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RESEARCH ON PEOPLE WITH DISABILITIES AND ACCESS

ACCESS—GENERAL

Access to health care services among people with chronic or disabling conditions: patterns and predictors.

Beatty PW, Hagglund KJ, Neri MT, Dhont KR, Clark MJ, Hilton SA. National Rehabilitation Hospital Center for Health and Disability Research, Medstar Research Institute, Washington, DC, USA. phillip.beatty@medstar.net Arch Phys Med Rehabil. 2003 Oct;84(10):1417-25.

OBJECTIVE: To examine patterns of access to a variety of specific health care services among people with chronic or disabling conditions, focusing on factors that predict access to services.

DESIGN: National survey of 800 adults with cerebral palsy (CP), multiple sclerosis (MS), spinal cord injury (SCI), or arthritis.

SETTING: Respondents were surveyed in the general community.

PARTICIPANTS: National convenience sample of adults with CP, MS, SCI, or arthritis.

INTERVENTIONS: Not applicable.

MAIN OUTCOME MEASURES: Access to services from primary care doctors, services from specialists, rehabilitative services, assistive equipment, and prescription medications. Cross tabulations and logistic regression analyses were performed on survey data to examine patterns and predictors of access to health care services.

RESULTS: Only half of all respondents received needed rehabilitative services. Respondents covered by fee-for-service health plans were more likely than those covered by managed care organizations to receive needed services from specialists. Respondents with the poorest health and with the lowest incomes were the least likely to receive all health services examined.

CONCLUSIONS: People with chronic or disabling conditions often require a comprehensive array of health care services. Reform of the current health care payment and delivery structures is needed so that health care is more responsive to those with the greatest service needs.

Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: a qualitative inquiry.

Kroll T, Jones GC, Kehn M, Neri MT. National Rehabilitation Hospital, Center for Health & Disability Research, Research Division, Washington, DC 20010-2949, USA. Health Soc Care Community. 2006 Jul;14(4):284-93.

Individuals with physical disabilities are less likely to utilise primary preventive healthcare services than the general population. At the same time they are at greater risk for secondary conditions and as likely as the general population to engage in health risk behaviours. This qualitative exploratory study had two principal objectives: (1) to investigate access barriers to obtaining preventive healthcare services for adults with physical disabilities and (2) to identify strategies to increase access to these services. We conducted five focus group interviews with adults (median age: 46) with various physically disabling conditions. Most participants were male Caucasians residing in Virginia, USA. Study participants reported a variety of barriers that prevented them from receiving the primary preventive services commonly recommended by the US Preventive Services Task Force. We used a health services framework to distinguish structural-environmental (to include inaccessible facilities and examination equipment) or process barriers (to include a lack of disability-related provider knowledge, respect, and skilled assistance during office visits). Participants suggested a range of strategies to address these barriers including disability-specific continuing education for providers, the development of accessible prevention-focused information portals for people with physical disabilities, and consumer self-education, and assertiveness in requesting recommended services. Study findings point to the need for a more responsive healthcare system to effectively meet the primary prevention needs of people with physical disabilities. The authors propose the development of a consumer- and provider-focused resource and information kit that reflects the strategies that were suggested by study participants.

Diabetic patient experiences in a Medicaid managed care system.

Womeodu RJ, Graney MJ, Gibson DV, Bailey JE. University of Tennessee Health Science Center, Departments of Preventive Medicine and Medicine, 66 N. Pauline, Suite 633, Memphis, TN 38105, USA. Tenn Med. 2003 Oct;96(10):465-9.

OBJECTIVE: When Tennessee received a federal waiver to place all Medicaid enrollees in managed care organizations (MCOs), patients with chronic conditions such as diabetes were deemed especially vulnerable. This survey assessed patients' perceptions of diabetic care, self-care procedures, and satisfaction with medical care before and after enrollment in a Medicaid MCO.

METHODS: A telephone survey was designed and pilot tested before surveying 57 patients meeting inclusion criteria of continuous enrollment in Medicaid for two years before, and in the MCO for two years after, the initiation of Tennessee's Medicaid managed care system (TennCare).

RESULTS: On average, patients were 56.1 +/- 8.9 years old (mean +/- SD), African American (87.7%), female (73.7%), disabled (64.8%), with 8.4 +/- 2.8 years of education and annual incomes below \$10,000 (54.4%). Mean age at diagnosis was 39.5 +/- 11.5 years, and most (75.5%) were currently prescribed insulin. Over one-third (39.6%) described the quality of healthcare received under managed care as excellent or very good and 38.9% felt prior Medicaid care was worse or much worse. Compared to Medicaid, patients reported no difference in being denied a test under managed care because of lack of approval (P = .754). However, significant improvements were reported in receiving detailed information about diabetes (89.5% vs. 73.7%, P = .022), and diet (89.5% vs. 77.2%, P = .039) for the TennCare period. Patients were more likely to perform finger stick blood glucose tests under the MCO (76.8% vs. 40.7%, P = .001), but did not report that blood glucose was controlled more of the time (P = .332).

CONCLUSION: Most patients were satisfied with their MCO care, and most reported that finger stick glucose monitoring increased under the MCO. However, no significant gains in controlling blood sugar were reported. From the perspective of most patients, enrollment in an MCO had positive outcomes and resulted in improved access to diabetes-related health information.

Disability, chronic condition, and iatrogenic illness.

Batavia AI, Batavia M. School of Policy and Management, College of Health and Urban Affairs, Florida International University, North Miami, USA. Arch Phys Med Rehabil. 2004 Jan;85(1):168-71.

People with disabilities and chronic conditions are disadvantaged by the US health care system. Some people receive too few of the services they need; others receive too many services from practitioners who do not understand their disability-related needs and thus subject them to iatrogenic illnesses (health problems arising from the health care process). We explore this deprivation and excess and focus on 3 categories of iatrogenic illness that can harm this patient population and impede their ability to live independently. Empirical studies of iatrogenic illness in people with disabilities and chronic illnesses are needed. Psychiatrists must play a central role in conducting such studies and in helping these persons access needed care while avoiding potential health problems associated with such care.

Evaluating a Medicaid home and community-based physical disability waiver.

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State Medicaid waivers have fostered innovative health delivery systems for persons with special needs. Yet their overall cost effectiveness remains poorly understood.

Changes were recently analyzed in Medicaid health services and costs for persons newly enrolled in the Kansas Physical Disability (PD) Waiver and found that ambulatory services increased, consistent with meeting enrollees' unmet medical needs and their access to enriched services. Home health, transportation, and personal care services also rose. Though not significant, hospital inpatient, outpatient, and long-term care services declined. This movement towards community-based service use in the short term reflects improved self-directed care and possible long-term cost savings.

Health information needs of visually impaired people: a systematic review of the literature.

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Beverley@sheffield.ac.uk Health Soc Care Community. 2004 Jan;12(1):1-24.

Access to, and provision of, information is key to reducing health inequalities in health and social care. However, information is not always accessible and does not always meet the needs of specific groups. One such group is people who are visually impaired. The aim of the present study was to identify the health information needs of visually impaired people, and highlight major gaps in the literature. A systematic review of the literature was undertaken following, where possible, the NHS Centre for Reviews and Dissemination framework. Modifications included the sources searched, the critical appraisal checklist used (Critical Skills Training in Appraisal for Librarians) and the method of data synthesis. Out of the 1114 references identified, only 16 met the inclusion criteria. Quality of reporting of the literature was poor, and this must be taken into consideration when interpreting the findings of this review. The majority of studies were concerned with information for healthy living (e.g. health promotion). The focus of the remaining studies was on information about visual impairment or coping with visual impairment, and about accessing health services (e.g. medication labels and appointment letters). The majority of studies conducted to date have concentrated on the format of information. There are surprisingly few empirical studies which have examined the health information needs of this group. A number of gaps in the literature have been identified. These relate to the types of health information, non-format aspects of information (e.g. content and timing), sources of health and social care information, treating visually impaired people as a heterogeneous group, and recognising the value of actively involving visually impaired people in the research process. Although this review has identified a number of implications for practice, the paucity of evidence places a heavier onus on future research. Visually impaired people are likely to have unique health and social care information needs which are worthy of exploration in their own right.

Patient-doctor communication.

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Communication is an important component of patient care. Traditionally, communication in medical school curricula was incorporated informally as part of rounds and faculty feedback, but without a specific or intense focus on skills of communicating per se. The reliability and consistency of this teaching method left gaps, which are currently getting increased attention from medical schools and accreditation organizations. There is also increased interest in researching patient-doctor communication and recognizing the need to teach and measure this specific clinical skill. In 1999, the Accreditation of Council for Graduate Medical Education implemented a requirement for accreditation for residency programs that focuses on “interpersonal and communications skills that result in effective information exchange and teaming with patients, their families, and other health professionals.” The National Board of Medical Examiners, Federation of State Medical Boards, and the Educational Commission for Foreign Medical Graduates have proposed an examination between the third and fourth year of medical school that “requires students to demonstrate they can gather information from patients, perform a physical examination, and communicate their findings to patients and colleagues” using standardized patients. One’s efficiency and effectiveness in communication can be improved through training, but it is unlikely that any future advances will negate the need and value of compassionate and empathetic two-way communication between clinician and patient. The published literature also expresses belief in the essential role of communication. “It has long been recognized that difficulties in the effective delivery of health care can arise from problems in communication between patient and provider rather than from any failing in the technical aspects of medical care. Improvements in provider-patient communication can have beneficial effects on health outcomes”. A systematic review of randomized clinical trials and analytic studies of physician-patient communication confirmed a positive influence of quality communication on health outcomes. Continuing research in this arena is important. For a successful and humanistic encounter at an office visit, one needs to be sure that the patient’s key concerns have been directly and specifically solicited and addressed. To be effective, the clinician must gain an understanding of the patient’s perspective on his or her illness. Patient concerns can be wide ranging, including fear of death, mutilation, disability; ominous attribution to pain symptoms; distrust of the medical profession; concern about loss of wholeness, role, status, or independence; denial of reality of medical problems; grief; fear of leaving home; and other uniquely personal issues. Patient values, cultures, and preferences need to be explored. Gender is another element that needs to be taken into consideration. Ensuring key issues are verbalized openly is fundamental to effective patient-doctor communication. The clinician should be careful not to be judgmental or scolding because this may rapidly close down communication. Sometimes the patient gains therapeutic benefit just from venting concerns in a safe environment with a caring clinician. Appropriate reassurance or pragmatic suggestions to help with problem solving and setting up a structured plan of action may be an important part of the patient care

that is required. Counseling around unhealthy or risky behaviors is an important communication skill that should be part of health care visits. Understanding the psychology of behavioral change and establishing a systematic framework for such interventions, which includes the five As of patient counseling (assess, advise, agree, assist, and arrange) are steps toward ensuring effective patient-doctor communication. Historically in medicine, there was a paternalistic approach to deciding what should be done for a patient: the physician knew best and the patient accepted the recommendation without question. This era is ending, being replaced with consumerism and the movement toward shared decision-making. Patients are advising each other to “educate yourself and ask questions”. Patient satisfaction with their care, rests heavily on how successfully this transition is accomplished. Ready access to quality information and thoughtful patient-doctor discussions is at the fulcrum of this revolution.

Prevalence of secondary conditions among people with disabilities.

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We analyzed data from 2075 respondents to the disability supplement of the 2001 Washington State Behavior Risk Factor Surveillance Survey to describe population prevalence of secondary conditions among adults with disabilities. Eighty-seven percent of respondents with disabilities and 49% without disabilities reported at least 1 secondary condition. Adjusted odds ratios for disability for 14 of 16 conditions were positive and significant. The association of disability with substantial disparities in common conditions shows a need for increased access to general and targeted prevention interventions to improve health.

Rates of access to assistive equipment and medical rehabilitation services among people with disabilities.

Bingham SC, Beatty PW. National Rehabilitation Hospital, Center for Health and Disability Research, 1016 16th St. NW Suite 400, Washington, DC 20036, USA. Disabil Rehabil. 2003 May 6;25(9):487-90.

PURPOSE: To determine rates of access to assistive equipment and medical rehabilitation services among people with disabilities in the US, and to determine whether health plan type is associated with rates of access to these health services.

METHODS: Results were derived from a nationwide US survey sample of people with cerebral palsy, multiple sclerosis or spinal cord injury. Analyses were restricted to working-age adults (n=500). Need for, and receipt of (1) assistive equipment in the last 12 months, and (2) rehabilitative services in the last 3 months, was determined.

RESULTS: Over half of the sample indicated a need for assistive equipment in the last 12 months. Nearly a third of those who indicated a need did not receive assistive

equipment every time it was needed. Forty per cent of the sample indicated a need for rehabilitative services in the last 3 months, and over half of those indicating a need did not receive rehabilitative services every time they were needed. Access rates did not differ appreciably between respondents covered by managed care and fee-for-service health plans.

CONCLUSION: Emphasis in healthcare for people with disabilities should shift from traditional acute healthcare models that focus on functional restoration, to preventive services, and maintenance of function, health and independence.

Rationing of health care: clinical decision making in an outpatient clinic for anxiety disorders.

Issakidis C, Andrews G. School of Psychiatry, University of New South Wales and the Clinical Research Unit for Anxiety Disorders, St Vincent's Hospital, Sydney, Australia. cathyi@crufad.unsw.edu.au J Anxiety Disord. 2003;17(1):59-74.

Anxiety disorders are prevalent and disabling and despite the fact that effective interventions are available, many people do not access effective treatment. Clinician decisions are fundamental determinants of access to this treatment. Despite this, treatment decisions have never been examined specifically in this group and are rarely examined in outpatient settings. The present study assessed 550 consecutive referrals to an anxiety disorders clinic in Sydney, Australia. Logistic regression was used to examine the predictors of decisions about treatment. Clinical patient variables (diagnosis and disability) were the strongest predictors of an offer of treatment but demographics and resource availability were also significant. Some of the same factors have been shown to influence the decision to seek treatment for anxiety. Both help-seeking behavior and treatment decision making are important determinants of access to care and both should be examined in future studies.

Understanding the consequences of access barriers to health care: experiences of adults with disabilities.

Neri MT, Kroll T. Disability & Rehabilitation. 25(2):85-96, 2003 Jan 21.

PURPOSE: The study explores: (1) the scope and nature of the consequences that adults with disabilities perceive as the result of inappropriate access to health care services; (2) the variability of these consequences by demographic attributes such as disability type, gender, and health insurance type; and (3) the inter-relatedness and multidimensionality of these consequences.

METHODS: Qualitative, semi-structured, in-depth interviews were administered over the telephone to 30 participants with spinal cord injury, cerebral palsy, or multiple sclerosis as part of a nation-wide study on access and utilization in the USA. Interviews were transcribed and coded for analysis using the qualitative analysis program, NVivo.

RESULTS: Consequences were grouped into one of five categories: social, psychological, physical, economic and independence issues. Responses differed slightly with regard to disability type, gender and health insurance type. There was substantial overlap among consequence categories. For most respondents, negative consequences were not limited to just one area—frequently, one consequence triggered others. CONCLUSION: Health insurers and providers need a better understanding of the multiple consequences of access barriers. Based on this knowledge, detrimental and costly effects of inappropriate service delivery could be more effectively prevented. Implications for health care services and policy are discussed.

AGING

Depression and Bipolar Support Alliance consensus statement on the unmet needs in diagnosis and treatment of mood disorders in late life.

Charney DS, Reynolds CF 3rd, Lewis L, Lebowitz BD, Sunderland T, Alexopoulos GS, Blazer DG, Katz IR, Meyers BS, Arean PA, Borson S, Brown C, Bruce ML, Callahan CM, Charlson ME, Conwell Y, Cuthbert BN, Devanand DP, Gibson MJ, Gottlieb GL, Krishnan KR, Laden SK, Lyketsos CG, Mulsant BH, Niederehe G, Olin JT, Oslin DW, Pearson J, Persky T, Pollock BG, Raetzman S, Reynolds M, Salzman C, Schulz R, Schwenk TL, Scolnick E, Unutzer J, Weissman MM, Young RC; Depression and Bipolar Support Alliance. National Institute of Mental Health, National Institutes of Health, Bethesda, MD, USA. Arch Gen Psychiatry. 2003 Jul;60(7):664-72.

OBJECTIVE: To review progress made during the past decade in late-life mood disorders and to identify areas of unmet need in health care delivery and research.

PARTICIPANTS: The Consensus Development Panel consisted of experts in late-life mood disorders, geriatrics, primary care, mental health and aging policy research, and advocacy.

EVIDENCE: (1) Literature reviews addressing risk factors, prevention, diagnosis, treatment, and delivery of services and (2) opinions and experiences of primary care and mental health care providers, policy analysts, and advocates.

CONSENSUS PROCESS: The Consensus Development Panel listened to presentations and participated in discussions. Workgroups considered the evidence and prepared preliminary statements. Workgroup leaders presented drafts for discussion by the Consensus Development Panel. The final document was reviewed and edited to incorporate input from the entire Consensus Development Panel.

CONCLUSION: Despite the availability of safe and efficacious treatments, mood disorders remain a significant health care issue for the elderly and are associated with disability, functional decline, diminished quality of life, mortality from comorbid medical conditions or suicide, demands on caregivers, and increased service utilization. Discriminatory coverage and reimbursement policies for mental health care are a challenge for the elderly, especially those with modest incomes, and for clinicians.

Minorities are particularly underserved. Access to mental health care services for most elderly individuals is inadequate, and coordination of services is lacking. There is an immediate need for collaboration among patients, families, researchers, clinicians, governmental agencies, and third-party payers to improve diagnosis, treatment, and delivery of services for elderly persons with mood disorders.

Sight loss in later life: a vision for health service intervention.

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Nurs Times. 2003 Apr 15-21;99(15):36-8.

The care and support of older people with visual impairment is a neglected public policy issue, despite the growing numbers affected by sight loss in later life. A recent study of 400 people aged above 55 has identified problem areas and ways to improve practice and service delivery. Improvements will depend on better patient care at the time of diagnosis and more effective follow-up, with implications for closer liaison between health and social care practitioners. The article highlights three significant issues: the quality of patient care at time of diagnosis; difficulties experienced receiving and gaining access to outpatient follow-up; and the consequences of low levels of registration.

CHILDREN

Children with special health care needs enrolled in the State Children's Health Insurance Program (SCHIP): patient characteristics and health care needs.

Szilagyi PG, Shenkman E, Brach C, LaClair BJ, Swigonski N, Dick A, Shone LP, Schaffer VA, Col JF, Eckert G, Klein JD, Lewit EM. Departments of Pediatrics and Community and Preventive Medicine, University of Rochester School of Medicine and Dentistry, Rochester, New York, USA. Pediatrics. 2003 Dec;112(6 Pt 2):e508.

BACKGROUND: Children with special health care needs (CSHCN) often require more extensive services than children without special needs. The State Children's Health Insurance Program (SCHIP) in many states typically provides less extensive benefits and services than do state Medicaid programs. To design SCHIP to address the needs of CSHCN adequately, it is important to measure the degree to which children who enroll in SCHIP have special health care needs and to assess their health status and unmet health care needs. Little is known about the characteristics or preenrollment experience of CSHCN who enroll in SCHIP.

OBJECTIVE: To use data from the Child Health Insurance Research Initiative to measure the prevalence of CSHCN in SCHIP in 4 states, describe their demographic and health care features at enrollment, and compare their sociodemographic characteristics, health status, prior health care experiences, and unmet needs versus children without special health care needs.

METHODS: Children (0-18 years old) newly enrolled in SCHIP in 4 states were eligible for the study: New York, Florida (adolescents only), Kansas, and Indiana (CSHCN only). Telephone interviews were conducted shortly after enrollment and identified CSHCN by using the Child and Adolescent Health Measurement Initiative CSHCN screener. A common set of core questions assessed demographic characteristics, health status, special health care need status, insurance experience, access, use, quality of health care, and unmet needs during the year before enrollment. Bivariate and multivariate analyses were used to compare characteristics of CSHCN with characteristics of children without special needs.

RESULTS: Interviews were completed for parents of 5296 children enrolled in SCHIP in the 4 states. By using the Child and Adolescent Health Measurement Initiative CSHCN screener, the prevalence of CSHCN among SCHIP enrollees was 17% (New York), 18% (Florida), and 25% (Kansas), higher than the prevalence of CSHCN reported in the general population in those states. More than half of CSHCN reported the use of a chronic medication. Demographic characteristics of CSHCN were similar to those of children without special needs, although CSHCN were more likely to reside in single-parent households. Although CSHCN had poorer health status than children without special needs, many CSHCN were reported to be in good health, suggesting a wide spectrum of severity of illnesses within the CSHCN group. Although CSHCN were more likely than children without special needs to have been insured before SCHIP, a large proportion of CSHCN were nevertheless uninsured for at least 12 months before SCHIP (New York, 56%; Florida, 68%; Kansas, 24%; Indiana, 25%). Although most SCHIP enrollees had a usual source of care (USC) before SCHIP and there was some variation across states, between 4% and 13% of CSHCN lacked a USC on enrollment, and 23% to 38% of CSHCN changed their USC after enrollment in SCHIP. The majority of all SCHIP enrollees (including CSHCN) had used some health care during the year before SCHIP including preventive, acute, or specialty care. A high proportion of all SCHIP enrollees, including >30% to 40% of CSHCN, were reported to have unmet health care needs at enrollment in SCHIP. A variety of unmet needs were reported by CSHCN including specialty care, mental health care, dental care, and prescription medications. Nevertheless, the vast majority of CSHCN as well as children without special needs rated the quality of their medical care before SCHIP highly on several specific quality measures. Findings from multivariate analyses were similar to bivariate results with CSHCN in several states having higher use of care and more unmet health care needs before enrollment.

CONCLUSION: SCHIP is enrolling many CSHCN, with the prevalence of these children occurring at least as high as the prevalence of CSHCN in the general population. CSHCN enrolled in SCHIP represent a heterogeneous population with a wide range of health status and health care needs. Although most CSHCN were already already connected to the health care system with a USC and prior health care visits, many had unmet health care needs before enrolling in SCHIP.

CONCLUSION: 1) SCHIP benefit packages need to adequately cover services required by CSHCN such as prescription medications and specialty, mental health, developmental, and home services; 2) because utilization of care will be high among this large group of children, alternative methods of financing and managing care should be considered such as risk adjustment and special programs that involve case management and care coordination; 3) coordination of care across programs (such as between SCHIP and the state Title V Maternal and Child Health Services program, a component of which serves CSHCN) and ensuring adequate access to primary care and specialty providers might improve access to services for CSHCN; and 4) it is critical to monitor the quality of care for CSHCN enrolled in SCHIP, because these children are among the most vulnerable children covered by public health insurance programs and many of them are enrolling in SCHIP.

Disparities in use of and unmet need for therapeutic and supportive services among school-age children with functional limitations: a comparison across settings.

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OBJECTIVES: To determine whether family resources predict use of therapeutic and supportive services and unmet needs in medical versus educational settings.

DATA SOURCE: Children 5-17 years of age with at least one functional limitation (n=3,434) from the 1994 to 1995 Disability Supplement to the U.S. National Health Interview Survey.

STUDY DESIGN: Family resources included the child's type of health insurance, household education level, and poverty status. Therapeutic services included audiology; social work; occupational, physical, or speech therapy. Supportive services included special equipment, personal care assistance, respite care, transportation, or environmental modifications. Need was controlled by child health status and the severity and type of functional limitation(s). Age, gender, race/ethnicity, family size, and structure were covariates.

DATA ANALYSIS METHODS: Logistic regression provided estimates of associations between-family resources and use of or unmet need for therapeutic and supportive services. Multinomial methods were used to determine therapeutic service outcomes in medical versus educational settings.

PRINCIPAL FINDINGS: Children with public insurance were two to three times more likely to use services than children with private or no insurance regardless of type of service. Household education and public insurance were associated with supportive and therapeutic service use, but for therapeutic services only among children receiving services beyond the school setting. Household education predicted unmet need for both

types of services and therapeutic services across settings. Findings should be interpreted cautiously, given the survey's dependence on respondent report to define the need for services and the potential for overrepresentation of children with more severe needs in the public insurance category.

CONCLUSIONS: Disparities in the use of services by household education level and by type of health insurance across service settings suggests inequitable access among the U.S. policies and programs serving children with functional limitations. Family income and education appear to give families an advantage in obtaining services and in identifying a child's unmet need.

Health care policy for medically fragile children.

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Medically fragile children are part of a growing population of children with special health care needs (CSHCN) who are dependent on technology for survival. Despite the extensive care needs characteristic of this population, many medically fragile children are cared for in their homes. Caregivers for these children are faced with numerous tasks, including the daily care of their child as well as the coordination of vital services. Inadequate access to health care, little service availability, limited insurance, and financial restraints may further complicate caring for a medically fragile child in the home. Although federally funded programs such as Supplemental Security Income (SSI) and State Title V CSHCN programs may be beneficial for these children and their families, current policies may limit access to these necessary services. As patient advocates, nurses may be instrumental in assisting medically fragile children and their families to obtain much-needed programs and vital services.

Mental health services use among school-aged children with disabilities: the role of sociodemographics, functional limitations, family burdens, and care coordination.

Witt WP, Kasper JD, Riley AW. Center for Healthcare Studies, Northwestern University, Chicago, IL 60611, USA. Health Serv Res. 2003 Dec;38(6 Pt 1):1441-66.

OBJECTIVE: To examine the use of mental health services and correlates of receiving services among community-dwelling children with disabilities, ages 6 to 17 years.

DESIGN: Data are from the 1994 and 1995 National Health Interview Survey Disability Supplements (NHIS-D), conducted by the National Center for Health Statistics. The study sample is 4,939 children with disabilities, representing an estimated eight million children with disabilities nationwide. Parents of children under 16 years of age reported (17-year-olds self-reported) on health, emotional and behavioral problems, mental health services use, and who, if anyone, coordinated the child's health care.

RESULTS: Among disabled children with poor psychosocial adjustment (11.5 percent), only 11.8 percent received mental health services in the past year. Multivariate logistic regression analysis showed service use was associated with poor psychosocial adjustment; communication, social, and learning-related functional impairments; public health insurance; and financial family burdens. Younger and black disabled children were less likely to receive mental health services. The odds of service use were greater with the involvement of a health professional in coordinating care, in contrast to no one or family only. Moreover, children with disabilities were more likely to use outpatient mental health services if their care was jointly coordinated by a family member and a health professional, compared to a health professional working alone. In contrast to inpatient and outpatient care, race and family burden were not associated with the likelihood of mental health counseling in special education school settings.

CONCLUSION: Findings indicate that only two in five disabled children with poor psychosocial adjustment receive mental health services. Differences by age, race, and insurance coverage suggest that inequalities to access exist. However, the school setting may be one in which some barriers to mental health services for disabled children are reduced. The study also shows that the involvement of health professionals in care coordination is associated with greater access to mental health care for disabled children. These findings underscore the importance of engaging both health care professionals and the family in the care process.

Unmet need for routine and specialty care: data from the National Survey of Children With Special Health Care Needs.

Mayer ML, Skinner AC, Slifkin RT; National Survey of Children With Special Health Care Needs. Cecil G. Sheps Center for Health Services Research, University of North Carolina, Chapel Hill, North Carolina 27599-7590, USA. michelle_mayer@unc.edu Pediatrics. 2004 Feb;113(2):e109-15.

OBJECTIVE: To assess the prevalence of unmet needs for routine and specialty care among children with special health care needs (CSHCN) and to identify factors associated with the likelihood of having unmet need for medical care.

METHODS: Data come from the respondents for 38 866 children interviewed for the National Survey of Children With Special Health Care Needs. Bivariate analyses were used to assess differences in unmet need for medical care by various environmental, predisposing, enabling, and need factors. Logit analyses were used to determine independent effects of these variables on the likelihood of having an unmet need for medical care.

RESULTS: Nationally, 74.4% and 51.0% of CSHCN needed routine and subspecialty physician care, respectively. Of those reporting that they needed routine care, 3.2% were unable to obtain these services. Of those reporting a need for specialty care, 7.2% reported not obtaining all needed specialty care. The prevalence of unmet need for specialty care significantly exceeded the prevalence of unmet need for routine care. In

logit analyses, African American children and children whose mothers had less than a high-school education faced twice the odds of having an unmet need for routine care. Compared with nonpoor children, children living below the federal poverty level were significantly more likely to have an unmet need for routine (adjusted odds ratio [aOR]: 1.97; 95% confidence interval [CI]: 1.23-3.14) and specialty (aOR: 2.50; 95% CI: 1.49-4.18) care. Near-poor children were also significantly more likely than nonpoor children to have unmet needs for routine and specialty care. Uninsured children were significantly more likely than continuously insured children to report an unmet need for routine (aOR: 7.51; 95% CI: 4.99-11.30) and specialty (aOR: 4.29; 95% CI: 2.99-6.15) care. Our findings also show that higher levels of general pediatrician supply, relative to the pediatric population, are associated with a significantly lower likelihood of having an unmet need for routine care. Likewise, a greater supply of pediatric subspecialists is associated with a decreased likelihood of having an unmet need for specialty care. **CONCLUSION:** Compared with previous reports of the general pediatric population, CSHCN have higher levels of unmet need for medical services. Our regression results emphasize that children vulnerable because of their social circumstances (eg, poverty, etc) have significantly greater odds of having unmet need for routine and specialty physician care. Furthermore, our findings highlight the importance of insurance coverage in ensuring access to needed routine and specialty medical services.

Use of telemedicine to follow special needs children.

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Telemed J E Health. 2003 Spring;9(1):57-61

Two remote telemedicine clinics were established linked to a tertiary care center to improve access for special health care needs children (SHCNC). The remote clinics were established at Lamar University's School of Nursing (1996) and Stephen F. Austin University's School of Nursing (1997), and they were linked to the pediatric interdisciplinary team at the University of Texas Medical Branch. These clinics were evaluated to determine if the tertiary interdisciplinary team could effectively assess and plan interventions for SHCNC and to assess patient and caregivers satisfaction with this intervention. The interdisciplinary team and the patients and their families were highly satisfied with this arrangement.

Who's enrolled in the State Children's Health Insurance Program (SCHIP)? An overview of findings from the Child Health Insurance Research Initiative (CHIRI).

Brach C, Lewit EM, VanLandeghem K, Bronstein J, Dick AW, Kimminau KS, LaClair B, Shenkman E, Shone LP, Swigonski N, Szilagyi PG; Child Health Insurance Research Initiative. Center for Delivery, Organization and Markets, Agency for Healthcare Research and Quality, Rockville, Maryland 20850, USA. cbrach@ahrq.gov

Pediatrics. 2003 Dec;112(6 Pt 2):e499.

BACKGROUND: The State Children's Health Insurance Program (SCHIP) was enacted in 1997 to provide health insurance coverage to uninsured low-income children from families who earned too much to be eligible for Medicaid.

OBJECTIVE: To develop a "baseline" portrait of SCHIP enrollees in 5 states (Alabama, Florida, Kansas, Indiana, and New York) by examining: 1) SCHIP enrollees' demographic characteristics and health care experiences before enrolling in SCHIP, particularly children with special health care needs (CSHCN), racial and ethnic minority children, and adolescents; 2) the quality of the care adolescents received before enrollment; and 3) the changes in enrollee characteristics as programs evolve and mature.

METHODS: Each of 5 projects from the Child Health Insurance Research Initiative (CHIRI) surveyed new SCHIP enrollees as identified by state enrollment data. CHIRI investigators developed the CHIRI common core (a set of survey items from validated instruments), which were largely incorporated into each survey. Bivariate and multivariate analyses were conducted to ascertain whether there were racial and ethnic disparities in access to health care and differences between CSHCN and those without. Current Population Survey data for New York State were used to identify secular trends in enrollee characteristics.

RESULTS: Most SCHIP enrollees (65% in Florida to 79% in New York) resided in families with incomes < or =150% of the federal poverty level. Almost half of SCHIP enrollees lived in single-parent households. A majority of SCHIP parents had not had education beyond high school, and in 2 states (Alabama and New York) approximately 25% had not completed high school. The vast majority of children lived in households with a working adult, and in a substantial proportion of households both parents worked. Children tended to be either insured for the entire 12 months or uninsured the entire 12 months before enrolling in SCHIP. Private insurance was the predominant form of insurance before enrollment in SCHIP in most states, but 23.3% to 51.2% of insured children had Medicaid as their most recent insurance.

HEALTH CARE USE AND UNMET NEEDS BEFORE SCHIP: The vast majority of all SCHIP enrollees had a usual source of care (USC) during the year before SCHIP. The proportion of children who changed their USC after enrolling in SCHIP ranged from 29% to 41.3%. A large proportion of SCHIP enrollees used health services during the year before SCHIP, with some variability across states in the use of health care. Nevertheless, 32% to almost 50% of children reported unmet needs. The prevalence of CSHCN in SCHIP (between 17% and 25%) in the study states was higher than the prevalence of CSHCN reported in the general population in those states. In many respects, CSHCN were similar to children without special health care needs, but CSHCN had poorer health status, were more likely to have had unmet needs, and were more likely to use the emergency department, mental health care, specialty care, and acute care in the year before enrolling in SCHIP than children without special health care needs.

RACE AND ETHNICITY: A substantial proportion of SCHIP enrollees were black non-Hispanic or Hispanic children (Alabama: 34% and <1%; Florida: 6% and 26%; Kansas: 12% and 15%; and New York: 31% and 45%, respectively). Minority children were poorer, in poorer health, and less likely to have had a USC or private insurance before enrolling in SCHIP. The prevalence and magnitude of the disparities varied among the states.

QUALITY OF CARE FOR ADOLESCENTS: Seventy-three percent of adolescent SCHIP enrollees engaged in one or more risk behaviors (ie, feeling sad or blue; alcohol, tobacco, and drug use; having sexual intercourse; and not wearing seat belts). Although almost 70% of adolescents reported having had a preventive care visit the previous year, a majority of them did not receive counseling in each of 4 counseling areas. Controlling for other factors, having a private, confidential visit with the physician was associated with an increased likelihood (2-3 times more likely) that the adolescent received counseling for 3 of 4 counseling areas.

TRENDS OVER TIME: New York SCHIP enrollees in 2001, compared with 1994 enrollees in New York's SCHIP-precursor child health insurance program, were more likely to be black or Hispanic, older, from New York City, and from families with lower education, income, and employment levels. A greater proportion of 2001 enrollees was uninsured for some time in the year before enrollment, was insured by Medicaid, and lacked a USC. Secular trends in the low-income population in the state did not seem to be responsible for these differences. Program modifications during this time period that may be related to the shift in enrollee characteristics include changes to benefits, outreach and marketing efforts, changes in the premium structure, and the advent of a single application form for multiple public programs.

CONCLUSION: SCHIP enrollees are a diverse group, and there was considerable variation among the 5 study states. Overall, SCHIP enrollees had substantial and wide-ranging health care needs despite high levels of prior contact with the health care system. A sizable minority of SCHIP enrollees has special health care needs. There is racial and ethnic diversity in the composition of enrollees as well, with racial and ethnic disparities present. The quality of care adolescents received before enrollment in SCHIP was suboptimal, with many reporting unmet health care needs and not receiving recommended counseling. The characteristics of SCHIP enrollees can be expected to change as SCHIP programs evolve and mature.

POLICY IMPLICATIONS: 1) Benefits should be structured to meet the needs of SCHIP enrollees, which are comparable to Medicaid enrollees' needs in many respects. 2) Provider networks will have to be broad if continuity of care is to be achieved. 3) Multiple outreach strategies should be used, including using providers to distribute information about SCHIP. 4) The quality of care delivered to vulnerable populations (eg, minority children, CSHCN, and adolescents) should be monitored. 5) States and health plans should actively promote quality health care with the goal of improving the care received by SCHIP enrollees before enrollment. 6) States will have to craft policies that fit their

local context. 7) Collecting baseline information on SCHIP enrollees on a continuous basis is important, because enrollee characteristics and needs can change, and many vulnerable children are enrolling in SCHIP.

DENTAL CARE

Designing and implementing a school-based dental program for students with developmental disabilities.

York JA, Holtzman JM. Department of Community Health and Restorative Dentistry, University of Medicine and Dentistry of New Jersey, New Jersey Dental School, Newark 07101, USA. yorkja@umdnj.edu Spec Care Dentist. 2004 Nov-Dec;24(6):308-12. Students with developmental disabilities in Atlantic County Special Services School District (ACSSSD) receive on-site dental care through a program created by UMDNJ-New Jersey Dental School (NJDS). The program's goal was to coordinate dental school resources with those of a school district, county agencies and the Delta Dental Foundation to provide quality dental services to the students, aged 3-21 years. The University developed a Needs Assessment Survey and distributed 450 surveys to the students' parent/guardian(s). Completed surveys were returned by 131 respondents. Of the 131 children represented, 75 had not been seen by a dentist within the past year. In response to guardian reported access problems, UMDNJ-NJDS and ACSSSD developed a school-based dental care delivery system and a program for health promotion and disease.

General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs.

Casamassimo PS, Seale NS, Ruehs K. Section of Pediatric Dentistry, The Ohio State University, USA. J Dent Educ. 2004 Jan;68(1):23-8. This study analyzed a data subset of a national survey of general dentists conducted in 2001 to determine their overall care of children with special health care needs (CSHCN). In the survey, dentists were asked to respond to questions in the following areas: did they provide care for CSHCN (children with cerebral palsy, mental retardation, and those who are medically compromised); what were their perceptions of the training they received in dental school related to CSHCN; what was their interest in additional training for CSHCN; and what factors influenced their willingness to provide care for CSHCN? Only about 10 percent see CSHCN often or very often, and only one in four respondents had hands-on experience with these patients in dental school. Postgraduate education in general practice or advanced general dentistry residency had no effect on willingness to care for CSHCN. Older dentists, those accepting Medicaid for all children, and those practicing in small communities were more likely to see CSHCN. Dentists willing to see CSHCN also were more likely to perform procedures associated with special needs and

underserved child populations including pharmacologic management and stainless steel crowns. Dentists with hands-on educational experiences in dental schools with CSHCN were less likely to consider such factors as level of disability and patient behavior as obstacles to care and were more likely to desire additional education in care of CSHCN.

Improving oral health disparities and access to care: challenges and opportunities for the states.

Henderson TM. J Calif Dent Assoc. 2005 Aug;33(8):635-9.

States and their dental reimbursement, practice, and education policies and programs have done little to address oral health disparities. Particular state policies and programs are often cited as having an adverse impact on oral health access for vulnerable populations. These include poor Medicaid and State Children's Health Insurance Program reimbursement, an inadequate safety net, the ban on the corporate practice of dentistry, and a lack of funding to prepare the dental workforce to treat special needs populations and provide culturally competent care. (The State Children's Health Insurance Program, created by the Balanced Budget Act of 1997, enacted Title XXI of the Social Security Act and allocated about dollar 20 billion over five years to help states insure more children.) While state health officials have paid less attention to oral health disparities, there has been increased interest by state policymakers in addressing the special health care needs of the elderly, disabled, and children. These include state responses to the 1999 Olmstead Supreme Court decision and state pharmaceutical assistance programs for the elderly and disabled. (In rejecting the state of Georgia's appeal to enforce institutionalization of individuals with disabilities, the Supreme Court in 1999 affirmed the right of individuals with disabilities to live in their community in its 6-3 ruling against the state of Georgia in the case Olmstead v. L.C and E.W.) However, a few states have begun to develop solutions to explicitly address oral health access problems. States are considering or testing the following programs and policies pertaining to 1) improving workforce supply and distribution, 2) education reform and increased public accountability, 3) practice reform, and 4) increased data collection and research.

Oral health for people with special needs: consensus statement on implications and recommendations for the dental profession.

Glassman P, Henderson T, Helgeson M, Niessen L, Demby N, Miller C, Meyerowitz C, Ingraham R, Isman R, Noel D, Tellier R, Toto K. Advanced Education in General Dentistry Program at the University of the Pacific Arthur A. Dugoni School of Dentistry, San Francisco, CA 94115, USA. J Calif Dent Assoc. 2005 Aug;33(8):619-23.

In November 2004, the Pacific Center for Special Care at the University of the Pacific Arthur A. Dugoni School of Dentistry, with support from the California Dental Association Foundation, hosted a conference to explore the issue of oral health for people with

special needs. This conference was held in conjunction with the joint meetings of Pacific's Statewide Task Force on Oral Health for People With Special Needs and Pacific's Statewide Task Force on Oral Health and Aging. These groups of interested stakeholders meet several times a year to discuss the increasing problems faced by people with disabilities, elderly individuals, and other special populations in obtaining access to oral health services and maintaining good oral health. The purpose of this conference was to explore the changing population of people with special needs, analyze the implications for the dental profession and society, and describe systems and strategies that might lead to improved oral health for these populations. This conference also served as a forum for developing oral health recommendations as a part of the California Commission on Aging's Strategic Plan for an Aging Population. Seven nationally recognized speakers presented draft papers on various aspects of this topic. These presentations are published as the additional papers in this and the next issue of the Journal. There was time for audience reaction and discussion with the speakers. The speakers and a designated group of reactors then developed this consensus statement and recommendations for addressing these issues.

Practical protocols for the prevention of dental disease in community settings for people with special needs: the protocols.

Glassman P, Anderson M, Jacobsen P, Schonfeld S, Weintraub J, White A, Gall T, Hammersmark S, Isman R, Miller CE, Noel D, Silverstein S, Young D. University of the Pacific School of Dentistry, USA. pglassman@pacific.edu Spec Care Dentist. 2003 Sep-Oct;23(5):160-4.

People with special needs have more dental disease and more missing teeth than the general population. They also have reduced access to oral health diagnostic, preventive, interceptive and treatment services. If services are available, they can be complicated and costly. It is critical to prevent dental diseases in these individuals. This article presents a set of practical protocols for preventing dental disease in people with special needs. These protocols are designed to be used in community settings outside of a dental office.

Who will provide dental care for housebound people with oral problems?

Simons D. Hertfordshire Partnership Trust CDS. Br Dent J. 2003 Feb 8;194(3):137-8. Comment in: Br Dent J. 2003 May 10;194(9):466.

There are currently 9(1/2) million people in England and Wales over retirement age and nearly 4 million of these are over 75 years. Age itself is not a disease and 70% of the population over 65 are functionally independent. However, ageing is associated with an increase in the prevalence of chronic disease and disability and 20% of people over 65 years are frail and a further 10% are functionally dependent, either homebound or institutionalised. The implications of this demographic change on oral health has been

investigated. Reports show oral health for the well elderly is improving, creating a demand for dental services, which this group are able to access, but maintenance of oral health and access to dental treatment is a problem for disabled elderly people, who, for their daily activity are dependent on carers.

DEVELOPMENTAL AND INTELLECTUAL DISABILITIES

Access to health care for individuals with developmental disabilities from minority backgrounds.

Reichard A, Sacco TM, Turnbull HR 3rd. Beach Center on Disability, University of Kansas, Haworth Hall, 1200 Sunnyside Ave., Room 3136, Lawrence, KS 66045-7534, USA. areichard@khi.org Ment Retard. 2004 Dec;42(6):459-70.

In this project we examined access to health care by individuals with developmental disabilities in Kansas from low-income populations and from minority backgrounds. Four criteria for determining access were employed: availability, accessibility, affordability, and appropriateness of care. Factors that pose barriers and that facilitate access are described and recommendations are set out, with particular reference to the 2002 Report of the Surgeon General of the United States, related to health status of people with mental retardation.

Access to specialty medical care for children with mental retardation, autism, and other special health care needs.

Krauss MW, Gulley S, Sciegaj M, Wells N. The Heller School for Social Policy and Management, MS 035, Brandeis University, PO Box 549110, Waltham, MA 02454-9110, USA. krauss@brandeis.edu Ment Retard. 2003 Oct;41(5):329-39.

Access to specialty medical care among children with mental retardation, autism, or other types of special health care needs was examined. Results from a national survey indicate that over a third of the children with autism, over a fifth with mental retardation, and over a fifth with other types of special health care needs had problems obtaining needed care from specialty doctors in the preceding year. The most common problems included getting referrals and finding providers with appropriate training. Children with unstable health conditions, autism, or those whose parent was in poor health were at greater risk for problems. Primary Medicaid coverage and public secondary health coverage were associated with fewer access problems. Implications for health services for children with special health care needs are discussed.

Addressing the need for education: curriculum development for nurses about intellectual and developmental disabilities.

Hahn JE. University of California Los Angeles School of Nursing, Factor Building Room 5-145, 700 Tiverton, Box 956919, Los Angeles, CA 90095-6919, USA.

jhahn@sonnet.ucla.edu Nurs Clin North Am. 2003 Jun;38(2):185-204.

People with disabilities and national and international agencies are voicing their views, forcing health care providers to look at how people with disabilities are treated in the health care system and to find ways to help them achieve equal access to quality care. Education about nursing care of patients with I/DD is limited in basic nursing education programs and for nurses who are in practice. A number of developmental disabilities nursing projects are addressing this need with curriculum development that has validated the need for education and has begun testing the various methods of instruction. As the curriculum is disseminated in written or Internet-accessible formats, nurses in education and practice will be able to find resources that target a specific topic area or a set of comprehensive instructions to acquire a better understanding of the comprehensive needs of people with I/DD and better ways to provide care. There is a need for a greater integration of curriculum about nursing care of people with developmental disabilities into basic nursing education at all levels and further evaluation of the impact of this curriculum on nursing care for people with I/DD. The hope is that these efforts can improve the education of nurses and other health care providers for the direct benefit of individuals with intellectual disabilities.

A cascade of disparities: health and health care access for people with intellectual disabilities.

Krahn GL, Hammond L, Turner A. Child Development and Rehabilitation Center, Oregon Health & Science University, Portland, OR 97207-0574, USA. krahng@ohsu.edu
Ment Retard Dev Disabil Res Rev. 2006;12(1):70-82.

People with ID represent approximately 2% of the population and, as a group, experience poorer health than the general population. This article presents recent conceptualizations that begin to disentangle health from disability, summarizes the literature from 1999 to 2005 in terms of the cascade of disparities, reviews intervention issues and promising practices, and provides recommendations for future action and research. The reconceptualization of health and disability examines health disparity in terms of the determinants of health (genetic, social circumstances, environment, individual behaviors, health care access) and types of health conditions (associated, comorbid, secondary). The literature is summarized in terms of a cascade of disparities experienced by people with ID, including a higher prevalence of adverse conditions, inadequate attention to care needs, inadequate focus on health promotion, and inadequate access to quality health care services. Promising practices are reviewed from the perspective of persons with ID, providers of care and services, and policies that influence systems of care. Recommendations across multiple countries and organizations are synthesized as guidelines to direct future action. They call for promoting principles of early identification, inclusion, and self-determination of people

with ID; reducing the occurrence and impact of associated, comorbid, and secondary conditions; empowering caregivers and family members; promoting healthy behaviors in people with ID; and ensuring equitable access to quality health care by people with ID. Their broadscale implementations would begin to reduce the health disparity experienced by people with ID.

Health status, utilization patterns, and outcomes of persons with intellectual disabilities: review of the literature.

Hayden MF, Kim SH, DePaepe P. The LBH Institute, 58 Inner Drive, St. Paul, MN 55115, USA. Ment Retard. 2005 Jun;43(3):175-95.

A literature review was conducted to analyze existing data on health status, health care utilization, and medical outcomes of persons with intellectual disabilities. We found that barriers exist, but evidence indicates that (a) individuals with intellectual disability and medical needs are living in the community, (b) people with significant medical conditions can be maintained in community settings, and (c) medical supports can and are provided to people with intellectual disabilities and allied medical conditions to enable community living. However, some people had unmet medical needs, and the availability of and access to community-based services were problematic for others. These contradictory findings indicate that it is possible to provide services in the community, but the service delivery system needs improvement.

Medical needs of people with intellectual disability require regular reassessment, and the provision of client- and carer-held reports.

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J Intellect Disabil Res. 2003 Feb;47(Pt 2):134-45.

BACKGROUND: Previous work has indicated a wide range of unmet medical health needs in people with intellectual disability (ID).

METHODS: A profile of recorded medical needs was produced for 589 people with ID through a detailed search of individual medical and nursing case records. Specialist optometric and audiological assessments were offered, and reports were provided in technical and plain English terms. A Health Watch project delivered folders with copies of the plain English reports to 60 individuals and carers.

RESULTS: The case record review indicated a wide range of medical disorders; however, exact diagnoses and counselling regarding underlying neurological conditions were seldom recorded. Assessed levels of hearing and vision loss were much greater than had been previously recognized. The Health Watch reports were welcomed by the clients and carers.

CONCLUSION: If satisfactory healthcare is to be achieved for people with ID, medical needs must be monitored, regular specialist reassessments offered, access to specialist services facilitated and reports clearly explained to carers.

Ocular and visual defects amongst people with intellectual disabilities participating in Special Olympics.

Woodhouse JM, Adler PM, Duignan A. Department of Optometry & Vision Sciences, Cardiff University, Cardiff CF10 3NB, UK. Ophthalmic Physiol Opt. 2003 May;23(3):221-32.

PURPOSE: To analyse data from vision screening of people with intellectual disabilities from the UK participating in Special Olympics during the National Summer Games in Cardiff 2001, in order to determine visual status and access to eye care.

METHODS: Athletes were invited to take part in vision screening, according to Special Olympics protocols.

RESULTS: Testability rates were high. Findings confirmed the high prevalence of eye and vision defects reported in other studies of people with intellectual disabilities. In particular, visual acuity was below normal for most athletes. Significant improvement to acuity could be achieved with spectacles although correction after full refraction did not always provide normal vision. Over 40% of athletes undergoing full refraction had below normal corrected acuity.

CONCLUSION: Athletes with intellectual disabilities were no more likely to access eye care and have adequate spectacle correction than other people with intellectual disabilities. Optometrists and carers need to be aware of the high prevalence of defects and the importance of regular eye examinations in people with intellectual disabilities.

Perspectives of physicians, families, and case managers concerning access to health care by individuals with developmental disabilities.

Reichard A, Turnbull HR. Kansas Health Institute, 212 SW Eighth Ave., Suite 300, Topeka, KS 66603, USA. areichard@khi.org Ment Retard. 2004 Jun;42(3):181-94.

This study of the status of medical care for Kansans with developmental disabilities consists of reports from physicians, service providers, and family members. Overall, these three groups indicated satisfaction with medical care across the four criteria of availability, accessibility, appropriateness, and affordability. The bases for these results are outlined, and suggestions for improving satisfaction with health care are presented.

Technology and the environment: supportive resource or barrier for people with developmental disabilities?

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IL 60612-7250, USA. hammel@uic.edu *Nurs Clin North Am.* 2003 Jun;38(2):331-49.

Findings from needs assessments and abandonment studies point to issues with health care providers, particularly in their ability to listen to the needs of the consumer and important others regarding AT-EI. Professionals need to listen to what people are telling them or, in many cases, what they are not telling them. Actions and nonverbal messages can speak very loudly. Strategies to communicate and collaborate with consumers need to be developed. Regardless of ability to communicate or the severity of the impairments the person may be experiencing, it is important to withhold judgments that may underestimate a person's potential or desire to be in control of life decisions. AT-EI service have often seen people labeled with severe or profound intellectual disabilities challenge that diagnosis after accessing a communication or access system. Likewise, a person with a severe disability has the right to supportive resources and to the same level of respect, dignity, and quality of life as any other member of society. Using the technology and adapting the environment to provide opportunities for consumers to "voice" their wishes and control their lives can be an effective strategy to collaborate. When focusing on a rights-based philosophy, recognizing the difference between physical independence (e.g., physical and/or cognitive ability to do a task by oneself) and self-care management (e.g., access to and power to manage the supportive resources to live in the community regardless of level of physical ability) is important. We all rely on supports in our lives, whether it be tools or technology to help us do a job or another person, yet when we evaluate people with disabilities, the expectation is for people to function independently [23,24]. They even receive lower scores on functional assessments if they are using a piece of technology to do an activity. By shifting the focus to management of and access to resources versus level of physical dependence or burden, health care professionals can play a role in linking people to such resources as AT-EI and related services and strategies to support community living. Such a shift in focus also enables professionals to validate interdependence; that is, the give-take relationships that people have with each other to support each other [25]. The use of AT-EI by people with developmental disabilities often involves an interdependent relationship in which another person may help set up the environment or technology and, in turn, the consumer can then reciprocate and engage in an activity or a relationship [1]. Health care professionals also need to better understand and take into consideration the social context, its influence on consumers' use or nonuse of AT-EI, and the long-term influence on community living and participation decisions [1]. Nurses can involve important others in the process by listening to and considering their needs, and ensuring that they are informed about options, the benefits of using AT-EI for the consumer and themselves, and how to set up and troubleshoot the AT-EI. In cases where important others are not supportive, health care professionals may be in a position to link the consumer with other consumers and advocacy groups such as Centers for Independent Living or Self Advocates Becoming Empowered that may offer that support as well as membership in a collective community engaged in systems change. Health care professionals can serve as a system interface by linking people to

information and resources to make informed decisions [26]. Resources on developmental disability and health, common issues that may occur, and life course planning help people identify functional issues and early signs of accelerated aging and proactively use the environment and technology to stay in living situations of choice. Few health care professionals are well prepared to provide services to people with developmental disabilities as they age; a great need exists for providers of such specialized services and for proactive later-life screenings that can identify issues early and make the most use of AT-EI strategies to address aging issues [26,28]. At any given point in time in the life of people with developmental disabilities, many different professionals and systems may be involved in decisions that could include AT-EI. Medical, educational, vocational, independent living, and case management systems may all be working with the person; however, there is often limited or no communication between them, particularly as the person ages or transitions between settings. Health care professionals, even when they are working with an individual on a limited basis, can and should take on active roles in linking consumers and important others with other systems and should ensure that information about their AT-EI needs is transferred accurately between systems. Most likely, nurses may be in a role to refer a person to specialized services, whether they may be medical, rehabilitative, AT-EI-specific, or disability advocacy groups that can help support the person as they face barriers or seek out AT. Nurses may also be in a role to pass on important information about the person's health and medical status that can help to better inform AT-EI decisions to ensure the AT meets the person's needs across contexts. As an interface, nurses may assume a role as a supporting advocate for accessing resources, not as a gatekeeper who makes decisions for people. This includes referring individuals with developmental disabilities to people and groups that know how to get AT-EI, how to fund it, and how to troubleshoot it, and linking them to other people with disabilities who are sharing strategies in person and on-line. It also includes focusing beyond basic self-care and considers AT-EI strategies that enable a person to participate in high meaning activities and roles in the home and the community. Participation in activities identified as highly meaningful and important to the person, such as participating in a religious community, networking with other people on-line, gardening, or being a member of a community group, to name a few, can positively contribute to health, wellness, and quality of life; the challenge is to create and adapt the environment (social, physical, and societal) to support participation choices and control.

Telehealth home health applications for adults with developmental disabilities.

Miller TW, Elliott B, Long K, Mazenac C, Moder M. School of Allied Health, University of Connecticut, Storrs, CT 06269, USA. Tom.miller@uconn.edu Telemed J E Health. 2006 Apr;12(2):137-45.

Telehealth technology for application in home healthcare for adult persons with developmental disabilities was examined. Utilization of telehealth by clinicians, including

the physician, nurse and physician assistant, physical therapist, occupational therapist, speech language pathologist, the dietitian, and psychologist for the healthcare needs of adults with developmental disabilities is discussed. Such utilization results in improved access to needed health services by reducing time and distance for this population. A telehealth model is offered, as are shifts in healthcare using telehealth technology in home health.

ENVIRONMENTAL BARRIERS

Environmental barriers to health care among persons with disabilities—Los Angeles County, California, 2002-2003.

Centers for Disease Control and Prevention (CDC). *MMWR Morb Mortal Wkly Rep.* 2006 Dec 8;55(48):1300-3.

In 2002, an estimated 51.2 million persons in the United States (approximately 18.1% of the population) had a disability. Recent data suggest that substantial disparities in health behaviors and overall health status exist between persons with and without disabilities. Nonetheless, when they have access to adequate health care, persons with disabilities can lead healthy lives. The World Health Organization's International Classification of Functioning, Disability, and Health stresses the importance of environment (e.g., physical environment, attitudes of others, or policies) as either a barrier or facilitator in the daily activities of persons with disabilities. In addition, increasing access to health and wellness treatment programs for persons with disabilities and reducing the proportion of persons with disabilities who report environmental barriers to participation in daily activities are goals of Healthy People 2010 (objectives 6-10 and 6-12). However, few population-based studies have explored how environment affects the lives of those with disabilities. To determine the prevalence of disability among persons in Los Angeles County, California, and assess the effects of environmental barriers on these persons, residents were surveyed during 2002-2003. The results of that survey suggested that persons with physical or sensory disabilities experienced several environmental barriers and that the prevalence of barriers varied by demographic characteristics, household income, and severity of disability. To improve quality of life among persons with disabilities, public and private health agencies should implement measures to remove environmental barriers to health care and other services.

EPILEPSY

A 'real puzzle': the views of patients with epilepsy about the organisation of care.

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BACKGROUND: Little is known about how individuals who have a diagnosis of epilepsy have experienced healthcare services or their views about how they should best be organised to meet their ongoing needs.

METHODS: Focus group interviews. Individuals with epilepsy were identified in 5 practices in Wales: 90 were invited, 40 confirmed attendance and 19 individuals attended interviews in 5 groups of size 6, 5, 4, 3 and 1 (Table 2). Inclusion criteria: individuals with a confirmed diagnosis of epilepsy, aged between 18-65. The exclusion criteria were learning disability or an inability to travel to interview locations.

RESULTS: The individuals in these group interviews were not 'epilepsy activists' yet they remained critical in extended discussions about the services encountered during their patient careers, wanting more information and advice about how to adapt to problems, particularly after initial diagnosis, more involvement in decision making, rapid access to expertise, preferably local, and improved communication between clinicians. A central concern was the tendency for concerns to be silenced, either overtly, or covertly by perceived haste, so that they felt marginalised, despite their own claims to own expert personal knowledge.

CONCLUSIONS: Users of existing services for epilepsy are critical of current systems, especially the lack of attention given to providing information, psychosocial support and the wishes of patients to participate in decision making. Any reorganisation of services for individuals with epilepsy should take into account these perceived problems as well as try to reconcile the tension between the distant and difficult to access expertise of specialists and the local but unconfident support of generalists. The potential benefit of harnessing information technology to allow better liaison should be investigated.

Patient attitudes about treatments for intractable epilepsy.

Swarztrauber K, Dewar S, Engel J Jr. Department of Neurology, Portland VAMC, Portland, OR 97207, USA. swarztra@ohsu.edu Epilepsy Behav. 2003 Feb;4(1):19-25.

OBJECTIVE: The goals of this study were to understand patient attitudes about the treatment of medically intractable epilepsy and to document potential barriers limiting patient access to the surgical treatment of epilepsy, highlighting the attitudes of adolescents and minorities.

METHODS: Focus groups of adults with intractable epilepsy (n=10), adolescents with intractable epilepsy (n=4), parents of adolescents with intractable epilepsy (n=4), and African-Americans with intractable epilepsy (n=6) were conducted at UCLA, Los Angeles, California.

RESULTS: Patients with intractable epilepsy communicated frustration with their continued disability despite trials of new medications. Their perceptions of the risks of the surgical treatment of epilepsy were exaggerated. Patients felt that their health care providers did not provide adequate information about epilepsy and portrayed epilepsy surgery negatively.

CONCLUSION: This study illuminated several factors that could change patient attitudes and help improve patient access to the surgical treatment of epilepsy, especially among minorities and adolescents.

GYNECOLOGICAL CARE

The sexual health needs of people with learning disabilities.

Cambridge P. Tizard Centre, University of Kent at Canterbury. Nurs Times. 2003 Sep 2-8;99(35):48-9.

The sexual health of people with learning disabilities raises important management and practice issues for health services, and should be examined in the context of the current policy emphasis on advocacy, person-centred services and social inclusion (Department of Health, 2001). People with learning disabilities may have limited access to mainstream health services, and sexual health and genitourinary medicine (GUM) services are no exception (DoH, 2001; 1998). They are often excluded from society, either because they are 'segregated' within specialist support services in the community or because they live in isolation with carers, and health and social care models do not always join up locally to meet their needs.

HEALTH INSURANCE

Access to health insurance, barriers to care, and service use among adults with disabilities.

Sommers AS. Health Policy Center, Urban Institute, Washington DC 20037, USA. asommers@ui.urban.org Inquiry. 2006-2007 Winter;43(4):393-405.

No studies to date have examined access to insurance coverage or medical care for a broadly defined population of uninsured nonelderly adults with disabilities. This analysis uses the 2002 National Survey of America's Families to examine access to coverage, access to care, and service use for a large sample of adults with disabilities, with a focus on the uninsured. All disabled groups reported unmet need and service use greater than their nondisabled counterparts with the same insured status. Access to coverage was most problematic for low-income adults with work limitations but no other indication of disability, with over one-third uninsured. This group deserves greater policy attention.

LEARNING DISABILITIES

Access to secondary care for people with learning disabilities.

American Association on Health & Disability
110 N. Washington Street • Suite 340-A • Rockville, MD 20850
301-545-6140 fax: 301-545-6144
www.aahd.us

Hunt C, Flecknor D, King M, Ashman L. Northamptonshire Healthcare Trust. Nurs Times. 2004 Jan 20-26;100(3):34-6.

A person-centred approach is needed to improve access to secondary health care for people who have learning disabilities. The Department of Health (1995a) drew attention to this issue when it reported that people with learning disabilities sometimes have problems maintaining their health because hospitals fail to work in an interdisciplinary manner with the specialist learning disability services. This article focuses on a case study where the difficulties in operating on a patient with learning disabilities and mental health problems were overcome through a multidisciplinary and patient-centred approach. The case study provides evidence of mainstream health staff and learning disability professionals working together and breaking down barriers to provide a seamless service.

Health facilitation for people with learning disabilities.

Corbett J, Thomas C, Prior M, Robson R. Wolverhampton City PCT. jo.corbett@wolvespct.nhs.uk Br J Community Nurs. 2003 Sep;8(9):404-10.

Health facilitation is a concept introduced in the white paper 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (DH, 2001a). A project was set up in the West Midlands regions to look at what Primary Care Trust and specialist learning disability services were planning to do in respect of health facilitation in learning disabilities and to develop a resource tool for use by individuals working in this role. This article reiterates the extent of unmet health need experienced by people with learning disabilities and suggests that everyone involved in a caring role should be responsible for addressing their health needs. Primary and secondary care staff from across the region were consulted, and a range of educational needs were identified for these professionals. Recommendations were made for health facilitators to support the primary and secondary care teams to enable improved access to mainstream health services for people with learning disabilities. The recommendations can be applied nationally.

Primary health care provision for adults with a learning disability.

Powrie E. Centre for Nurse Practice, Education and Development, Robert Gordon University, Aberdeen, UK. e.powrie@abdn.ac.uk J Adv Nurs. 2003 May;42(4):413-23. BACKGROUND: During the last decade, primary care has been designated as the main provider of health care to people with learning disabilities. Practice nurses based in primary care teams are increasingly the first points of contact with health services. They make an important contribution to promoting good health, with health screening and illness prevention work being a significant part of their role. However, little is known about their views or involvement regarding the provision of primary care for people with learning disabilities. There is therefore a need to explore the nursing perspective, from within primary care, on the current provision of care for people with a learning disability.

RESEARCH AIM: To inform the learning disability service of the role of primary care in current service provision for people with learning disabilities.

RESEARCH METHODS: A survey of all practice nurses currently employed by Grampian Health Board in Aberdeen was conducted in June 2001. An initial pilot study was conducted in primary care and learning disability services. Data collection took place during June and July 2001. All practice nurses working in the geographical region of Grampian were invited to participate.

RESULTS: Communication barriers exist, preventing access to health screening and treatment for some people with learning disabilities. Independent living skills, for example dietary management and budgeting, require additional community support. These conditions pose complex problems for practice nurses and other members of the primary care team.

CONCLUSION: This study indicates a need for closer support and partnership with the learning disability service. The factors necessary for providing health care to people with learning disabilities extend beyond the domain of primary care teams. The findings of this survey have important implications for education and support to enable carers and professionals to provide a high standard of care.

MULTIPLE SCLEROSIS

Access to health services in Ireland for people with Multiple Sclerosis and Motor Neurone Disease.

Hardiman O, Corr B, Frost E, Gibbons P, Mahon L, Traynor BJ. Neurology, Beaumont Hospital, Dublin, Ireland. ohard@iol.ie Ir Med J. 2003 Jul-Aug;96(7):200-3.

We conducted a telephone questionnaire to determine the utilisation of hospital and community based services by patients with Motor Neurone Disease and Multiple Sclerosis in Ireland. 94 MND and 188 MS patients participated in the study. MND patients were more likely to have free medical care than MS patients, despite legislation favouring the converse. Severely disabled MND patients were more successful at accessing free community-based services than were severely disabled MS patients. Private medical insurance conferred no advantage when obtaining services or purchasing equipment. Many patients were unaware of the specific roles of the various clinical professionals. There are significant deficiencies in patients' ability to access multidisciplinary services. Voluntary organisations often bridge the gap in service provision. An investment in services for people with chronic neurological disability is urgently required.

PREVENTATIVE SERVICES AND HEALTH PROMOTION

Accessibility of health clubs for people with mobility disabilities and visual impairments.

Rimmer JH, Riley B, Wang E, Rauworth A. National Center on Physical Activity and Disability and Rehabilitation Engineering Research Center Rectech, Department of Disability and Human Development, University of Illinois at Chicago, 60608-6904, USA. jrimmer@uic.edu Am J Public Health. 2005 Nov;95(11):2022-8.

OBJECTIVE: We sought to examine the accessibility of health clubs to persons with mobility disabilities and visual impairments.

METHODS: We assessed 35 health clubs and fitness facilities as part of a national field trial of a new instrument, Accessibility Instruments Measuring Fitness and Recreation Environments (AIMFREE), designed to assess accessibility of fitness facilities in the following domains: (1) built environment, (2) equipment, (3) swimming pools, (4) information, (5) facility policies, and (6) professional behavior.

RESULTS: All facilities had a low to moderate level of accessibility. Some of the deficiencies concerned specific Americans with Disabilities Act guidelines pertaining to the built environment, whereas other deficiency areas were related to aspects of the facilities' equipment, information, policies, and professional staff.

CONCLUSIONS: Persons with mobility disabilities and visual impairments have difficulty accessing various areas of fitness facilities and health clubs. AIMFREE is an important tool for increasing awareness of these accessibility barriers for people with disabilities.

Barriers to wellness activities for Canadian women with physical disabilities.

Odette F, Yoshida KK, Israel P, Li A, Ullman D, Colantonio A, Maclean H, Locker D. Department of Physical Therapy, University of Toronto, Ontario, Canada. Health Care Women Int. 2003 Feb;24(2):125-34.

Although there is a great deal of interest in women's health, research on the health and well being of women with disabilities has not increased. In this article we present internal and structural barriers to wellness activities experienced by women with disabilities. We also discuss women's actual and recommended strategies to address these barriers. Data were collected in six focus groups in urban and rural Ontario, Canada. The participants represented a diversity of disability, age, and ethnoracial backgrounds. Our findings suggest that individual and structural barriers exist for the women, with structural barriers (physical, informational, and systemic access) being predominant. Barriers prevented women from engaging in desired wellness activities. Women discussed actual strategies to address these barriers, such as collective efforts to buy nutritious foods and recommendations to create greater access (e.g., increase health professionals' training in disability issues).

Bridging the equity gap: health promotion for adults with intellectual and developmental disabilities.

Marks BA, Heller T. Department of Disability and Human Development (DHD), University of Illinois at Chicago (UIC), 1640 West Roosevelt Road, Chicago, IL 60608, USA. marks1@uic.edu Nurs Clin North Am. 2003 Jun;38(2):205-28.

Health is influenced by political, economic, social, cultural, environmental, behavioral and biological conditions—either positively or negatively. Health promotion aims to make these factors more favorable through health advocacy. Advocating for physical, mental, and social health requires that individuals with I/DD have opportunities to identify and realize their aspirations, develop the capacity to satisfy their needs, and possess the ability to adapt and/or cope with the environment. Because health is both an individual and a social responsibility, effective health promotion strategies must incorporate linkages between health and development, particularly for vulnerable and disadvantaged groups where deprivation in health and economic resources exist simultaneously and reinforce each other [6]. Incorporating health and development at the core of health promotion activities addresses issues of poverty, poor health, and unemployment, while accounting for social, cultural and economic differences. Health promotion enables people with I/DD to achieve their health goals by ensuring equal opportunities and resources. This includes having supportive environments, access to information, and life skills and opportunities to make healthy choices. People cannot achieve their health goals unless they can control health determinants. Health promotion efforts require coordinated action from all interested groups (e.g., government entities, health and other social and economic sectors, nongovernmental and voluntary organizations, local authorities, industry and media), including individuals, families and communities. Community-based health promotion emphasizes community participation, along with empowerment of community members to address inequities and increase control over their health [3]. Individual satisfaction and participation are critical components in community coalitions that are providing health promotion programs. Moreover, community leadership, shared decision-making, linkages with other organizations, and organizational climate can predict satisfaction, participation, and planning. Health becomes a resource for everyday life when individuals with I/DD are empowered and can participate in health promotion activities that are based in their community.

Community health and nutrition screening for Special Olympics athletes.

Cotugna N, Vickery CE. Department of Nutrition and Dietetics, University of Delaware, Newark, DE 19716-3301, USA. ncotugna@udel.edu J Community Health. 2003 Dec;28(6):451-7.

Since 1961, Special Olympics has provided sports training and athletic competition for people with mental retardation. A recent addition to these Olympics has been the Healthy Athletes Program, designed to help the athletes improve their health and fitness, leading to enhanced sports experiences and well being. Original health services

included dental and eye screening. In 2002, Special Olympics Delaware piloted a Wellness Park to add nutrition, blood pressure, and flexibility screening. Faculty from a university's health college trained discipline-specific students to conduct the screenings. Thirty nutrition and dietetics students measured height, weight, waist circumference, and calculated body mass index (BMI) for the athletes. Figures and risk-assessments were recorded on a "health report card." Two hundred ten athletes attended the nutrition screening. Ages ranged from 8 to 63 years; 81 percent males and 19 percent females. According to BMI standards, 32 percent of the athletes were overweight; 17 percent were obese. Twenty-five percent of adult males and 73 percent of adult females had a high risk waist circumference. Athletes at high risk for obesity-related diseases were referred to their primary physician for follow up. Nutrition education handouts included a simplified Food Guide Pyramid, tips for healthy eating in restaurants, 5 A Day information, and healthful hydration guides. Approximately 1,250 athletes participate in Special Olympics Delaware each year, providing a great opportunity to do some much needed health screening and improve access to health care for this often neglected population.

A conceptual framework for improving the accessibility of fitness and recreation facilities for people with disabilities.

Riley BB, Rimmer JH, Wang E, Schiller WJ. Department of Disability and Human Development, University of Illinois at Chicago, Chicago, IL 60608,USA. J Phys Act Health. 2008 Jan;5(1):158-68.

Access to fitness and recreation facilities is an important issue for people with disabilities. Although policy and legislation have helped to remove various environmental barriers, there remain a substantial number of inaccessible features in fitness and recreation facilities. This article presents an approach for improving the accessibility of fitness and recreation environments that enables participation and input from members of the community, as well as persons with expertise in accessibility. Through a collaboration between facilities, persons with disabilities and accessibility consultants, the approach provides a process of incremental change through readily achievable barrier removal and by providing an information and educational resource concerning barrier removal, disability awareness, and economic and information resources. Technology is incorporated to facilitate accessibility assessment, interaction between various stakeholders, and the creation of an accessibility solutions database. Policy implications of this approach are discussed.

The conspicuous absence of people with disabilities in public fitness and recreation facilities: lack of interest or lack of access?

Rimmer JH. Rehabilitation Engineering Research Center-RecTech, Department of Disability and Human Development, University of Illinois at Chicago, 1640 West

Roosevelt Road, Chicago, IL 60608-6904, USA. jrimmer@uic.edu Am J Health Promot. 2005 May-Jun;19(5):327-9, ii. Critical Issues and Trends More than 50 million Americans have a disability. These people face enormous physical, social, and attitudinal barriers toward their participation in physical and recreational activities that they need to maintain their health and wellness. Furthermore, the concept of being "healthy" and "disabled" or "physically active" and "disabled" is not a common visualization in the mainstream media. This paper calls for a more inclusive vision within public health messages that target physical activity participation among its citizens, especially those with disability who are at greater risk for developing health problems associated with sedentary living.

Designed to deter. Community barriers to physical activity for people with visual or motor impairments.

Kirchner CE, Gerber EG, Smith BC. American Foundation for the Blind, New York, New York 10001, USA. Corinne@afb.net Am J Prev Med. 2008 Apr;34(4):349-52.

BACKGROUND: People with disabilities are more likely to be obese, in poor health, and get less physical activity than the general population. However, research on community factors for physical activity has generally either excluded most people with disabilities, or overlooked relevant factors of community accessibility. This exploratory study investigated environmental factors affecting people with motor impairments and people with visual impairments in urban neighborhoods.

METHODS: Quantitative and qualitative methods were used with a nonrandom sample (n=134) of users of four types of assistive mobility technologies: guide dogs, long canes, and motorized and manual wheelchairs. From July 2005 to August 2006, the sample participated in two telephone surveys. Between the surveys, a stratified random subsample (n =32) engaged in an ethnographic phase of observation and interviews.

RESULTS: Most participants in all groups using assistive mobility technologies rated their neighborhoods as accessible, although they also reported many specific barriers. Users of assistive mobility technologies differed in the amount of reported physical activity and on specific barriers. Problems with sidewalk pavement and puddles/poor drainage were the most frequently mentioned environmental barriers, by 90% and 80%, respectively. Users of assistive mobility technologies were more similar on main strategies for dealing with barriers. All groups reported having to plan routes for outings, to alter planned routes, to go more slowly than planned, or to wait for a different time.

CONCLUSIONS: Despite legislative requirements for accommodation, people with disabilities face barriers to physical activity, both in the built and social environments. Determined people with disabilities were able to overcome barriers, but required additional expenditure of resources to do so. Community design that can include people with disabilities requires detailed understanding of barriers specific both to types of impairments and to different types of assistive mobility technologies.

Evaluation of consumer health website accessibility by users with sensory and physical disabilities.

Chiang MF, Starren J. Department of Biomedical Informatics, Columbia University, New York, NY 10032, USA. chiang@dbmi.columbia.edu Medinfo. 2004;11(Pt 2):1128-32. Growth of the World Wide Web is beginning to create new opportunities for direct patient access to health care resources. At the same time, advances in medical care have produced demographic shifts in which an increasing number of patients have sensory and physical disabilities that may limit their ability to access these new information tools. This study uses automated and manual methods to measure the compliance of 30 popular consumer health websites with the World Wide Web Consortium (W3C) content accessibility guidelines. Among these 30 sites, 22 failed to satisfy at least one W3C Priority-1 accessibility checkpoint, making it impossible for some groups of disabled users to access information from them. All websites failed to satisfy at least one Priority-2 checkpoint, making it difficult for some groups to access information from the sites. These results suggest that accessibility of many consumer health websites to disabled users is very limited. The health informatics community must become more aware of this problem, particularly because many critical accessibility problems may be easily addressed if they are recognized.

Physical activity participation among persons with disabilities: barriers and facilitators.

Rimmer JH, Riley B, Wang E, Rauworth A, Jurkowski J. Department of Disability and Human Development, University of Illinois at Chicago, Chicago, Illinois 60608-6704, USA. jrimmer@uic.edu Am J Prev Med. 2004. Jun;26(5):419-25.

BACKGROUND: The purpose of this study was to identify various barriers and facilitators associated with participation in fitness and recreation programs/facilities among persons with disabilities.

METHODS: Focus groups were conducted in ten regions across the United States in 2001 to 2002 with four types of participants: (1) consumers with disabilities, (2) architects, (3) fitness and recreation professionals, and (4) city planners and park district managers. Sessions were tape-recorded and content analyzed; focus group facilitators took notes of identified barriers and facilitators to access.

RESULTS: Content analysis of tape recordings revealed 178 barriers and 130 facilitators. The following themes were identified: (1) barriers and facilitators related to the built and natural environment; (2) economic issues; (3) emotional and psychological barriers; (4) equipment barriers; (5) barriers related to the use and interpretation of guidelines, codes, regulations, and laws; (6) information-related barriers; (7) professional knowledge, education, and training issues; (8) perceptions and attitudes of persons who are not disabled, including professionals; (9) policies and procedures both at the facility and community level; and (10) availability of resources.

CONCLUSIONS: The degree of participation in physical activity among people with disabilities is affected by a multifactorial set of barriers and facilitators that are unique to this population. Future research should utilize this information to develop intervention strategies that have a greater likelihood of success.

Relationships between level of disability and receipt of preventive health services.

Diab ME, Johnston MV. Bronx Veterans Affairs Medical Center, Bronx, NY, USA.

Arch Phys Med Rehabil. 2004 May;85(5):749-57.

OBJECTIVES: To examine relationships between level of disability and receipt of certain preventive health services, including demographic and systems variables that may explain or confound these relationships.

DESIGN: Analysis of recent (1998 and 2000) data from the Behavioral Risk Factor Surveillance System, a nationwide telephone survey.

SETTING: States reporting data on disability (13 in 1998, 18 in 2000).

PARTICIPANTS: Noninstitutionalized persons living in the community.

INTERVENTIONS: Not applicable.

MAIN OUTCOME MEASURES: Frequency of receipt of recommended preventive health services, including colorectal, cervical, and breast cancer screening, and influenza and pneumococcal vaccination. An ordinal index of disability severity was constructed from questions on activity limitations.

RESULTS: In 2000, people with mild and moderate disability received influenza and pneumonia vaccinations somewhat more frequently than people without disabilities, but people with the most severe disabilities least frequently received vaccinations that year. Disabled women received fewer Papanicolaou tests and clinical breast examinations, but significant differences did not occur for mammograms in 2000. Fewer differences as a function of disability level were apparent in 2000 than 1998. Demographic variables affected receipt of most preventive services. Access to routine checkups affected all preventive services independent of disability level in both years.

CONCLUSIONS: Severity of disability is related to receipt of certain preventive services but not necessarily in a simple or unidirectional way. Regardless of disability, receipt of a checkup was an important determinant of receipt of preventive health services. For almost all services and groups studied, preventive care remained below targeted goals for Healthy People 2010.

RURAL RESIDENTS WITH DISABILITIES

Rural residents with disabilities confront substantial barriers to obtaining primary care.

Iezzoni LI, Killeen MB, O'Day BL. Harvard Medical School, 330 Brookline Avenue RO-137, Boston, MA 02215, USA. Health Serv Res. 2006 Aug;41(4 Pt 1):1258-75.

OBJECTIVE: To learn about the health care experiences of rural residents with disabilities.

STUDY SETTING: Rural areas in Massachusetts and Virginia.

STUDY DESIGN: Local centers for independent living recruited 35 adults with sensory, physical, or psychiatric disabilities to participate in four focus group interviews.

DATA COLLECTION METHODS: Verbatim transcripts of interviews were reviewed to identify major themes.

PRINCIPAL FINDINGS: Interviewees described the many well-recognized impediments to health care in rural America; disability appears to exacerbate these barriers. Interviewees reported substantial difficulties finding physicians who understand their disabilities and sometimes feel that they must teach their local doctors about their underlying conditions. Interviewees described needing to travel periodically to large medical centers to get necessary specialty care. Many are poor and are either uninsured or have Medicaid coverage, complicating their searches for willing primary care physicians. Because many cannot drive, they face great difficulties getting to their local doctor and especially making long trips to urban centers. Available public transportation often is inaccessible and unreliable. Physicians' offices are sometimes located in old buildings that do not have accessible entrances or equipment. Based on their personal experiences, interviewees perceive that rural areas are generally less sensitive to disability access issues than urban areas.

CONCLUSIONS: Meeting the health care needs of rural residents with disabilities will require interventions beyond health care, involving transportation and access issues more broadly.

SUBSTANCE ABUSE

Access barriers to substance abuse treatment for persons with disabilities: an exploratory study.

Krahn G, Farrell N, Gabriel R, Deck D. Oregon Health and Science University, Portland, OR 97207, USA. krahng@ohsu.edu J Subst Abuse Treat. 2006 Dec;31(4):375-84. Epub 2006 Aug 17.

Research in substance abuse (SA) treatment has demonstrated that persons with disabilities (PWDs) are at substantially higher risk for SA than persons without disabilities. Despite their higher risk, PWDs access SA treatment at a much lower rate than persons without disabilities. Using the Behavioral Model for Vulnerable Populations as a research framework, we identified reasons for differences in access to SA treatment for Medicaid-eligible adults with disabilities in Oregon through a multiphase study. Analyses of demographic and referral source data, along with interviews with key state agency representatives, adults with disabilities, and treatment program personnel, helped identify barriers to SA treatment access. These barriers are reflected as attributes of PWDs, contextual variables that enable or impede access, recognition of

the need for SA treatment, and characteristics of treatment services. The findings suggest needed policy and practice changes to increase access rates for PWDs. They provide direction for future research.

Physical inaccessibility negatively impacts the treatment participation of persons with disabilities.

West SL, Luck RS, Capps CF. Department of Rehabilitation Counseling, Virginia Commonwealth University, P. O. Box 980330, Richmond, VA 23298-0330, United States. Addict Behav. 2007 Jul;32(7):1494-7. Epub 2007 Jan 29.

This research assessed the impact that physical inaccessibility of provider locations has on the substance abuse treatment participation of two groups of persons with disabilities. A random sample of treatment providers in the Mid-Atlantic region were surveyed and asked if they had declined services to persons with spinal cord (SCI) or traumatic brain (TBI) injuries due to the inaccessibility of their practices. Over half of those who had been approached by persons with SCI and nearly half of those approached by persons with TBI were unable to provide services due to physical barriers. The inability to serve such individuals was not related to practice affiliation (public or private) or practice type (hospital based, non-medical residential, or outpatient). These findings support earlier research indicating the treatment participation of persons with disabilities is negatively affected by physical accessibility concerns.

WEB CONTENT

Web content accessibility of consumer health information web sites for people with disabilities: a cross sectional evaluation.

Zeng X, Parmanto B. Department of Health Information Management, School of Health and Rehabilitation Sciences, University of Pittsburgh, Pittsburgh, PA 15260, USA. xizst9@pitt.edu J Med Internet Res. 2004 Jun 21;6(2):e19.

BACKGROUND: The World Wide Web (WWW) has become an increasingly essential resource for health information consumers. The ability to obtain accurate medical information online quickly, conveniently and privately provides health consumers with the opportunity to make informed decisions and participate actively in their personal care. Little is known, however, about whether the content of this online health information is equally accessible to people with disabilities who must rely on special devices or technologies to process online information due to their visual, hearing, mobility, or cognitive limitations.

OBJECTIVE: To construct a framework for an automated Web accessibility evaluation; to evaluate the state of accessibility of consumer health information Web sites; and to investigate the possible relationships between accessibility and other features of the Web sites, including function, popularity and importance.

METHODS: We carried out a cross-sectional study of the state of accessibility of health information Web sites to people with disabilities. We selected 108 consumer health information Web sites from the directory service of a Web search engine. A measurement framework was constructed to automatically measure the level of Web Accessibility Barriers (WAB) of Web sites following Web accessibility specifications. We investigated whether there was a difference between WAB scores across various functional categories of the Web sites, and also evaluated the correlation between the WAB and Alexa traffic rank and Google Page Rank of the Web sites.

RESULTS: We found that none of the Web sites we looked at are completely accessible to people with disabilities, i.e., there were no sites that had no violation of Web accessibility rules. However, governmental and educational health information Web sites do exhibit better Web accessibility than the other categories of Web sites ($P < 0.001$). We also found that the correlation between the WAB score and the popularity of a Web site is statistically significant ($r = 0.28$, $P < 0.05$), although there is no correlation between the WAB score and the importance of the Web sites ($r = 0.15$, $P = 0.111$).

CONCLUSIONS: Evaluation of health information Web sites shows that no Web site scrupulously abides by Web accessibility specifications, even for entities mandated under relevant laws and regulations. Government and education Web sites show better performance than Web sites among other categories. Accessibility of a Web site may have a positive impact on its popularity in general. However, the Web accessibility of a Web site may not have a significant relationship with its importance on the Web.

WOMEN

Access to breast cancer screening services for women with disabilities.

Mele N, Archer J, Pusch BD. University of Memphis, Loewenberg School of Nursing, 610 Goodman Street, Memphis, TN 38152, USA. nmele@memphis.edu J Obstet Gynecol Neonatal Nurs. 2005 Jul-Aug;34(4):453-64.

OBJECTIVE: To identify barriers to breast cancer screening services encountered by women with physical disabilities.

DESIGN: Phenomenologic design using a semi-structured interview guide to explore the experiences of women with disabilities seeking breast cancer screening services.

SETTING: Face-to face interviews conducted in the homes of women from the urban and rural mid-south.

PATIENTS/PARTICIPANTS: A purposive sample of women with motor or sensory disabilities, age 21 to 65, was recruited for this study based on community type and type and severity of disability. Community collaborators working with people with disabilities identified eligible participants.

RESULTS: Although the study focused on breast cancer screening services, women also described financial, architectural, environmental, and attitudinal barriers that

affected all of their health care services. Women described poor transportation, heavy doors, and inaccessible exam tables and bathrooms. They felt devalued by their providers and believed that their symptoms were often overlooked. Women with disabilities want to be partners in their own health care.

CONCLUSIONS: Women with physical disabilities face both financial and nonfinancial barriers to access that may result in delayed detection and increased risk of poorer outcomes from breast cancer. Providers require education about working with women with disabilities.

Accessible online health promotion information for persons with disabilities.

Smeltzer SC, Zimmerman V, Frain M, DeSilets L, Duffin J. Villanova University College of Nursing, PA, USA. suzanne.smeltzer@villanova.edu Online J Issues Nurs. 2004 Jan 31;9(1):11.

Online health promotion materials have great potential to reach persons with disabilities and provide valuable information to this vulnerable population. While health promotion efforts are important for everyone, they are crucial for individuals with disabilities. Yet information needed to support these efforts is often presented in such a way that its access is limited or its content is inappropriate for this population. Whether designing or selecting online materials for individuals with disabilities, nurses can benefit from knowledge about strategies to make web sites more accessible or to assess the accessibility of existing web sites. The task of providing health promotion information to women with disabilities was undertaken as part of the "Health Promotion for Women with Disabilities Project" at Villanova University's College of Nursing. A web site was created as one method of providing information. This paper presents strategies that are used to make this site accessible.

Achieving effective health promotion for women with disabilities.

Hughes RB. Department of Physical Medicine and Rehabilitation, Baylor College of Medicine, Houston, TX 77289, USA. rhughes@bcm.edu Fam Community Health. 2006 Jan-Mar;29(1 Suppl):44S-51S. Center for Research on Women with Disabilities.

The field of health promotion has yet to acknowledge the unique needs of women with disabilities, a population representing approximately 1 of 5 women in the United States. Compared with women without disabilities, women with disabilities have critical needs for evidence-based health promotion services. Women with disabilities face a lack of access to multitudinous opportunities for maintaining and improving their overall health. Inaccessible exercise equipment and other disability-related barriers discourage women with physical disabilities from engaging in health-promoting behaviors. This article identifies 10 essential elements for achieving effective health promotion research and interventions for women in this population.

Disability and receipt of clinical preventive services among women.

Wei W, Findley PA, Sambamoorthi U. Institute for Health, Health Care Policy, and Aging Research, Rutgers University, New Brunswick, New Jersey 08854, USA.

weiwenhui@gmail.com Womens Health Issues. 2006 Nov-Dec;16(6):286-96.

BACKGROUND: More individuals are surviving catastrophic injuries and living longer with persistent disability; however, their receipt of clinical preventive services is not well understood as compared with those without disabilities given the dual focus of care on both primary prevention and the prevention of secondary complications related to their disabilities.

METHODS: Longitudinal analyses of 1999-2002 Medical Expenditure Survey (MEPS). Study sample consisted of 3,183 community-dwelling women aged 51-64 years and followed for 2 full years. Women with disabilities were defined as having reported any limitation in any area of activity of daily living in 2 years. Recommended clinical preventive services were defined as receiving the following at the recommended intervals: colorectal, cervical, and breast cancer; cholesterol screening; and influenza immunization. chi(2) tests and multiple logistic regressions were used to examine variations in use of clinical preventive services.

RESULTS: Overall, 23% of the women in the study (n = 835) were disabled. Disabled women, however, were less likely to receive mammography and Pap smears within the recommended intervals. However, disabled women were more likely to receive influenza immunization, cholesterol screening, and colorectal screening within the recommended intervals. Among the disabled, usual source of care and health insurance remained significant predictors of receipt of clinical preventive services across all types,

CONCLUSIONS: Disabled women were less likely to receive some of the cancer screening services, suggesting a need for targeted interventions to promote breast cancer and cervical cancer screening. Increased access to health care insurance and health care providers may also help.

Health care for women with disabilities: population-based evidence of disparities.

Parish SL, Huh J. School of Social Work, University of North Carolina at Chapel Hill, 27599-3550, USA. parish@email.unc.edu Health Soc Work. 2006 Feb;31(1):7-15.

Despite having similar or better potential access to health care, women with disabilities experience worse health care and worse preventive care than nondisabled women. This study examined the health care of a national probability sample of 8,721 disabled and 45,522 nondisabled women living in the United States. Logistic regression models, adjusted for age and household income, were estimated for eight measures of health care, including three measures of potential access to care, two measures of receipt of preventive services, and postponement of care. Findings signal potentially serious consequences for women with disabilities, who require care at higher rates than their nondisabled counterparts and are at increased risk of developing secondary conditions if their care needs are not met.

Health needs of women with disabilities across the lifespan.

Piotrowski K, Snell L. Department of Nursing, at D'Youville College in Buffalo, NY 14201, USA. KarenP3216@aol.com J Obstet Gynecol Neonatal Nurs. 2007 Jan-Feb;36(1):79-87.

Women with disabilities experience a variety of unique health needs from adolescence to older age. They require compassionate and comprehensive health care services to manage their physical disabilities and to prevent secondary conditions. Unfortunately, many women with disabilities encounter attitudinal, informational, environmental, and geographic barriers as they seek access to health care. A variety of measures can be implemented to overcome these barriers and to improve the quality of health care that women with disabilities receive.

Health, preventive health care, and health care access among women with disabilities in the 1994-1995 National Health Interview Survey, Supplement on Disability.

Chevarley FM, Thierry JM, Gill CJ, Ryerson AB, Nosek MA. Erratum in : Womens Health Issues, 2007 Jan-Feb: 17(1):61. Agency for Healthcare Research and Quality, Rockville, Maryland 20850, USA. Fran.Chevarley@AHRQ.hhs.gov Womens Health Issues. 2006 Nov-Dec;16(6):297-312.

OBJECTIVES: This study presents national estimates on the health, preventive health care, and health care access of adult women with disabilities. We compared women with 1 or 2 functional limitations (FLs) and > or =3 FLs with women with no FLs. Topics covered included demographic characteristics, selected reported health measures, selected clinical preventive services, and selected access to care indicators and health care coverage.

METHODS: Estimates in this report were based on data from the 1994-1995 National Health Interview Survey, Supplement on Disability (NHIS-D). The sample size for women > or =18 years of age used in producing the estimates from the combined 1994 and 1995 NHIS-D was 77,762.

RESULTS: An estimated 16% of women > or =18 years of age had difficulty with at least 1 FL. Women with FLs were less likely to rate their health as excellent or very good and more likely to report their health as fair or poor when compared with women with no FLs. Women with FLs were also more likely to report being a current smoker, having hypertension, being overweight, and experiencing mental health problems. Among women > or =65 years of age, those with FLs were also less likely to have received Pap smear tests within the past year and those with > or =3 FLs were less likely to have received mammograms within the past year than women with no FLs. Women with > or =3 FLs were more likely to report being unable to get general medical care, dental care, prescription medicines, or eyeglasses, regardless of age group, compared with women with no FLs. The main reasons reported for being unable to receive general care were

financial problems or limitations in insurance. These findings suggest that increased attention to the health care needs of women with disabilities from researchers, clinicians, and public health professionals is warranted.

The meaning of health for women with physical disabilities: a qualitative analysis.

Nosek MA, Hughes RB, Howland CA, Young ME, Mullen PD, Shelton ML. Department of Physical Medicine and Rehabilitation, Center for Research on Women with Disabilities, Baylor College of Medicine, Houston, TX 77046, USA. Fam Community Health. 2004 Jan-Mar;27(1):6-21.

Researchers used qualitative research methods to explore determinants of and barriers to the health of women with physical disabilities. Semistructured, open-ended interviews were conducted with one focus group (n=9) and 9 individual women with various physical disabilities. Participants: (1) defined physical health as a correlate of functional capacity; (2) noted the importance of a positive mental state; (3) recognized the effect of having or lacking social support; (4) described the role of health behaviors in health promotion, as adapted to their functional limitations; and (5) described problems with their medical practitioners' lack of knowledge. Barriers included certain disability characteristics, stress, inadequate social support, societal attitudes, and lack of resources.

Perspectives of women with disabilities on reaching those who are hard to reach.

Smeltzer SC, Sharts-Hopko NC, Ott BB, Zimmerman V, Duffin J. Center for Nursing Research, Villanova University College of Nursing, Villanova, PA, USA. suzanne.smeltzer@villanova.edu J Neurosci Nurs. 2007 Jun;39(3):163-71.

Healthcare needs of women with disabilities are often neglected, even for women who are well connected to the community and to the healthcare system. So-called "hard-to-reach" women, whose degree of disability impedes use of community resources, have even greater difficulty obtaining health care. The purpose of this study was to gain insight into the perceptions of women with mobility and sensory limitations about several healthcare issues that may affect them: barriers to obtaining care, sources of information about health issues, ways to improve access to care, and ways to help hard-to-reach women overcome barriers to health care and health information. Researchers conducted six focus groups, comprising 43 women with limitations of mobility, hearing, or vision. To validate the women's input, researchers conducted two additional focus groups: the first comprised female physicians with special interest in the health care of women with disabilities, and the second included professional administrative staff of agencies that provide services for people with disabilities. In several cases, members of the physician and agency focus groups were themselves women with disabilities. In addition, 16 women with disabilities participated in an online survey; their responses were used to validate the findings of the face-to-face focus groups. Transcribed data were content

analyzed and 10 themes identified. Seven of those themes are discussed in this article: communication barriers; lack of knowledge and awareness among healthcare providers; access issues; working the system; system issues; outreach to healthcare providers; and reaching hard-to-reach women. The findings of this study can provide direction to development of more effective outreach to hard-to-reach women with disabilities, resulting in better integration of healthcare services for this population.

Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities.

Smeltzer SC. Villanova University College of Nursing, PA 18085, USA. suzanne.smeltzer@villanova.edu Fam Community Health. 2006 Jan-Mar;29(1 Suppl):35S-43S.

Although the Americans With Disabilities Act was enacted 15 years ago in an effort to improve access of people with disabilities to a broad range of services, women with physical disabilities continue to receive less preventive health screening than women without disabilities and less than is recommended. Furthermore, women with more severe disabilities undergo less screening than those with mild or moderate severity of disability. This article reviews findings of studies on health screening for breast and cervical cancer and osteoporosis in women with physical disabilities and identifies practice and research implications on the basis of those findings to improve the health status of women with physical disabilities.

Women with cognitive limitations living in the community: evidence of disability-based disparities in health care.

Parish SL, Saville AW. School of Social Work, University of North Carolina at Chapel Hill, Chapel Hill, NC 27599-3550, USA. parish@email.unc.edu Ment Retard. 2006 Aug;44(4):249-59.

Using data from the Medical Expenditure Panel Survey for 2000 and 2002, we compared potential and realized use of health care for a national sample of working-age women with cognitive disabilities. Despite having similar likelihoods of potential access to health care as compared to nondisabled women, they had markedly worse rates of receiving cervical cancer and breast cancer screenings, similar rates of routine check-ups, and yet had better rates of receipt of influenza shots. They were also less likely to be satisfied with their medical care than were nondisabled women. Policy recommendations are suggested to address the disability-based disparities in reproductive health care for women with cognitive limitations.

YOUNG ADULTS

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

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Callahan ST, Cooper WO. 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.

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