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RESEARCH ON PEOPLE WITH DISABILITIES AND HEALTHCARE TRANSITION

ACCESS TO CARE

Access to care for youth with special health care needs in the transition to adulthood.

Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Department of Pediatrics, David Geffen School of Medicine, University of California-Los Angeles, Los Angeles, California 90024, USA. dlotstein@mednet.ucla.edu J Adolesc Health. 2008 Jul;43(1):23-9. Epub 2008 Apr 25. Comment in: J Adolesc Health. 2008 Jul;43(1):6-7.

PURPOSE: To describe access to care and identify factors associated with access for low-income young adults who aged out of a public program for children with special health care needs (CSHCN).

METHODS: This was a cross-sectional survey of graduates of the Title V CSHCN program in one California county. Subjects were 77 graduates (55% female) aged 21-24 years with ongoing health care needs. Measures of access to care included having the following: a regular source of care for the main health condition; all needed care since turning 21 years of age; any delayed or forgone care in the past 6 months; health insurance; and continual insurance since turning age 21. Individuals lacking any one access measure were defined as experiencing an adverse transition event.

RESULTS: Of the subjects, 24% lacked a usual source of health care, 27% had gone without some needed health care since turning 21, and 39% had delayed needed care. Although 10% of respondents were uninsured at the time of the survey; 40% had a gap in insurance coverage since turning age 21. Overall, 65% reported at least one adverse transition event affecting access to care. Factors associated with experiencing no adverse transition event were receiving Supplemental Security Income (SSI, $p = .007$), having received special education services ($p = .003$), and having been born with the main health condition ($p = .013$).

CONCLUSIONS: Insurance gaps and delayed care are prevalent among these low-income young adults despite ongoing health problems. Greater transition support might improve access by linking them with a usual source of care, identifying insurance options, and encouraging regular use of care.

Access to health care for young adults with disabling chronic conditions.

Callahan ST, Cooper WQ. Division of Adolescent Medicine and Behavioral Science, Department of Pediatrics, Vanderbilt University Medical Center, Nashville, TN 37232, USA. todd.callahan@vanderbilt.edu Arch Pediatr Adolesc Med. 2006 Feb;160(2):178-82.

OBJECTIVE: To assess health insurance status and health care access of young adults with disabilities attributable to a chronic condition.

DESIGN AND SETTING: We analyzed data from the National Health Interview Survey from 1999 to 2002. We present bivariate analysis and multiple logistic regression of reported health care access barriers in the United States stratified by health insurance status.

PARTICIPANTS: The study population included 1109 survey respondents with and 22 481 without disabling chronic conditions, aged 19 to 29 years.

MAIN OUTCOME MEASURES: Delayed or unmet health needs owing to cost, no contact with a health professional in the prior year, and no usual source of care. **RESULTS:** Thirty-five percent of respondents with and 15% without disabling chronic conditions reported an unmet health care need owing to cost ($P < .001$). Uninsurance rates for young adults with and without disabling chronic conditions were similar (26% vs 28%, respectively), and uninsurance was significantly associated with unmet health care needs. More than two thirds of uninsured respondents with a disabling chronic condition reported an unmet health need and 45% reported no usual source of care. After adjusting for sociodemographic factors, uninsured young adults with disabling chronic conditions had 8 times greater odds of reporting unmet health care needs and 6 times greater odds of having no usual source of care relative to insured respondents with disabling chronic conditions.

CONCLUSIONS: Despite increasing attention to issues of health care transition for young adults with disabling chronic conditions, this study suggests that uninsurance is as common among these young adults as nondisabled peers and is significantly associated with health care access barriers in this population.

Caring for an underserved population: Helping pediatric patients with disabilities transition to adulthood.

Milbrath C. Gillette Children's Specialty Healthcare, St. Paul, Minnesota, USA.

CMilbr@gillettechildrens.com *Creat Nurs.* 2008;14(2):66-9.

Improving the processes to assist adolescent patients in their transition into the adult health care community reveals the challenges encountered by adults with disabilities. A service gap between pediatric care providers and adult care providers is bridged by a program providing direct care, education, and advocacy.

Continuity of health insurance coverage among young adults with disabilities.

Callahan ST, Cooper WO. Division of Adolescent Medicine, Vanderbilt University Medical Center, Nashville, Tennessee, USA. todd.callahan@vanderbilt.edu *Pediatrics.* 2007 Jun;119(6):1175-80.

OBJECTIVES: Although considered critical to facilitate the successful transition from pediatric to adult health care, the continuity of insurance coverage for young adults with disabilities as they make the transition to adulthood has not been well characterized. The purpose of this work was to compare the continuity of insurance coverage reported by a nationally representative sample of young adults 16 to 25 years old with and without disabilities during a consecutive 36-month period.

METHODS: We performed secondary analysis of data from the 2001 Survey of Income Program and Participation. Data for the survey were collected at 4-month intervals from

February 2001 through January 2004 for 5170 young adults. Subjects with disabilities were those who reported limitations in activities of daily living or work, used assistive devices, and/or had learning disabilities, mental retardation, or other mental disorders. The primary outcome was uninsurance defined for each study month in which there was no coverage by private, public, or military programs. We present bivariate analyses of the months of uninsurance according to disability status using longitudinal weights and design-effect adjustments to account for the complex sample design.

RESULTS: The sample consisted of 599 subjects with and 4571 without reported disabilities, representing 3,970,000 and 30,800,000 young adults in the United States, respectively. At study entry, 22% of the young adults with disabilities were uninsured. During the 36-month follow-up period, 56% of the young adults with disability reported gaps in insurance coverage with a mean of 15 months of uninsurance. The proportion of uninsured subjects did not significantly differ by disability status.

CONCLUSIONS: The majority of young adults with disabilities reported gaps in insurance coverage, and many were uninsured for a substantial portion of the study period. As an increasing number of children with special health care needs make the transition to adulthood, improving the continuity of health insurance coverage for this population warrants specific attention.

A critical appraisal of literature reviews about the transition to adulthood for youth with disabilities.

Stewart D, Stavness C, King G, Antle B, Law M. CanChild Centre for Childhood Disability Research, McMaster University, School of Rehabilitation Science, Hamilton, Ontario, Canada. stewartd@mcmaster.ca Phys Occup Ther Pediatr. 2006;26(4):5-24. A critical appraisal of five review articles on the transition to adulthood for youth with disabilities was conducted to identify evidence about (1) the factors that help or hinder the transition process, and (2) "what's working" in transition services. The appraisal identified a number of important "success" factors and elements of service delivery that are worthy of consideration by service providers and researchers. These include the need for skill development of youth with disabilities, environmental supports, and an individualized approach to service delivery. All of the reviews identified the need for more evidence to support the implementation and evaluation of best practice models/approaches that address the complex issue of the transition from paediatric to adult services for youth with disabilities.

Health, education, work, and independence of young adults with disabilities.

Blomquist KB. Healthy & Ready to Work National Center, Kentucky Commission for Children with Special Health Care Needs. Orthop Nurs. 2006 May-Jun;25(3):168-87. **PURPOSE:** Healthy People 2010, the U.S. government's goal for a healthier nation, calls for improved data collection to understand the health status of relatively small population groups, such as young adults with disabilities. This study looks at the transition outcomes of graduates of pediatric systems of care for children with disabilities and chronic conditions.

METHODS: Young adult graduates of a state program for children with special healthcare needs and a specialty children's hospital were sent a mail survey that focused on their healthcare access and use, insurance status, health behaviors and

perceptions, education, work, and markers of independent living. The survey was based on the National Longitudinal Survey of Youth, Behavioral Risk Factor Surveillance System, the U.S. Census and other surveys done by the state and hospital programs. Experts in healthcare and school-to-work transition of youth with special needs, health and labor economists, independent living center counselors, program administrators, nurses, social workers, and physicians offered ideas on various versions of the instrument that were piloted on youth before mailing to graduates. A follow-up mailing was sent to all those who did not respond to the first mailing. Results from the surveys of these young people with special healthcare needs are compared with data on typical young adults to determine the disparities.

SAMPLE: Mail surveys were sent to all patients aged 18 years and older at the time of their discharge in the preceding fiscal (state program) or calendar (children's hospital) year. The response rate was 51%. Ninety-one percent of the respondents were Whites and 61% were women, with a median age of 21.1 years; 69% reported independence in activities of daily living.

RESULTS AND DISCUSSION/CLINICAL RESULTS: Eighty percent of graduates reported having a usual source of care, but 42% used the emergency room compared with 25% of typical young adults. Twenty-nine percent had no health insurance and only 11% had insurance through their work. Only 44% of respondents were working compared with 56% of all 19 year olds and 72% of 18-29 year olds in studies of typical youth; 67% of those not working wanted to work. One great concern is the 26% who are not working, in school, or at home with children. Nurses working with children, families, and young adults can use the information to improve pediatric and adult healthcare systems and collaborate with educational, independent living, and workforce development agencies to improve transition to adult roles and responsibilities for young people with disabilities.

Implementing community-based systems of services for children and youths with special health care needs: how well are we doing?

McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ, Newacheck PW.

Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland, USA. mmcpherson@hrsa.gov Pediatrics. 2004 May;113(5 Suppl):1538-44.

OBJECTIVE: To provide a baseline measure of the proportion of US children who meet the Maternal and Child Health Bureau's core outcomes for children with special health care needs (CSHCN). Those core outcomes include the following: 1) families of CSHCN will partner in decision making and will be satisfied with the services that they receive; 2) CSHCN will receive coordinated, ongoing comprehensive care within a medical home; 3) families of CSHCN will have adequate private and/or public insurance to pay for the services that they need; 4) children will be screened early and continuously for special health care needs; 5) community-based service systems will be organized so that families can use them easily; and 6) youths with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

METHODS: A national household survey was conducted using telephone interviews. We analyzed data on 38,866 CSHCN included in the 2001 National Survey of CSHCN and

13,579 children included in the 2001 National Health Interview Survey. We assessed the proportion of US children who met each of the 6 core outcomes for CSHCN using data from 2 surveys.

RESULTS: Success rates ranged from 6% (the core outcome on successful transition to adulthood) to 74% (the core outcome on organization of the service system). For 5 of the 6 core outcomes, success rates exceeded 50%.

CONCLUSION: Our results indicate that, for the most part, the United States is well positioned to meet the 6 core outcomes. However, much more work lies ahead before success can be claimed. This is especially true for the core outcome on transition to adulthood, for which only 6% of children in the target population are now meeting this goal.

Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices.

McLaughlin SE, Diener-West M, Indurkha A, Rubin H, Heckmann R, Boyle MP.

Robert Wood Johnson Clinical Scholars Program, Johns Hopkins University School of Medicine, Baltimore, Maryland, USA. mclaugh@ummhc.org Pediatrics. 2008 May;121(5):e1160-6.

OBJECTIVES: More than 500,000 adolescents with special health care needs age into adulthood each year in the United States, and there is growing recognition of the need for support of their transition to adult-oriented health care. Because of improved survival, cystic fibrosis has experienced this increasing transition need, and cystic fibrosis policy leaders responded by mandating the transition of adults with cystic fibrosis to adult-focused cystic fibrosis care programs by 2000. The primary objective of this study was to characterize in detail recent transition practices at US cystic fibrosis programs, to identify areas for improvement and to serve as a model for other diseases. A secondary objective of this study was to develop and validate a survey for formal assessment of transition practices.

METHODS: A 105-question survey on key aspects of transition was administered to cystic fibrosis care team members from all 195 US Cystic Fibrosis Care programs. Rates of adherence to recommended components of transition care were measured.

RESULTS: A total of 448 surveys were obtained from 170 (87%) of 195 cystic fibrosis programs. Although transfer of care occurs at a median age of 19 years, initial discussion of transition does not occur until a median age of 17 years, limiting time to foster self-care skills. Only half of programs consistently perform a transition readiness assessment, 28% of centers offer visits focused on transition, and <10% have a written list of desirable self-management skills.

CONCLUSIONS: There is significant variability in transition support provided to young adults with cystic fibrosis, but there are simple steps that may lead to more consistent delivery of transition services. Methods of assessment and lessons learned from transitioning young adults at US cystic fibrosis programs may serve to improve transition for individuals with other childhood diseases.

Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care.

Zack J, Jacobs CP, Keenan PM, Harney K, Woods ER, Colin AA, Emans SJ.

Division of Adolescent Medicine, Children's Hospital Boston and Harvard Medical School, Boston, Massachusetts 02115, USA. Pediatr Pulmonol. 2003 Nov;36(5):376-83. Comment in: Pediatr Pulmonol. 2003 Nov;36(5):363-5.

The purpose of this study was to investigate how adolescents and adults with cystic fibrosis (CF) view preventive counseling and their transition to adult-centered care within a children's hospital. Thirty-two patients ≥ 16 years old diagnosed with CF were recruited from a pediatric tertiary care setting. During face-to-face interviews, patients were asked 27 structured questions and completed a 30-item self-administered questionnaire on preventive counseling by healthcare providers and on transition issues. The median age of patients was 25.5 years (range, 16-43 years); 69% of patients identified a pulmonologist as their "main doctor," even though 78% had a primary care provider. Participants felt that 13-16 years of age was the best time for them to begin spending time alone with their main doctor. Less than half of the participants recalled receiving preventive counseling during the previous 12 months, and more patients wanted to discuss issues than actually did. Qualitative data emphasized the importance of independence in making decisions in healthcare and establishing relationships with providers, and many patients did not desire to transfer care to an adult hospital. Participants identified adult-focused services such as inpatient rooms, discussion groups, work options, and social service support that would enhance care. In conclusion, the majority of adolescent/young adult patients with CF receiving care in a pediatric institution reported satisfaction with their healthcare. However, patients identified preventive issues that they desired to be more regularly addressed, starting in early adolescence, and changes in the delivery of services to enhance transition to adult-oriented care. This study underscored the understanding of the integration of transition planning into the facilitation of healthcare decision-making by the adolescent in issues of self-care, sexuality, education, and finances. Future initiatives to enhance the care of patients with CF should provide training of pulmonologists in preventive care and increased attention to helping patients utilize appropriate primary-care services during the adult years. In addition, prospective studies are needed to compare outcomes of CF patients who have transitioned and transferred to adult hospitals and those transitioning to adult-oriented services in a pediatric institution.

State and national estimates of insurance coverage and health care utilization for adolescents with chronic conditions from the National Survey of Children's Health, 2003.

Okumura MJ, McPheeters ML, Davis MM. Child Health Evaluation and Research Unit, Division of General Pediatrics, University of Michigan, Ann Arbor, Michigan, USA. okumuram@peds.ucsf.edu J Adolesc Health. 2007 Oct;41(4):343-9. Epub 2007 Jul 12. Comment in: J Adolesc Health. 2007 Oct;41(4):319-20.

PURPOSE: To examine health and insurance characteristics of adolescents with special health care needs (ASHCN), at state and federal levels.

METHODS: We used the National Survey of Children's Health 2003, a nationally representative sample of children in the United States, to study adolescents 14-17 years of age. We present descriptive statistics and regression analyses of adolescents with and without special health care needs, regarding measures of health care use and insurance coverage.

RESULTS: Approximately 22% of adolescents 14-17 years old have a special health care need. On average, ASHCN have one more annual office visit per year than their non-SHCN peers ($p < .001$). ASHCN report three times the rate of unmet medical needs compared to their non-SHCN peers ($p < .001$), despite higher rates of insurance coverage (94% vs. 88%, $p < .001$). Overall, 26.9% of ASHCN have public coverage. Nationally, more than half of those ASHCN with public coverage report incomes above 100% of the federal poverty level (FPL), which puts them at risk for losing coverage when they age into adulthood. Across states, proportions of ASHCN on public coverage and with incomes $> 100\%$ FPL range from 3.2% to 37.5%.

CONCLUSIONS: One in six ASHCN currently has public coverage with household income that would make them ineligible by income criteria for continuing public coverage as adults. It is imperative to examine insurance continuity and corresponding health outcomes for ASHCN as they transition from child to adult health care settings, and to evaluate options for policy interventions that can sustain health care coverage for this vulnerable population.

Transition of adolescents with special health care needs: review and analysis of the literature.

Betz CL. USC UCEDD at Childrens Hospital, Los Angeles, Los Angeles, CA, USA. cbetz@chla.usc.edu *Issues Compr Pediatr Nurs.* 2004 Jul-Sep;27(3):179-241.

A review and analysis of 43 transition studies published from 1982 through 2003 was conducted. The studies reviewed represent the diverse purposes of international researchers for examining transition issues and questions. Findings of this literature review indicate that transition research is in early stages of development. A number of limitations were associated with these studies, including the lack of theoretical frameworks, the use of valid and reliable instruments, and research designs lacking adequate controls. Future research studies are needed that overcome the design limitations of past investigations.

Transition to adulthood in spina bifida: changing roles and expectations.

Mukherjee S. Pediatric and Adolescent Rehabilitation Medicine, Rehabilitation Institute of Chicago and Children's Memorial Hospital Spina Bifida Clinic, Northwestern University Feinberg School of Medicine, Chicago, IL, USA. smukherjee@ric.org *ScientificWorldJournal.* 2007 Nov 26;7:1890-5.

Survival to adulthood for people with Spina Bifida now exceeds 85% due to improvements in medical and surgical management. Rates remain lower than expected for community participation, healthy lifestyle choices, employment and independent living. The importance of transition programming to help adolescents with disabilities prepare for adult life roles is now understood. Literature currently is mainly conceptual or descriptive, but informs the process of developing transition program models. The need for competent and effective adult care providers is discussed. Both the transition to adulthood and the transfer of care to adult care clinics are important and distinct components of spina bifida lifespan care.

What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida.

Binks JA, Barden WS, Burke TA, Young NL. Laurentian University, Sudbury, ON, Canada. Arch Phys Med Rehabil. 2007 Aug;88(8):1064-73.

OBJECTIVES: To address the lack of synthesis regarding the factors, processes, and outcomes specific to the transition from child-centered to adult-centered health care for people with cerebral palsy (CP) and spina bifida (SB); more specifically, to identify barriers, to outline key elements, to review empirical studies, and to make clinical and research recommendations.

DATA SOURCES: We searched Medline and CINAHL databases from 1990 to 2006 using the key words: transition, health care transition, pediatric health care, adult health care, health care access, health care use, chronic illness, special health care needs, and physical disability. The resulting studies were reviewed with a specific focus on clinical transition for persons with CP and SB, and were supplemented with key information from other diagnostic groups.

STUDY SELECTION: All studies meeting the inclusion criteria were included.

DATA EXTRACTION: Each article classified according to 5 criteria: methodology, diagnostic group, country of study, age group, and sample size.

DATA SYNTHESIS: We identified 149 articles: 54 discussion, 21 case series, 28 database or register, 25 qualitative, and 34 survey articles (some included multiple methods). We identified 5 key elements that support a positive transition to adult-centered health care: preparation, flexible timing, care coordination, transition clinic visits, and interested adult-centered health care providers. There was, however, limited empirical evidence to support the impact of these elements.

CONCLUSIONS: This review summarizes key factors that must be considered to support this critical clinical transition and sets the foundation for future research. It is time to apply prospective study designs to evaluate transition interventions and determine long-term health outcomes.

FAMILIES

Addressing transition to adult health care for adolescents with special health care needs.

Scal P, Ireland M. Division of General Pediatrics and Adolescent Health, University of Minnesota Medical School, Minneapolis, Minnesota 55455, USA. scal0005@umn.edu Pediatrics. 2005 Jun;115(6):1607-12.

OBJECTIVE: To determine the factors associated with addressing the transition from pediatric to adult-oriented health care among US adolescents with special health care needs.

METHODS: Data for 4332 adolescents, 14 to 17 years of age, from the 2000-2001 National Survey of Children With Special Health Care Needs were used. The adequacy of transition services was determined by parent self-report. Explanatory variables, including parental education, family poverty status, race/ethnicity, measures of the severity and complexity of conditions, health insurance status, having a personal doctor, and the quality of the parent's relationship with the adolescent's doctor, were entered into a regression model.

RESULTS: Overall, 50.2% of parents reported that they had discussed transition issues with their adolescent's doctor and 16.4% had discussed and developed a plan for addressing those needs. In a multivariate regression analysis, correlates of the adequacy of transition services included older age, female gender, complexity of health care needs, and higher quality of the parent-doctor relationship.

CONCLUSIONS: Among adolescents with special health care needs, those who were older and those with more complicated needs were more likely to have addressed the transition from a pediatric to adult-oriented system of care. Furthermore, this analysis demonstrated a strong association between a high-quality parent-provider relationship and the extent to which transition issues were addressed. The importance of transition services for adolescents with less complex needs and the overall impact of health care transition services were not assessed in this study and remain important questions for future investigations.

Growing up ready: a shared management approach.

Gall C, Kingsnorth S, Healy H. Life Skills Institute at Bloorview Kids Rehab, Tronto, Ontario, Canada. cgall@bloorviewmacmillan.on.ca Phys Occup Ther Pediatr. 2006;26(4):47-62.

In order to help youth with physical disabilities and their families to plan for the transition to adulthood, well-planned service delivery is essential. This paper provides an account of the work of a children's rehabilitation centre to develop a transition framework reflecting evidence-based practice. Examination of current transition practices, a review of the literature, and site visits to health care facilities and universities were conducted to identify promising practices in the field of transition to adult services. A transition framework was designed to facilitate the adoption of a shared management approach for helping families and their children to grow up ready. Key elements of the transition framework are described and future plans discussed.

Health care transition: youth, family, and provider perspectives.

Reiss JG, Gibson RW, Walker LR. Institute for Child Health Policy, University of Florida, Gainesville, FL 32608, USA. jgr@ichp.ufl.edu Pediatrics. 2005 Jan;115(1):112-20. Comment in: Pediatrics. 2005 May;115(5):1449-50; author reply 1450.

OBJECTIVE: This study examined the process of health care transition (HCT) posing the following questions: What are the transition experiences of youths and young adults with disabilities and special health care needs, family members, and health care providers? What are promising practices that facilitate successful HCT? What are obstacles that inhibit HCT?

METHODS: A qualitative approach was used to investigate these questions. Focus group interviews were conducted. Content and narrative analyses of interview transcripts were completed using ATLAS.ti.

RESULTS: Thirty-four focus groups and interviews were conducted with 143 young adults with disabilities and special health care needs, family members, and health care providers. Content analysis yielded 3 content domains: transition services, which presents a chronological understanding of the transition process; health care systems, which presents differences between pediatric and adult-oriented medicine and how these differences inhibit transition; and transition narratives, which discusses transition

experience in the broader context of relationships between patients and health care providers.

CONCLUSION: This study demonstrated the presence of important reciprocal relationships that are based on mutual trust between providers and families and are developed as part of the care of chronically ill children. Evidence supports the need for appropriate termination of pediatric relationships as part of the transition process. Evidence further supports the idea that pediatric and adult-oriented medicines represent 2 different medical subcultures. Young adults' and family members' lack of preparation for successful participation in the adult health care system contributes to problems with HCT.

Portfolio of health advice for young people with disabilities transferring to adult care.

Tan MJ, Klimach VJ. Paediatric Department, Colwyn Bay Hospital, Conwy, UK. tanyeo001@aol.com Child Care Health Dev. 2004 May;30(3):291-6.

BACKGROUND: The transition from paediatric to adult services for young people with complex disabilities is fraught with anxieties for families. To facilitate the transition process a portfolio comprising reports from parents, paediatrician and therapists was collected and given to the young person and family on leaving school.

AIM: To evaluate the young people and their parents' views of the usefulness of portfolios in providing comprehensive picture of their health needs.

METHODS: A prospective study was performed. Eight families were interviewed and semi-quantitative feedback obtained using standardized questionnaires.

RESULTS: Seven out of eight young people and their families were satisfied with the portfolios they received. All of them found the portfolios worthwhile and useful. A quarter of the families would like to have been consulted more about the content of the individual reports.

CONCLUSIONS: Portfolios of health reports facilitate transfer of information when young people with disabilities move from paediatric to adult services. Ideally portfolios should be interagency, and include reports from education and social services.

Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs.

Lotstein DS, McPherson M, Strickland B, Newacheck PW. Department of Pediatrics, David Geffen School of Medicine, University of California, Los Angeles, CA 90095-1752, USA. dlotstein@mednet.ucla.edu Pediatrics. 2005 Jun;115(6):1562-8.

OBJECTIVE: To describe the proportion of youth with special health care needs (YSHCN) who are receiving services for medical transitions and to describe which sociodemographic and health care-related factors are associated with receiving transition services.

METHODS: We analyzed responses to questions about medical transitions from the 2001 National Survey of Children With Special Health Care Needs (NS-CSHCN). Parents or guardians of youth aged 13 to 17 years who screened positive for the survey were asked (1) whether they had discussed with health care providers how their child's health care needs might change in adulthood, (2) if they had a plan to address these changing needs, and (3) if their child's health care providers had discussed having their

child eventually see a doctor who treats adults. Bivariate and multivariate associations were estimated to identify sociodemographic and health care factors related to receiving medical-transition services.

RESULTS: Overall, 50% of respondents had discussed their child's changing health care needs with their physicians, although significantly fewer Hispanic youth compared with other youth reported these discussions. Youth who met criteria for a medical home were more likely to have discussed changing needs and to have a plan addressing these needs. Of those who had discussed changing needs, 59% had a plan to address these needs and approximately 42% had reported discussing shifting care to adult-oriented providers. Younger teens and non-Hispanic black children were less likely to have discussed changing providers. Fifteen percent of YSHCN met the Maternal and Child Health Bureau's core outcome for medical transitions. A multivariate logistic-regression model found that older age and having a medical home were significantly associated with increased odds of meeting the outcome measure.

CONCLUSION: The proportion of YSHCN meeting the medical-transition outcome measure is quite low, particularly for youth from ethnic minorities. Higher rates are seen for older teens and those receiving care within a medical home. Significant efforts will be required to meet the proposed goal of all YSHCN receiving the services necessary to transition to adult health care.

MEDICAL HOME

Providing a primary care medical home for children and youth with cerebral palsy.
Cooley WC; American Academy of Pediatrics Committee on Children With Disabilities.
Pediatrics. 2004 Oct;114(4):1106-13.

Children and youth with cerebral palsy present pediatricians with complex diagnostic and therapeutic challenges. In most instances, care also requires communication and comanagement with pediatric subspecialists and pediatric surgical specialists, therapists, and community developmental and educational teams. The importance of family resilience to the patient's well-being broadens the ecologic scope of care, which highlights the value of a primary care medical home from which care is initiated, coordinated, and monitored and with which families can form a reliable alliance for information, support, and advocacy from the time of diagnosis through the transition to adulthood. This report reviews the aspects of care specific to cerebral palsy that a medical home should provide beyond the routine health maintenance, preventive care, and anticipatory guidance needed by all children.

PROVIDERS (NURSES, PROFESSIONALS)

Dimensions of the transition service coordinator role.

Betz CL, Redcay G. University of Southern California Center for Excellence in Developmental Disabilities, Children's Hospital, Los Angeles, USA. J Spec Pediatr Nurs. 2005 Apr-Jun;10(2):49-59.

ISSUES AND PURPOSE: This article describes the development and implementation of an innovative advanced practice role, as a transition service coordinator for nurses who work with adolescents with special healthcare needs. Transition services for adolescents with special healthcare needs is an area of growing clinical need requiring that all healthcare professionals, including advanced practice nurses develop new clinical knowledge and skills to practice effectively.

CONCLUSION: This emerging specialty area will require advanced practice nurses to provide direct services blending both pediatric and adult healthcare needs and to function in advanced practice roles such as case managers who can ensure the coordination of services between these two very different systems of care while promoting the youth's acquisition of goals for adulthood. This nursing role was first created to provide and coordinate transition services to youth seen in a piloted clinic titled Creating Healthy Futures.

PRACTICE IMPLICATIONS: This article describes the various components of this nursing role that incorporated the advanced practice dimensions of clinical expert, consultant, change agent, leader, researcher, and educator that can be replicated in other clinical settings.

Enhancing success in transition service coordinators: use of transformational leadership.

Rearick E. Community Health Nursing and Leadership in Nursing at Worcester State College in Worcester, Massachusetts, USA. emrearick@gmail.com Prof Case Manag. 2007 Sep-Oct;12(5):283-7.

PURPOSE: The lifespan of children with special healthcare needs has been extended because of improved technology and medical advances. Successful transition to the adult arena of healthcare, social services, and education by adolescents with special healthcare needs (ASHCN) is lacking. The transition service coordinator (TSC) is a multifaceted role of advanced practice nursing that provides highly specialized transition services to adolescents with special healthcare needs. The use of key concepts from the transformational leadership theory may improve healthcare outcomes.

PRIMARY PRACTICE SETTINGS: This article applies to pediatric and adult primary care and case management services that serve adolescents with special healthcare needs.

CONCLUSION: Employing key concepts of transformational leadership theory will enhance the success of the TSC to improve both collaboration among stakeholders in the transitional team and young adults' transition to the world of adult services.

IMPLICATIONS FOR CASE MANAGEMENT PRACTICE: Enhanced communication resulting in improved sharing of information, understanding of the stakeholder roles, and provision of formal linkages between pediatric and adult medical providers is a significant outcome affecting the ASHCN. Improved collaboration will produce a smooth transition for the ASHCN to the world of adult social services education, and employment. Incorporating the transformational leadership dimensions of idealized influence, inspirational motivation intellectual stimulation, and individualized consideration will enhance the ability of the TSC to improve collaboration among stakeholders in the transitional team and the quality of services for the ASHCN.

Facilitating the transition of adolescents with developmental disabilities: nursing practice issues and care.

Betz CL. USC University Center for Excellence in Developmental Disabilities at Children's Hospital Los Angeles, Los Angeles, CA 90027, USA. cbetz@chla.usc.edu J Pediatr Nurs. 2007 Apr;22(2):103-15.

The purpose of this article is to provide an overview of salient issues that adolescents with developmental disabilities face as they approach adulthood. For nurses who provide services to this population of youth, knowledge of these significant issues is essential to developing a youth-centered transition plan that addresses their comprehensive health needs. Health care professionals, including pediatric nurses, have important roles as service coordinators, consultants, or direct service providers to ensure that the health-related transition needs of the youth are met. Transition assessment, planning, and intervention strategies that can be integrated into a comprehensive plan of care are discussed.

Improving oral health for individuals with special health care needs.

Crall JJ. Section of Pediatric Dentistry, University of California, Los Angeles, USA. jcrall@dent.ucla.edu Pediatr Dent. 2007 Mar-Apr;29(2):98-104.

The purpose of this paper was to highlight information and issues raised in a keynote address for the American Academy of Pediatric Dentistry's Symposium on Lifetime Oral Health Care for Patients with Special Needs held in November, 2006. Topics include: (1) relevant statistics and definitions; (2) the prevalence and impact of common oral diseases in individuals with special health care needs (ISHCN); (3) an overview of oral health care delivery for ISHCN; (4) key delivery system and policy issues; and (5) a synopsis of major contextual initiatives related to ISHCN. In light of the Academy's primary interest in infants, children, and adolescents--including children with special health care needs--the major focus is on children. Significant oral health and oral health care issues for adults with special needs, however, generally parallel those for children and are of interest to the Academy, particularly as they relate to the transition from pediatric care to adult care, a critical period for extending the level of oral health and health trajectory established during childhood.

Nurse's role in promoting health transitions for adolescents and young adults with developmental disabilities.

Betz CL. Department of Nursing, University of Southern California, University Center on Disability at Childrens Hospital, Los Angeles, CA, USA. cbetz@usc.edu Nurs Clin North Am. 2003 Jun;38(2):271-89.

This article examines the impact of cultural factors influencing the youth's transition process and includes recommendations for addressing these needs within the context of nursing practice. Youth-centered transition planning begins with a comprehensive, culturally competent assessment of adolescent and family needs in order to foster youth autonomy and family support during this important stage of development. Nurses who work with youth with developmental disabilities are faced with many questions from youth and families regarding the how, what, when, and where of transition planning, such as "Where do I find an adult health care provider who has the clinical expertise and sensitivity to my disability concerns?" and "Where can I get health insurance coverage

when I "age out" of the health insurance program I am currently enrolled in?" The questions youth and families have not only reflect their needs for services and supports, but also represent the cultural context of their experiences. Who is this youth who is fast growing up, soon to become an adult? What has been this young person's experiences as a boy or a girl, a person with a developmental disability, a member of his or her family, and a member of the community? Each youth's experiences have an enormous impact shaping his or her progression through adolescence, and the impact continues with adult development. Nurses can serve as pivotal members of the team assisting these youths with developmental disabilities and their families in confronting the challenges and excitement of successfully transitioning to adulthood.

Perspectives on transitions: rethinking services for children and youth with developmental disabilities.

Rosenbaum P, Stewart D. School of Rehabilitation Science, and CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada.

rosenbau@mcmaster.ca Arch Phys Med Rehabil. 2007 Aug;88(8):1080-2.

Transition to adulthood for youth with developmental disabilities has become an important concern internationally of service providers working with these young people. Reflecting on the useful review by Binks and colleagues in this issue of the Archives, we argue as developmentalists that this is an ideal time to step back from our traditional preoccupation with "treatment" of childhood disability and to reconsider broadly what our goals for intervention ought to be. We invoke the concepts of the International Classification of Functioning, Health and Disability framework and draw on research that taps the voices of young people with disabilities-voices we believe have a lot to tell us about what has and has not worked for them. We suggest that there are unparalleled opportunities to enhance transition to adulthood for young people with developmental disabilities, in part by a feed-forward of the best of childhood services, and to work to prevent many of the difficulties faced by the current generation making this challenging transition.

Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care.

Burke R, Spoerri M, Price A, Cardosi AM, Flanagan P. Warren Alpert School of Medicine of Brown University, Division of General Academic Pediatrics, Hasbro Children's Hospital, Department of Pediatrics, Providence, RI 02903, USA.

robert_burke@brown.edu Clin Pediatr (Phila). 2008 May;47(4):347-54. Epub 2008 Jan 7.

The transition and transfer from pediatrics to adult health care of youth with and without special health care needs has become a focus of professional organizations, health care insurers, national policy makers, and providers. To understand transition and transfer at a primary care practice level, all primary care pediatricians in Rhode Island were surveyed. Responses were received from 103 of 169 (60.9%) practicing pediatricians. Few responders had practice policies on transfer. Most reported that transition should begin later than recommended. Few practices communicated with adult providers at transfer. Most reported that health insurers were of little help in transfer. Many pediatric practices had young adults after age 22 and many with special needs. Responders

reported adolescents left their practices by 1 of 6 methods. The survey indicates the need for further study of transition and transfer and the need for additional training and education if transfers are to be successful.

Transition to adulthood: the important role of the pediatrician.

Olsen DG, Swigonski NL. The Indiana Parent Information Network, Inc, Indianapolis, Indiana, USA. Pediatrics. 2004 Mar;113(3 Pt 1):e159-62.

This article, written by a parent of 2 youths with special health care needs and a pediatrician, builds on the Medical Home framework to give concrete examples of what physicians and families can and should do to prepare families for transition(s). The article consists of 3 parts. The first part is an introduction giving an overview of the importance of transition. "Developing a Life (not Illness) Plan: Begin With the End in Mind," emphasizes that no matter how challenging the disability or compromising the chronic illness, we owe it to our children to take the risk of thinking about the future and beginning to help them to develop a life (not illness) plan. The third part, "With a Little Help from My Friends," looks at how linking families with other parents, young adults, and adults living with disabilities and serious chronic illness can be a source of information to both families and physicians as they plan for the future.

Transition of care: health care professionals' view.

Por J, Golberg B, Lennox V, Burr P, Barrow J, Dennard L. Florence Nightingale School of Nursing and Midwifery, King's College London, 57 Waterloo Road, London SE1 8WA, UK. jitna.por@kcl.ac.uk J Nurs Manag. 2004 Sep;12(5):354-61.

There is much anxiety regarding the transfer of adolescents with chronic illness to adult services. Transfer of patients can be haphazard if the transition has not been planned. Problems and obstacles to transition have been identified and discussed by various authors. The purpose of this small study was to explore the views and needs of health care professionals from one National Health Service trust regarding the transition of care for adolescents with a chronic condition from children's to adult services and to identify possible ways to improve the current services for this particular group of young adults. The sample comprised 40 health care professionals, nurses from the children's department and adult ward, doctors, psychologists, physiotherapists and pharmacists currently working in the same hospital trust. A postal survey was conducted. The data were analysed using descriptive statistics and content analysis. The main findings suggest that there is a need for a planned transition programme, supported by a clinical protocols and a specialist unit for adolescents. Health care professionals' views of patients and family/carers' needs and how such needs may be met were identified.

Transition programs in cystic fibrosis centers: perceptions of team members.

Flume PA, Taylor LA, Anderson DL, Gray S, Turner D.

Department of Medicine, Medical University of South Carolina, Charleston, South Carolina 29425, USA. flumepa@musc.edu Pediatr Pulmonol. 2004 Jan;37(1):4-7.

Comment in: Pediatr Pulmonol. 2004 Jan;37(1):1-3.

We previously surveyed cystic fibrosis (CF) center directors and adult patients with CF to assess their perceptions regarding transition from a pediatric to an adult setting. An

important finding in those studies was a lack of standard programs for transfer of young adults with CF from pediatric to adult care settings. Patients with CF typically receive care from clinics utilizing a multidisciplinary approach, suggesting that every member of the CF team can impact the transition process. Our purpose in this study was to gain an appreciation for various team members' perspectives on transition. An Internet survey was offered to all CF centers across the country to be completed by team members, excluding physicians. We received 291 completed surveys, nearly half completed by nurses, but our respondents included social workers, nutritionists, respiratory therapists, and a few team members with other training. Nearly half of the respondents work for both pediatric and adult teams. The majority of respondents (71.8%) reported that their adult patients receive care from an internist in a separate adult program, but nearly 20% reported that a pediatrician follows their adult patients. A minority thought that age (37.4% of respondents), marriage (16.2%), and pregnancy (27.1%) were criteria for transfer, though most (86.2%) suggested that patients should be transferred by age 21 years. Criteria precluding transfer included patient/family resistance (45%), disease severity (34%), and developmental delay (31.3%). It was uncommon (11.4%) for an introduction to the concept of transition at the time of diagnosis. Over one-half of patients did not meet the adult team until time of transfer. Team members' perceptions of patients' concerns were similar to what we had previously measured in physicians, again far greater than what we have measured in patients themselves. In many ways, what we have measured here in team members reflects what we have reported by physicians, demonstrating slow development of standard transition programs and an overestimate of patients' concerns regarding transition. These differences may impede the successful transition of patients into an adult program. It is clear from this study that team members have an interest in and opinions on transition, and are likely play a vital role in the transition process. Standard programs of transition should be developed, and team members should be engaged in that process.

Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs.

Geenen SJ, Powers LE, Sells W. Center on Self-Determination, Oregon Institute on Disability and Development, Oregon Health Sciences University, Portland, Oregon 97202, USA. geenens@ohsu.edu J Adolesc Health. 2003 Mar;32(3):225-33.

PURPOSE: To evaluate the role of health care providers in the transition from pediatric to adult health care for adolescents with disabilities and special health care needs (SHCN) from both the families' and providers' perspectives.

METHODS: A total of 753 parents of adolescents with SHCN (e.g. developmental, physical, behavioral/emotional, learning, or health-related disabilities) were surveyed by questionnaire to assess their perceptions of their health care provider's level of involvement in various transition activities and the extent to which they felt it was the provider's responsibility to assist in a particular activity. One hundred forty-one health care providers (primarily pediatricians) completed a parallel survey to assess their level of participation in the same transition activities and the extent to which they felt it was their responsibility to assist with each transition activity. The questionnaire listed 13 different transition activities health providers may engage in to help young people prepare for adulthood and also asked questions about areas such as employment and health insurance. To investigate whether parents and providers share the same views

regarding the involvement and responsibility of providers across the 13 transition activities, two sets of Student's t-tests were calculated.

RESULTS: There were significant differences between providers and parents concerning both the level of provider involvement and the extent to which it was the provider's responsibility to assist in various transition activities (e.g., health providers reported significantly more involvement than did parents for 11 of the 13 transition activities and, compared with parents, providers reported that it was more within their role to assist in these 11 transition activities).

CONCLUSIONS: The findings suggest a need for health care providers and parents to have open discussions about the nature and extent to which providers assist families in key transition activities.

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