resources and Services Administration, 2001):

1. All children with special health-care needs (CSHCN) will receive regular ongoing comprehensive care within a medical home.
2. All families of CSHCN will have adequate private and/or public insurance to pay for the services they need.
3. All children will be screened early and continuously for special health-care needs.
4. Services for CSHCN and their families will be organized in ways that families can use them easily.
5. Families of CSHCN will participate in decision making at all levels and will be satisfied with the services they receive.
6. All youth with special health-care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

This review is designed to provide a comprehensive overview of the literature pertinent to the history of these guidelines and to provide hints for successful implementation. To streamline this process, we have distilled the six outcomes listed above into three core categories for assuring quality health care for the ASHCN population.

They are the following: (a) improving access to comprehensive care for ASHCN, (b) improving transition to an adult health-care system, and (c) improving collaborative relationships among the health-care community, the ASHCN, and their families.

## **ACCESS TO CARE**

Concern for the American adolescent population's access to and utilization of health services and transition to adult care are magnified in the cohort of adolescents with chronic health conditions and cognitive disabilities<sup>1</sup> (McPherson et al., 1998). An estimated 12.8% of the U.S. population between the ages of 10 and 24 years have a special health-care need (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004), which often requires greater access to health and related services (Ozer et al., 1998). Of these, an estimated 88.8% have health insurance, either public or private, leaving 11.2%, or 1.3 million, children nationally, without any form of insurance coverage (Newacheck et al.) (Newacheck, McManus, Fox, Hung, & Halfon, 2000).

State Children's Health Insurance Program (SCHIP) is an insurance program that provides health insurance coverage for all children whose families' incomes make them ineligible for Medicaid, but insufficient for purchasing private insurance. SCHIP provides an important opportunity to provide high-quality health care for the population of adolescents historically denied health coverage. Despite this, poor or near-poor children (below 100% of the poverty level or between 100% and 200% of the poverty level, respectively) are more than four times as likely to be uninsured as their counterparts in families with incomes at or above 200% of the poverty level, leaving a sizeable proportion of the ASCHN population unable to get care as frequently as needed because of cost (Newacheck, McManus, Fox, Hung, & Halfon, 2000). Access is not merely a function of presence or lack of insurance, however. For example, in two recent studies by Haque and Telfair (2000) and Telfair et al. (2003), rural African Americans with sickle cell disease had more difficulties getting needed care because of socioeconomic, structural, and transportation limitations. Limitations such as these can prove as troublesome to ASCHN and their families as inability to obtain insurance.

The changing delivery of health-care services presents challenges in availability and coordination between primary and specialty care, competing health-care plans and administrative bureaucracies, managed care "gate-keeping," financing, and reimbursement systems, and quality of care assurances (McPherson et al., 1998; Newacheck et al., 1998). The shift to managed care occurring in both the public and private sectors must systematically plan accordingly for the ASHCN population or key services such as mental health, rehabilitation (OT and PT) and respite will be inadequately provided or cease to exist (English, Kapphahn, Perkins, & Wiblelsman, 1998; NAHIC, 1998). Given the reality of clinical improvements for ASHCN, state Title V CSHCN Programs are increasingly challenged in their attempts to provide supportive case management services, which can lead to improved quality of life for ASHCN. Further, numbers of ASHCN are expected to increase, due primarily to significant decreases in morbidity and mortality and extended survival from childhood through adolescence and into adulthood for this population (Betz & Redcay, 2002; Wierenga, Hambleton, & Lewis, 2001). This decrease in morbidity and mortality and subsequent increased survival is attributed primarily to the enormous educational and technological efforts that have led to vast improvements in the treatment and management of these conditions over the last 15 years (American Academy of Pediatrics [AAP], 1996a, 98:1203–1206, 1996b, 97:275–278; Castro, Chicoye, Greenberg, Haynes, & Peterson, 1994), efforts that have left some providers, insurance, and health maintenance companies behind. In an effort to provide timely and adequate care for the variety of health problems encountered by ASCHN, multiple environments, including schools, should be utilized.

## **COMPREHENSIVE HEALTH CARE**

According to Blum (1998), "we must move from a goal of 'problem-free' to a goal of positive youth health constructs." Driven by a historically narrow, physical view of health, providers for ASHCN have spent most of their time providing direct services for illness-related problems (e.g., intermittent symptom flare-ups) as compared with general psychological problems (Drotar et al., 1997). Although ASCHN are significantly more likely to experience more days in bed because of illness, more days absent from school, more physician contacts and days spent in the hospital than those who do not have special needs, they are also significantly more likely

to be less satisfied with their medical care and to have a greater proportion of unmet health needs. ASHCN visit their health-care provider 2.5 times more frequently than adolescents without special health-care needs (Foundation for Accountability [FACCT], 2001). Because of the high frequency of encounters with the health system, many ASHCN are likely to be affected by a health-care system that is not comprehensively meeting their health-care concerns (Scal et al., 1999). Biologically based "problem-focused" interventions that are narrow in scope appear not to work (Blum, 1998). The World Health Organization (1948) defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Certainly, health outcomes for ASHCN should not deviate from this goal. In fact, examination of current policy and legislation for ASHCN highlights the importance of moving beyond only biological and physical needs and venturing into psychological, social, and cultural arenas (Brindis, Kirkpatrick, Macdonald, VanLandeghem, & Lee, 1999).

Increased survival rates mandate transitioning into adult systems, where ASHCN are faced with further challenges such as limited access to health care, limited employment opportunities, educational barriers, adjustments to independent living, development of social and recreational skills, and limited health insurance coverage (Betz & Redcay, 2002). ASCHN often find themselves not fully prepared to master these new challenges (Wagner, 1992). Thompson, Gustafson, and Gil (1992) have shown that lack of mastery of these challenges puts ASCHN at risk for chronic dependency, low self-esteem, high stress, ineffective coping skills, psychological difficulties (e.g., increased anxiety, depression, and decreased self-efficacy), and functional failure within their families and in adult social and health-care systems (McAnarney, 1985). ASCHN are more likely to suffer from increased behavioral (Gortmaker, Walker, Weitzman, & Sobol, 1990) and emotional problems (Ireys, Werthamer-Larsson, Kolodner, & Gross, 1994; Wolman, Resnick, Harris, & Blum, 1994) than their counterparts without special needs. Additionally, a recent online assessment of 2,000 adolescents aged 13–17 years identified those with special health-care needs as less healthy, less self-confident in dealing with life situations and less connected to their communities (FACCT, 2001). Despite this, however, there is some evidence to suggest that ASCHN may be more resilient in the face of adjustment to the challenges posed by their chronic condition than was once thought (Olsson et al., 2003).

As such, ASCHN are not immune to the problems experienced by the general adolescent population. In a North Carolina study by Britto et al. (1998), the prevalence and age of onset of common risky behaviors (including substance use and sexual experience) by teenagers with cystic fibrosis and sickle cell disease was compared with behaviors of adolescents in the general population. Although the rates of risky behavior were lower than the comparison population, Britto et al. (1998) reported alarming risky behavior in sexual activity and substance abuse. Additionally, ASCHN may also be particularly vulnerable to sexual abuse or exploitation (AAP, 1996a; Wingfield, Healy, & Nicholson, 1994). Sensitive domains, such as reproductive and sexual health, may pose problems not only for ASCHN, but also for the individuals (e.g., parents, care providers) faced with explaining adult relationships and sexuality (AAP, 1996b; McConkey & Ryan, 2001). Because the development of a sexual identity is an important milestone in the development of all adolescents, parents and health-care providers must be prepared for these issues to arise (Selekman & McIlvain-Simpson, 1991), although some professionals argue that sex education for ASCHN, particularly those with developmental disabilities or cognitive impairment, is far from adequate (McCabe, 1993). In providing comprehensive and sensitive care, there is a need to focus on the self-perception of ASHCN in relation to how their condition affects their lives and the services they identify as important (Ford, Bearman, & Moody, 1999; Millstein et al., 2000; Rew, 1995; Telfair & Mulvihill, 2000). However, information about sexual relationships needs to be conveyed in a manner accessible to the ASCHN, which may be more difficult to do for adolescents with severe cognitive impairment or developmental disabilities (AAP, 1996a, 1996b).

Issues regarding sexuality are often closely tied with issues surrounding patient confidentiality, particularly for a population accustomed to heavy parental involvement during interactions with health-care providers. Only 39% of ASHCN report having had a private and confidential visit with their health-care provider in the last 12 months (FACCT, 2001). Some ASCHN report foregone health care as a result of not wanting parents to know about their utilization (Ford et al., 1999). Although confidentiality is assured to all adolescents (AAP, 1989),

these findings point to the need for increased awareness of confidentiality in the provision of health and related services to this population, particularly in the areas of reproductive and sexual health. ASHCN need guidance, support, access to confidential counseling services and information from their health-care providers as they develop through the challenges of issues such as sexuality, vocation and career, physical and emotional development, future education, and living independently (AAP, 1996a; FACCT, 2001; Ford et al., 1999).

### **Cultural Competency**

Cultural competence is a set of congruent behaviors, attitudes, and policies that come together on a continuum in a system, agency, or individual that enable that system, agency, or individual to function effectively in transcultural interactions (National Maternal and Child Health Center on Cultural Competency, 1996). The cultural environment in which ASHCN function and identify has an important influence on healthcare perceptions. To adequately serve their clients, the health-care community must provide services that are welcoming to all cultures represented by the U.S. ASHCN population.

In addressing the psychological, social, and cultural needs of adolescents, program design and development must ensure that appropriate services are offered (Martinez, 1998; OMH, 2000; Telfair & Mulvihill, 2000). As such, the U.S. DHHS (2001b) has developed national Culturally and Linguistically Appropriate Services (CLAS) standards to assure culturally competent health care. Furthermore, culture competence has been proposed as a needed fourth principal to state Title V CSHCN Programs, in addition to family-centered, community-based, and coordinated health services (Telfair & Mulvihill, 2000). As part of a broader provider education campaign on addressing the health concerns of ASHCN, there is a need to address lack of knowledge by providers of cultures (including racial/ethnicity, sexual orientation) other than their own (Brindis et al., 1997; Martinez, 1998).

### **Health Care in Schools and in the Community**

In pursuit of providing comprehensive services to meet the needs of the ASHCN population, alternative and nonclinical sites must be utilized. ASHCN spend a large portion of their weekday in a school setting. However, ASHCN are significantly less likely than adolescents without special healthcare needs to feel affiliated with their school (53% and 70%, respectively) (FACCT, 2001). The Individuals With Disabilities Education Act (Public Law 101-476) attempts to address this as well as a variety of other school-related concerns. It suggests that the educational transition process begin within the school system beginning at the age of 14 years and recommends a transition plan be developed as a part of each student's annual Individual Education Program by the age of 16 years (Lewis-Gary, 2001). In addition to this, in-school health education and care needs to be expanded as well. For example, Brindis et al. (1997) points out a need to develop comprehensive educational policies that include health topics such as oral health and STIs/HIV. The establishment of school-based health clinics and school-linked health centers is a successful strategy that facilitates ASCHN's access to needed services (Betz & Redcay, 2002).

Physical activity and nutrition are two important components of a healthy lifestyle for all adolescents. Often, because of system barriers and lowered expectations, these components are challenging to acquire for ASHCN, yet are critical to improving their overall health. In a recent study, only 56% of ASHCN reported regular exercise, compared with 66% of adolescents without special health-care needs (FACCT, 2001). ASHCN may find it difficult to participate in community activities that promote health such as recreation, leisure, health services, and educational opportunities because of problems with accessibility of facilities and/or communication (Hergenroeder, 2002). Telfair et al. (2003) used focus group methodology to interview ASHCN, young adults with disabilities and chronic health conditions, and parents of these individuals. Findings reveal that ASHCN identify various ways to maintain a healthy lifestyle (including proper nutrition and financial resources) as well as offer suggestions to combat barriers to a healthy lifestyle (ie. adolescent-friendly care). Parents of these ASHCN revealed concerns for their children at the individual, community, school, and societal levels. The need for improved access to all environments and to services and supports is critical so that the ASHCN population can fully participate in these developmentally important activities to the best of their ability.

## **TRANSITION FROM ADOLESCENT- TO ADULT-CENTERED CARE**

In a position paper for the Society for Adolescent Medicine, Blum et al. (1993) defined transition as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from a child-centered to adult-oriented health care system." According to the AAP (2002), the goal of transition is "to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination" (p. 1304). Just 25 years ago, transition was not a concern in ASHCN care. Few adolescents with chronic conditions survived past adolescence, making it a moot issue. In the late 1980s, however, focus on transition increased, and with more and more ASCHN currently reaching adulthood, effective and appropriately timed transition continues to be an issue of extreme importance.

### **Transition Models**

A survey by the National Center for Youth With Disabilities (1995) identified four models providers are using to support the transition of ASHCN from pediatric to adult care: (a) disease-focused, (b) adolescent-focused, (c) primary care, and (d) transition coordination. Some programs combine models, such as the adolescent-focused and transition coordination model Creating Healthy Futures, a pilot transition clinic serving the transition needs of ASHCN (Betz & Redcay, 2002). Based on the Creating Healthy Futures experience, barriers to transition for the ASHCN population were categorized as relating to health care, employment, education, independent living, social and recreational skills, and the service system. Specific obstacles of each classification and suggested solutions for addressing the obstacles, realistic in relation to the competencies of consumers, are presented in detail in the findings. For example, for health-care providers having limited or no knowledge of referral agencies, a suggested solution is development of a "referral pad" outlining contact information of agencies that families can use for easy reference to access transition resources. Additionally, because ASCHN can often find the much more impersonal nature of an adult provider's office daunting, the services coordinator in the Creating Healthy Futures program was instrumental in encouraging youth to not personalize encounters with adult providers, thus providing support for ASHCN to continue the often-overwhelming transition process.

Betz and Redcay (2002) also highlight financial access barriers faced if the transition process' initiation is delayed, such as having pending health insurance termination deadlines. This is a barrier that is exaggerated even more for ASHCN who do not speak English as a first language, as completion of subsequent application forms can be a time- intensive process.

A multidisciplinary, family-friendly team approach to the ASHCN transition process is recommended (Betz & Redcay, 2002; Lewis-Gary, 2001). Lewis-Gary (2001) highlights the importance of having a strategy to aid providers and ASHCN in understanding the transition process. For providers, it is important that the pediatric team develop a summary report of the ASHCN's medical history to distribute to the adult provider, and possibly even attend a healthcare visit with the adult providers. For ASHCN, development of a pamphlet (as illustrated in the article) that can serve as a guide regarding what to expect in the transition process is suggested. A key feature in the pamphlet is contact information for financial and social services available to assist ASHCN through the transition process, including services of vocational rehabilitation, employment, and the Supplemental Security Income (SSI) program that provides cash payments to individuals on limited income if they are unmarried and meet financial and disability requirements.

The provision of a mentor who has been through the transition process is another mode of support for the ASHCN (Lewis-Gary, 2001). Although there continues to be an increase in the number of adults with chronic conditions and disabilities, which is projected to increase by 15% by the year 2010 (Newacheck et al., 1998), ASHCN often comment that they rarely encounter these adults or have the opportunity to learn from them about effectively planning for the future. Role models and mentors can have a powerful impact on how youth internalize their values about themselves, their communities, and their futures. The need for ASHCN to have

increased opportunities to meet successful role models/mentors is vital if ASHCN are to attain and sustain desired levels of independent living and self-efficacy.

### **Transition Process**

For all ASHCN, "the severity of the illness or disability, the level of maturity, acceptance and understanding of the patient, additional environmental and family stresses, the need for control by parents or health care provider, a distorted perception (by parents or health care provider) of potential patient outcomes, and lack of patient or family support systems all may contribute to transition stress" (AAP, 1996a; Conway, 1998).

Adolescents with severe developmental or cognitive disabilities require special consideration because of their lack of medical independence and enhanced reliance on parents or other caregivers. Other ASCHN may be unwilling to seek out the services of an adult provider after having developed a strong relationship, and perhaps reliance upon, their pediatrician (Betz, 1998a; Callahan, Feinstein, & Keenan, 2001). As a result, many ASHCN, their primary caretakers and their healthcare providers have had a very difficult time both understanding and successfully navigating the process of competent transition into independent adult care and life (Hauser & Dorn, 1999; Thompson et al., 1992). It does not help that most transition programs have historically been "a patchwork quilt of healthcare services" fashioned from all available sources (Reiss & Gibson, 2002). The rapid advancements in the treatment and care of ASHCN have not been matched by development of effective programs focused on the acquisition of the needed personal, interpersonal and social life skills, independent living, self-advocacy, medical self-management and system negotiation, education, and vocational readiness for young people (Reinholt & Oberg, 1993).

The general principles of transition endorsed in a position paper by the AAP (2002) include the following: identification of a qualified and committed adult team; development of a specific transition plan by the age of 14 years; early exposure of patients to the adult team; identification of the core knowledge and skills required to provide developmentally appropriate healthcare transition services to ASCHN; preparation and maintenance of an up-to-date medical summary that is both portable and accessible; and, involvement of the family in the transition process. However, despite the preference expressed for involvement of and participation from the family, it is important to note that most discussions on ASHCN transition in the literature have been considered from the provider perspective (Betz & Redcay, 2002). Expanding transition studies to include the perspectives of ASHCN and their caregivers, in addition to the provider perspective, provides a holistic view of the transition process. ASCHN and their caregivers express a host of concerns regarding transition that include the following: being exposed to infection; leaving previous medical caregivers behind; having to meet a new team of medical caregivers; leaving familiar people, a comfortable place, and people whom they trust; and a potential decrease in quality of care provided by adult medical team (Boyle, Farukhi, & Nosky, 2001; Hauser & Dorn, 1999). Parents have significantly higher levels of concern about their child's ability to care for their special health-care need independently and the effect of transition on their role in the provision of health care for their child than do ASCHN (Boyle, Farukhi, & Nosky, 2001). Conversely, ASCHN are concerned that their parents will never be able to let them grow up or take control of their own health-care interactions (Hauser & Dorn, 1999). Thus, there is a need for providers to systematically plan and aid ASHCN and their parents in making transition (AAP, 1996a, 1996b) and for pediatricians and primary care providers to assist in transfer of the medical home to an adult health-care team (Conway, 1998; Scal, 2002).

Work throughout the late 1980s and into the 1990s made much progress in identifying factors that impact transition, in the development of transition demonstration projects, in the description of key transition program components, and in pointing out needed changes in professional knowledge, skills, and attitudes (Reiss & Gibson, 2002). Given the increase in the number of ASHCN and the comparable rise in concern about this population, transition has again become an issue of concern. Results of two decades of study and anecdotal observation by those caring for ASCHN suggest that they recognize that their relationships with nurses, medical providers, and those within their social environments can play a critical role in realization of a successful transition to adult care. The following recommendations, based on review of the literature and clinical

observations, are believed to be achievable by nurses in planning and implementing a successful transition program for ASCHN:

1. Recognize and utilize peer and family networks as well as social support networks/groups and community services in the planning, promotion, and implementation of transition activities.
2. Encourage, support, and provide assistance to adolescents in achieving empowerment and enhancement of self-efficacy at their own pace.
3. Encourage, support, and provide assistance to multidisciplinary providers in the study and development of an understanding of the critical role client self-determination plays in assuring the success of the transition program.
4. Encourage, support, and provide assistance to multidisciplinary providers to foster development of an understanding of the critical role played by families and significant others in the transition process.
5. Where available, encourage, support, and provide assistance for peer education outreach programs and peer-led instruction, because these hold great promise as approaches that are adolescent-centered and adolescent-delivered. This recommendation recognizes the fact that, through their own social networks, young people can reach out to parts of the population that are difficult for older people to reach.
6. Encourage family and health-care providers to support training peers in schools, in community health settings and in other natural environments. This empowers young people by placing them in leadership roles. Taking responsibility for others will go a long way in helping adolescents take responsibility for themselves. In addition, providing leadership opportunities for young people builds their self-esteem and advances self-efficacy enhancement and empowerment efforts among young people.
7. Encourage and support efforts aimed at creating and maintaining an environment of care that allows for the accommodation of diversity among the adolescents that are served. It is important to keep in mind that diversity is greater than racial and ethnic differences. It incorporates recognition of cultural, geographic and belief systems as well. It is critical that nurses and others who provide care strive toward developing and eventually achieving a culturally competent system of care for ASHCN.

By following these structural, intrapersonal, relationship, and social/environmental guidelines, nurses, health-care providers, institutions, and programs can go a long way toward ensuring a successful transition process for ASHCN.

## **SUMMARY**

Growing up as an ASHCN is both similar and different in important and fundamental ways from growing up without special health-care needs. Being accepted in community and peer groups and developing a positive self-concept and self-esteem is a priority for all youth. ASHCN are influenced by the same developmental, social, and cultural forces facing all adolescents regarding the initiation and maintenance of healthy behaviors and lifestyles, as well as engagement in at-risk behaviors. These forces include peer pressure, the media, beliefs, family, relationships, and the fast-paced society. However, ASHCN must also deal with society's lack of disability awareness. The responses of others, and especially peers, to their health condition can serve as significant barriers for ASHCN's in developing the capacity to set realistic expectations for day-to-day activities, school and employment, development of peer relationships, access to health care, and in becoming or staying active and involved in their community.

Health-care professionals have traditionally lacked training in identifying and addressing longterm issues of ASHCN and their families. The health-care provider/client relationship is a critical component of successful health care for all youth. For ASHCN, limited knowledge and sensitivity about disability and chronic conditions among health-care providers can compromise this relationship. Provider education is needed in individual specialties (e.g., nursing) as well as in interaction with other providers in the ASHCN's network, particularly during the transition process to adult care. This type of training will require not only didactic learning, but also hands-on experience working with professionals of different backgrounds, as well as preceptor or advocacy work with ASHCN and their families.

There is a relationship between the extent to which the health-care provider listens to and respects the perspectives and developmental and cultural concerns of the adolescents and their family and involves the adolescents in their own healthcare management to the degree of the adolescent's satisfaction with the provider or health-care system. For all adolescents, especially ASHCN, the provision of respectful and developmentally and culturally appropriate health care is more likely to assure that ASHCN and their families trust the health-care system and engage in healthy behaviors. Working collaboratively in acknowledging the opinions of ASHCN, the views of their families and the expertise of their network of providers is the key to quality health care for ASHCN.

## CONCLUSION

The challenges and barriers outlined above fall well within the boundaries of nursing care. Nurses play a unique role in the development of ASHCN. From acting as a liaison among ASHCN, parents, and providers and advocating for services that meet the needs of adolescents and family (Betz, 1998b) to providing comprehensive and developmentally appropriate sexuality education (Carr, 1995), nurses have an integral role in all aspects of ASHCN's care, not only within the health-care system but also in schools and communities. Nurses can enhance their care of ASHCN by engaging in multidisciplinary service activities, working closely with families of ASHCN and in the design and implementation of programs and services as outlined in the six recommendations for the transition process delineated earlier in this article.

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## Notes:

<sup>1</sup> Children with special health-care needs is defined as, which is adopted by the MCHB, "children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138).

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