

Measuring and monitoring youth transition experiences is important to determine if programming is effective. States and other agencies can use existing data sources to track the effectiveness of their programming. Data sources are listed with their websites and some examples of how data from local surveys can be compared with data from these sources. KY TEACH Project (Kentucky's HRTW Project) data are used in the examples.

This list is not comprehensive but offers a sample of respected data sources. More information is available through:

- MEASURING AND MONITORING OF COMMUNITY-BASED SYSTEMS OF CARE FOR CSHCN
Early Intervention Research Institute, Utah State University, Logan UT
<http://eiri.usu.edu/projects/MandM/>
 - KY TEACH PROJECT <http://chs.ky.gov/commissionkids>
 - HEALTHY & READY TO WORK NATIONAL CENTER www.hrtw.org
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DATA SOURCES

Behavioral Risk Factor Surveillance System (BRFSS)

<http://www.cdc.gov/brfss/> This survey, conducted through the Centers for Disease Control, provides annual state-level data based on a randomized sample of the general adult population. Information is gathered regarding usual source of health care, insurance coverage, and employment status broken down in age categories including ages 18-24 so it is particularly useful in measuring indicators related to successful transition to adult health care. Some states have added questions to this survey to obtain data on particular health conditions (such as asthma, diabetes, and depression) and more information on health care costs and barriers.

Examples: 33% of Kentucky Commission graduates and 20% of Shriners Hospital, Lexington, graduates say they have no health insurance as compared with 28.5% of 18-24 year olds in Kentucky and 27.3 of 18-24 year olds in the US (from the 2000 KBRFSS); 30% of Commission and 25% of Shriners Hospital, Lexington, smoke compared with 35.1% of Kentucky young adults ages 18-24 (2000 KBRFSS)

National Health Interview Survey (NHIS conducted yearly) and National Health Interview Survey-Disabilities (NHIS-D last conducted in 1997) conducted by the National Center for Health Statistics

<http://www.cdc.gov/nchs/nhis.htm> National Center Health Statistics has two major types of data systems: systems based on populations, containing data collected through personal interviews or examinations; and systems based on records, containing data collected from vital and medical records. The website describes the surveys and results and offers access to Health US, *latest year*, which summarizes health surveys. The NHIS-D is a telephone survey of a randomized sample of children and adults with developmental disabilities, specific health conditions, behavior problems, sensory loss, or physical disabilities. The survey contains questions related to medical home, transition, screening, and access to community-based services. Although data are provided at a regional level, some states have 'purchased' additional data collection to acquire state-level data. Questions from these surveys can also be used by states as a model in the development of their own surveys.

Example: 78% of KY Commission and 85% of Shriners Hospital, Lexington, graduates have a family doctor or clinic compared with 75.1% of Americans ages 18-24 (NHIS, 2001)

Medical Expenditure Panel Survey (MEPS)

www.meps.ahrq.gov This survey uses a nationally-representative sub-sample drawn from households that participated in the prior year's National Health Interview Survey. The objective is to produce annual estimates for a variety of measures of health status, health insurance coverage, health care use and expenditures, and sources of payment for health services. These data are particularly important because statisticians and researchers use them to generalize to people in the civilian non-institutionalized population of the United States, as well as to conduct research in which the family is the unit of analysis. The panel design of the survey, which features several rounds of interviewing covering 2 full calendar years, makes it possible to determine how changes in respondents' health status, income, employment, eligibility for public and private insurance coverage, use of services, and payment for care are related.

National Survey of CSHCN

<http://www.cdc.gov/nchs/about/major/slait/cshcn.htm> and **www.cshcndata.org**
The Maternal and Child Health Bureau (MCHB) in collaboration with the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC) sponsored this survey through the State and Local Area Integrated Telephone Survey (SLAITS). States are provided with a prevalence rate for the broadly defined population of children with special health care needs. Data are available in areas of medical home, adequacy of insurance, access to services and family satisfaction and participation in decision making. MCHB plans to repeat this survey every four years.

US Census Data

www.census.gov Information about the American population offered in a variety of ways such as state-specific or age group-specific and is useful in comparing information on youth with SHCN with typical populations.

Example: 65% of Commission and 75% of Shriners Hospital, Lexington, graduates had completed high school compared with 85% of 18-24 year olds nationally (US Census, 2000).

Current Population Survey (CPS)

www.bls.census.gov/cps The Current Population Survey (CPS) is a monthly survey of about 50,000 households conducted by the Bureau of the Census for the Bureau of Labor Statistics. The survey has been conducted for more than 50 years and is the primary source of information on the labor force characteristics of the U.S. population. The sample is scientifically selected to represent the civilian non-institutional population. Respondents are interviewed to obtain information about the employment status of each member of the household 15 years of age and older. The sample provides estimates for the nation as a whole and serves as part of model-based estimates for individual states and other geographic areas. Estimates obtained from the CPS include employment, unemployment, earnings, hours of work, and other indicators. They are available by a variety of demographic characteristics including age, sex, race, marital status, and educational attainment. They are also available by occupation, industry, and class of worker. Supplemental questions to produce estimates on a variety of topics including school enrollment, income, previous work experience, health, employee benefits, and work schedules are also often added to the regular CPS questionnaire. Website is a gateway to other related surveys.

Example: 20% of Commission and Shriners Hospital, Lexington, graduates are married (or ex) compared with 10% of men and 18% of women ages 18-24 in the US (CPS, 2000) and 18.8% of 20-24 year olds (CPS, 1998).

National Maternal Child Health Clearinghouse

<http://childstats.gov> This web site offers easy access to federal and state statistics and reports on children and their families, including: population and family characteristics, economic security, health, behavior and social environment, and education. Reports of the Federal Interagency Forum on Child and Family Statistics include *America's Children: Key National Indicators of Well-Being*, the annual Federal monitoring report on the status of the Nation's children.

National Center for Educational Statistics

<http://nces.ed.gov> NCES is the primary government agency for collecting and analyzing data that are related to education in the US and other nations.

National Institute on Disability and Rehabilitation Research (NIDRR)

<http://www.ed.gov/about/offices/list/osers/nidrr/index.html?src=mr>

NIDRR provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. Programmatic efforts are aimed at improving the lives of individuals with disabilities from birth through adulthood. Multiple reports focusing on health, education, work, and community participation status of people with disabilities.

Example: Almost 60% of Commission and Shriners, Lexington, graduates who are not working would like to be compared with 84% of people 18-44 with disabilities in America who say they would like to be working (NIDRR, 1998).

National Adolescent Health Information Center (NAHIC)

<http://youth.ucsf.edu/nahic> The overall goal of NAHIC is to improve the health of adolescents by serving as a national resource for adolescent health information and research and to assure the integration, synthesis, coordination and dissemination of health information.

National Longitudinal Surveys of Youth

<http://stats.bls.gov/nls/home.htm> Survey of young men and women born in the years 1980-84; respondents were ages 12-17 when first interviewed in 1997.

Example: 50% of Commission and 40% of Shriners Hospital, Lexington, graduates are working now compared with 88% of 18-24 year olds in the National Longitudinal Study of Youth; 56% of graduates of the Commission and Shriners, Lexington, live with their parents compared with 40% of young adults in the NLSY and 56% of men and 43% of women aged 18-24 (CPS, 2000).

National Organization on Disability/Harris Survey of Americans with Disabilities, 2000

www.nod.org and **www.harrisinteractive.com** (search disabilities)
Results of on-line surveys of people with disabilities compared with people without disabilities.

Examples: 70% of graduates of the Commission and Shriners say they go grocery shopping a lot or sometimes compared with 55% of adults with disabilities and 85% of adults without disabilities; 50% of Commission and 55% of Shriners, Lexington, graduates say they go to church a lot or sometimes compared with 47% of PWD and 65% of people without disabilities who attend church at least once a month (NOD/Harris Poll, 2000)

National Longitudinal Study of Special Education Students

<http://www.sri.com/policy/cehs/dispolicy/> Study tracked, collected data from, and reported on the experiences of more than 8,000 secondary school students with disabilities nationwide for six years. Data were collected repeatedly from telephone interviews with youth and parents, from school records for multiple years, and from surveys of teachers and administrators in the schools attended by sample members. Descriptive and explanatory analyses provided, including school performance and school completion, social integration, arrest rates, employment status and quality, and independent functioning. The influences of individual and household characteristics and of school experiences and related services on these outcomes were assessed.

National Longitudinal Study of Adolescent Health

<http://www.cpc.unc.edu/projects/addhealth/> ADD Health is a school-based study of the health-related behaviors of adolescents in grades 7 to 12. It has been designed to explore the causes of these behaviors, with an emphasis on the influence of social context. ADD Health postulates that families, friends, schools, and communities play roles in the lives of adolescents that may encourage healthy choices or may lead to unhealthy, self-destructive behavior. A third wave of the study was designed to explore the transition from adolescence into young adulthood.

Child and Adolescent Health Measurement Initiative (CAHMI)

www.facct.org FACCT: Foundation for Accountability has several studies of children and adolescents in progress. Results of an on-line survey of adolescents, A Portrait of Adolescents in America, with the Robert Wood Johnson Foundation are available. Special risk groups with risky behaviors, symptoms of depression, and special health care needs (ages 13-17).

Example: 50% of Shriners Hospital, Lexington, and 37% of Commission graduates perceive their health to be Excellent/very good compared with 64% of teens without special needs and 43% of teen with special needs (A Portrait of Adolescents in America, 2002) and compared with 63% of Kentuckians 18-24 (KBRFSS, 2000).

Kids Count

www.kidscount.org KIDS COUNT, a project of the Annie E. Casey Foundation, is a national and state-by-state effort to track the status of children in the U.S. By providing policymakers and citizens with benchmarks of child well-being, KIDS COUNT seeks to enrich local, state, and national discussions concerning ways to secure better futures for all children.

US Government's Gateway to Disability Information

www.disability.gov In the Search field type "Disability Statistics" for a list of a variety of statistical sources. Click on the "Health" tab at the top to find health information; one category along the left margin is disability statistics.

National Council on Disability

www.ncd.gov The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate. NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Disability Statistics Center

www.dsc.ucsf.edu The Disability Statistics Center at the University of California, San Francisco produces and disseminates policy-relevant statistical information on the demographics and status of people with disabilities in American society. The Center's work focuses on how that status is changing over time with regard to employment, access to technology, health care, community-based services, and other aspects of independent living and participation in society. A wide variety of statistical information about people with disabilities is available including: Disability Statistics Reports, Disability Abstracts, and "Disability Watch: The Status of People with Disabilities in the United States."

Social Security Administration

www.socialsecurity.gov Various reports offer information about Social Security and SSI beneficiaries including use of SSI Work Incentives.

US National Library of Medicine

www.nlm.nih.gov Home page of the US National Library of Medicine, the world's largest medical library and the creator of MEDLINE, provides information about library programs; services; links to NLM online services; specialized NLM Web databases; and multimedia features such as the Visible Human Project and Profiles in Science.

Commonwealth Fund

www.cmwf.org The Commonwealth Fund is a private foundation that supports independent research on health and social issues and makes grants to improve health care practice and policy. The Fund is dedicated to helping people become more informed about their health care, and improving care for vulnerable populations such as children, elderly people, low-income families, minority Americans, and the uninsured. Chartbook on Pediatric Health Care, released spring 2004, includes list of many data resources on health care of children and adolescents.

Cornell University Rehabilitation Research and Training Center for Economic Research on Employment Policy for Persons with Disabilities

http://www.ilr.cornell.edu/ped/dep/rrtc.html RRTC's coordinated research, training, and dissemination activities are aimed at deepening the understanding of policy makers and other stakeholders about how the economy, public policies, and other socio-political factors affect the employment and economic self-sufficiency of persons with disabilities. The *Policy Brief: Summary Review of Data Sources for School to Work Transitions by Youths with Disabilities* lists and critiques potential data sources to examine school-to-work transitions by youth with disabilities.

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