



HRTW National Resource Center

**Data Sources for Tracking Youth
Transitioning to Adulthood**
Revised and updated November 18, 2009

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 outcomes of their programming. This list of data sources with their websites offers a sample of respected data sources.

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Data Resources on ALL Youth and Young Adults

FEDERAL GOVERNMENT AGENCIES

FEDSTATS

www.fedstats.gov

Fedstats is a window on the full range of official statistical information available to the public from the Federal government. The search engine can be used to find data on youth and/or disabilities

AGENCY FOR HEALTH CARE RESEARCH AND QUALITY (AHRQ)

Medical Expenditure Panel Survey (MEPS)

www.meps.ahrq.gov

MEPS is the most complete source of data on the cost and use of health care and health insurance coverage. The Medical Expenditure Panel Survey, which began in 1996, is a set of large-scale surveys of families and individuals, their medical providers (doctors, hospitals, pharmacies, etc.), and employers across the United States. MEPS collects data on the specific health services that Americans use, how frequently they use them, the cost of these services, and how they are paid for, as well as data on the cost, scope, and breadth of health insurance held by and available to U.S. workers. MEPS currently has two major components: the Household Component and the Insurance Component. The Household Component provides data from individual households and their members, which is supplemented by data from their medical providers. The Insurance Component is a separate survey of employers that provides data on employer-based health insurance

CENSUS BUREAU

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.

- **American Community Survey**

<http://www.census.gov/acs/www/SBasics/>

The American Community Survey (ACS) is a nationwide survey designed to provide communities a fresh look at how they are changing. It is a critical element in the Census Bureau's reengineered decennial census program. The ACS collects and produces population and housing information every year instead of every ten years.

- **US Census - Health Insurance Statistics**

www.census.gov/hhes/www/hlthins.html

View reports, briefs (short reports), and data on health insurance.

- **Current Population Survey (CPS)**

<http://www.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. Conducted for more than 50 years, the CPS 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. However, published data focus on those ages 16 and over. 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.

- **US Census Bureau - Disability**

<http://www.census.gov/hhes/www/disability/disability.html>

Portal to reports and data on disability from the US Census Bureau.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

www.cdc.gov

CDC is recognized as the lead federal agency for protecting the health and safety of people, at home and abroad; providing credible information to enhance health decisions; and promoting health through strong partnerships. CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States.

- **Healthy People 2010 and Healthy People 2020**

www.healthypeople.gov

The goals for the health of the US population and various subgroups for the year 2010 that direct federal and state health funding and programming. Describes efforts under way to develop HP2020.

- **Improving the Health of Adolescents and Young Adults: A Guide for States and Communities**

<http://nahic.ucsf.edu/index.php/companion/index/>

Improving the Health of Adolescents & Young Adults: A Guide for States and Communities is a companion to *Healthy People 2010*, the U.S. Department of Health and Human Services' comprehensive, nationwide health promotion and disease prevention agenda. The document

helps communities and individuals translate the *Healthy People 2010* objectives that are key to adolescent health and safety into a vision for improving adolescent health and well-being. It provides a framework for helping communities to establish priorities, take collective action, and measure progress toward the shared goal of improving the health, safety, and well-being of their adolescents and young adults.

- **Morbidity & Mortality Weekly Reports (MMWR)**

www.cdc.gov/mmwr

The *MMWR Weekly* contains data on specific diseases as reported by state and territorial health departments and reports on infectious and chronic diseases, environmental hazards, natural or human-generated disasters, occupational diseases and injuries, and intentional and unintentional injuries. Also included are reports on topics of international interest and notices of events of interest to the public health community. For example, *MMWR Surveillance Summaries, July 17, 2009 / Vol. 58 / No. SS-6, Sexual and Reproductive Health of Persons Aged 10-24 Years, United States, 2002--2007*

- **National Center for Chronic Disease Prevention and Health Promotion**

www.cdc.gov/nccdphp/index.htm

Chronic diseases—such as heart disease, cancer, and diabetes—are the leading causes of death and disability in the United States. These diseases account for 7 of every 10 deaths and affect the quality of life of 90 million Americans. Although chronic diseases are among the most common and costly health problems, they are also among the most preventable. Adopting healthy behaviors such as eating nutritious foods, being physically active, and avoiding tobacco use can prevent or control the devastating effects of these diseases. The center conducts studies to better understand the causes of these diseases, supports programs to promote healthy behaviors, and monitors the health of the nation through surveys. Critical to the success of these efforts are partnerships with state health and education agencies, voluntary associations, private organizations, and other federal agencies.

- **National Initiative to Improve Adolescent Health by the Year 2010**

<http://www.cdc.gov/healthyyouth/AdolescentHealth/NationalInitiative/index.htm>

A partnership of CDC and MCHB with others to elevate national and state focus on the health, safety, and well-being of adolescents and young adults (aged 10–24 years) and foster cooperation among different partners, including states, for attaining all 21 Critical Health Objectives for adolescents and young adults from *HP2010*.

CDC - National Center for Health Statistics (NCHS)

<http://www.cdc.gov/nchs/nhis.htm>

Site describes the National Health Interview Survey (NHIS), National Health and Nutrition Examination Survey (NHANES), National Health Care Surveys, and other surveys.

- **Health, United States, with Chartbooks on Trends in the Health of Americans**

www.cdc.gov/nchs/hus.htm

Health, United States is an annual report on trends in health statistics. The report consists of two main sections: A chartbook containing text and figures that illustrates major trends in the health of Americans; and a trend tables section that contains detailed data tables. The two main components are supplemented by an executive summary, a highlights section, an extensive appendix and reference section, and an index. Note that Chartbook for *Health, United States 2008* has Special Feature on the Health of Young Adults (see p 90).

- **National Health Interview Survey (NHIS) conducted yearly**

- **National Health Interview Survey-Disabilities (NHIS-D) last conducted in 1997**

www.cdc.gov/nchs/nhis.htm

Some National Center for Health Statistics data systems and surveys are ongoing annual systems while others are conducted periodically. NCHS 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 access to *Health US* 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.

- **SLAITS, State and Local Area Integrated Telephone Survey**

- www.cdc.gov/nchs/slaits.htm

- **National Survey of Children's Health**

- **National Survey of Children with Special Health Care Needs**

- **Survey of Adult Transition and Health**

The State and Local Area Integrated Telephone Survey (SLAITS) collects important health care data at State and local levels. This data collection mechanism was developed by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC). It supplements current national data collection strategies by providing in-depth state and local area data to meet various program and policy needs in an ever-changing health care system. Website includes the questionnaires for the MCHB National Survey on Children with Special Health Care Needs (NS-CSHCN 2001 and 2005-6), National Survey of Children's Health from 2003 and 2007, and the Survey of Adult Transition and Health which is a 2007 follow-back of families surveyed in the 2001 NS-CSHCN. Other resources include data, surveys, initiatives, and research programs.

- **National Survey of Children's Health, 2003 and 2007**

- <http://www.cdc.gov/nchs/slaits/nsch.htm>

- Survey examines the physical and emotional health of children ages 0-17 years of age. Special emphasis is placed on factors that may relate to well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. Website has survey forms, methodology and reports for both rounds of the NSCH. Plans are to repeat survey about every 4 years

- **National Survey of Children with Special Health Care Needs, 2001 and 2005-2006**

- <http://www.cdc.gov/nchs/slaits/cshcn.htm>

- The primary goals of these modules are to assess the prevalence and impact of special health care needs among children in all 50 States and the District of Columbia and evaluate change since 2001. This survey explored the extent to which children with special health care needs (CSHCN) have medical homes, adequate health insurance, and access to needed services. Other topics include functional difficulties, care coordination, satisfaction with care, and transition services. Interviews were conducted with parents or guardians who know about the child's health. More than 3,000 households with children were screened to identify 750 CSHCN in each State and DC. In the 2005-6 round, a national referent sample of approximately 5,000 children *without special health care needs* was also selected, so that characteristics of CSHCN may be compared with characteristics of children without special health care needs. Website has survey forms, methodology and reports for both rounds of the NS-CSHCN; for interactive use of the data, go to www.childhealthdata.org

- **Survey of Adult Transition and Health**

- <http://www.cdc.gov/nchs/slaits/sath.htm>

- This nationwide survey looks at the health of young people who were 19 to 23 years old in 2007, whose parents were originally interviewed in 2001 when the subjects were 14 to 17 years old. The primary goals of this follow-up survey are to examine their current health care needs and transition from pediatric health care providers to adult health care providers. Website has survey instruments, methodology, strengths and limitations and reports.

- **Behavioral Risk Factor Surveillance System (BRFSS)**

<http://www.cdc.gov/brfss/>

The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. For many states, the BRFSS is the only available source of timely, accurate data on health-related behaviors. BRFSS was established in 1984 by the Centers for Disease Control and Prevention (CDC); currently data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. More than 350,000 adults are interviewed each year, making the BRFSS the largest telephone health survey in the world. States use BRFSS data to identify emerging health problems, establish and track health objectives, and develop and evaluate public health policies and programs. Many states also use BRFSS data to support health-related legislative efforts. The BRFSS gives extensive information about the health status, risk behaviors, and access to care and insurance for different age groups, including young adults. 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. States may add questions to obtain data on particular health conditions (such as asthma, diabetes, and depression) and more information on health care costs and barriers.

- **Youth Risk Behavior Surveillance System (YRBSS)**

www.cdc.gov/healthyyouth/yrbs

The Youth Risk Behavior Surveillance System (YRBSS) monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the Centers for Disease Control and Prevention (CDC) and state, territorial, tribal, and local surveys conducted by state, territorial, and local education and health agencies and tribal governments. YRBSS surveys 7th, 9th and 11th graders on health risk behaviors exploring behavioral risk factors associated with the most important causes of mortality and morbidity in youth and adults. Surveys are done every 2 years. Results are on the website for the 2007 YRBS. Data from the 2009 YRBS will be available in summer 2010.

- **National Prevention Information Network**

<http://www.cdcnpin.org/>

The CDC National Prevention Information Network (NPIN) is the U.S. reference and referral service for information on HIV/AIDS, viral hepatitis, sexually transmitted diseases (STDs), and tuberculosis (TB). NPIN collects, catalogs, processes, and electronically disseminates materials and information on HIV/AIDS, viral hepatitis, STDs, and TB to organizations and people working in those disease fields in international, national, state, and local settings. All NPIN services are designed to facilitate sharing of information and resources on education and prevention services, published materials, research findings, and trends among users.

DEPARTMENT OF EDUCATION

National Center for Education Statistics

www.nces.ed.gov

<http://nces.ed.gov/quicktables/>

The National Center for Education Statistics (NCES), located within the U.S. Department of Education and the Institute of Education Sciences, is the primary federal entity for collecting and analyzing data related to education. Currently available is : High School Dropout and Completion Rates in the United States: 2007. The Quicktable link is a search tool lets you locate all tables/figures/charts published in the inventory of NCES' National Education Data Resource Center (NEDRC).

**DEPARTMENT OF LABOR
Bureau of Labor Statistics**

- **National Longitudinal Surveys of Youth 1979 and 1997**

<http://www.bls.gov/nls/>

The National Longitudinal Surveys (NLS) are a set of surveys designed to gather information at multiple points in time on the labor market activities and other significant life events of several groups of men and women. NLSY79 is a nationally representative sample of 12,686 young men and women who were 14-22 years old when they were first surveyed in 1979. These individuals were interviewed annually through 1994 and are currently interviewed on a biennial basis. NLSY97 consists of a nationally representative sample of approximately 9,000 youths who were 12 to 17 years old when interviewed in 1997. In that round, both the eligible youth and one of that youth's parents received hour-long personal interviews. Youth continue to be interviewed on an annual basis.

- **Survey of Income and Program Participation (SIPP)**

<http://www.sipp.census.gov/sipp/>

The main objective of SIPP is to provide accurate and comprehensive information about the income and program participation of individuals and households in the United States, and about the principal determinants of income and program participation. SIPP offers detailed information on cash and noncash income on a sub-annual basis. The survey also collects data on taxes, assets, liabilities, and participation in government transfer programs. SIPP data allow the government to evaluate the effectiveness of federal, state, and local programs.

FEDERAL INTERAGENCY FORUM ON CHILD AND FAMILY STATISTICS

www.childstats.gov/

The Forum is a working group of Federal agencies that collect, analyze, and report data on issues related to children and families. The Forum has partners from 22 Federal agencies as well as partners in private research organizations. The Forum's signature report, *America's Children: Key National Indicators of Well-Being*, is an annual indicators report that details the status of children and families in the United States.

- ***America's Children: Key National Indicators of Well-Being, 2009: Government Report Finds Gains and Losses in Children's Health*** www.childstats.gov/americaschildren/

**HHS - OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
Office of Human Services Policy (HSP)**

<http://aspe.hhs.gov/hsp>

HSP focuses on welfare, poverty, service delivery issues, data for research, policies affecting children, youth, and families, and economic matters affecting the Department. HSP is in the Office of the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services.

Trends in the Well-Being of America's Children and Youth, 2003

<http://aspe.hhs.gov/HSP/03trends/>

This report provides information on more than 80 indicators within the domains of population, family, neighborhood, economic security; health conditions and health care; social development and behavioral health, including teen fertility; and education and achievement. Indicators are drawn from more than 20 data sources including federally collected data, national surveys, and specific studies from peer-reviewed journals.

HRSA/ MCHB – TITLE V SYSTEMS INFORMATION DATA

State Data Forms: <https://perfddata.hrsa.gov/mchb/mchreports/forms.asp>

Block Grant Reports: https://perfddata.hrsa.gov/mchb/mchreports/states_Narrative.asp

NOTE: New key word search function allows users to identify state Block Grant Reports by specific activities/terms.

Data from 59 US States, Territories, and Jurisdictions are from the States' annual Block Grant applications and reports. Data on MCH programs and number of children and youth with special health care needs served by State Title V Programs. Block Grant report and status on progress to meet performance measures.

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.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

www.samhsa.gov

Statistics on substance abuse and mental health from the federal agency.

- **Office of Applied Studies – results from a variety of surveys**
<http://oas.samhsa.gov/>

2008 National Survey on Drug Use & Health provides the latest data on prevalence and correlates of substance use, serious psychological distress, depression, related problems, and treatment in the civilian population aged 12 or older in the U.S.

US GOVERNMENT ACCOUNTABILITY OFFICE

<http://www.gao.gov/>

The U.S. Government Accountability Office (GAO) is known as "the investigative arm of Congress" and "the congressional watchdog." GAO supports the Congress in meeting its constitutional responsibilities and helps improve the performance and accountability of the federal government for the benefit of the American people.

- **GAO Report: Young Adults With Serious Mental Illness: Some States and Federal Agencies Are Taking Steps to Address Their Transition Challenges**

GAO-08-678 June 23, 2008

<http://www.gao.gov/products/GAO-08-678>

Due to concerns about young adults with serious mental illness transitioning into adulthood, GAO was asked to provide information on (1) the number of these young adults and their demographic characteristics, (2) the challenges they face, (3) how selected states assist them (CT, MD, MA, and MS), and (4) how the federal government supports states in serving these young adults and coordinates programs that can assist them.

US GOVERNMENT INTERAGENCY WEBSITE: Find Youth Info: Resources to Strengthen American Youth

<http://www.findyouthinfo.gov>

FindYouthInfo.gov is the U.S. government Web site that helps you create, maintain, and strengthen effective youth programs. Included are youth facts, funding information, and tools to help you assess community assets, generate maps of local and federal resources, search for evidence-based youth programs, and keep up-to-date on the latest, youth-related news. FindYouthInfo.gov was created by the Interagency Working Group on Youth Programs (IWGYP), which is composed of representatives from 12 Federal agencies that support programs and services focusing on youth. The IWGYP promotes the goal of positive, healthy outcomes for youth in three significant ways:

NON-GOVERNMENTAL PROGRAMS

ACE Study - Effects of Adverse Childhood Experiences on Adult Health and Well-Being

www.acestudy.org

<http://www.cdc.gov/nccdphp/ace/>

The ACE Study is one of the largest investigations ever conducted on the links between childhood maltreatment and later-life health and well-being. As collaboration between the Centers for Disease Control and Prevention and Kaiser Permanente's Health Appraisal Clinic in San Diego, Health Maintenance Organization (HMO) members undergoing a comprehensive physical examination provided detailed information about their childhood experience of abuse, neglect, and family dysfunction. Over 17,000 members chose to participate. To date, over 30 scientific articles have been published and over 100 conference and workshop presentations have been made. ACE is looking at dose-response effects of adverse childhood experiences such as abuse and household dysfunction (growing up with family member in prison, mother treated violently, alcoholic or drug using family member, mentally ill family member) and physical and mental health of adults in their 50s including obesity, cardiac and pulmonary diseases, diabetes and behaviors such as smoking and sexual practices.

American Youth Policy Forum (AYPF)

<http://www.aypf.org/about/index.htm>

AYPF, a nonprofit, nonpartisan professional development organization based in Washington, DC, provides learning opportunities for policy leaders, practitioners, and researchers working on youth and education issues at the national, state, and local levels. AYPF focuses on three overlapping themes: Education, Youth Development and Community Involvement, and Preparation for Careers and Workforce Development. AYPF publishes a variety of nationally disseminated youth policy reports and materials.

Annie E. Casey Foundation

www.caseyfoundation.org

www.caseylifeskills.org

www.kidscount.org

The Annie E. Casey Foundation focuses particularly on programming for foster children to transition to adulthood. A description of the programs implemented throughout the country using the Casey methods and the Annie E Casey Life Skills Assessment and the Ansell-Casey Life Skills Assessment for different age groups to determine strengths and areas for focus can be found online. Imbedded in these life-skills assessments are desired outcomes for successful adulthood

Association of Maternal and Child Health Programs (AMCHP)

www.amchp.org

AMCHP represents state public health leaders and others working to improve the health and well being of women, children, youth and families, including those with special health care needs. AMCHP accomplishes its mission through the active participation of its members and vital partnerships with government agencies, families and advocates, health care purchasers and providers, academic and research professionals, and others at the national, state and local levels. AMCHP's mission is to provide leadership to assure the health and well being of all women, children, youth and families, including those with special health care needs.

- **AMCHP MCH Data Resource Portal**

http://www.amchp.org/topics/a-g/data_resources.php

AMCHP has developed a portal that brings together different data query resources developed by our partners for easy access by our members. This portal is a work in progress as we are always expanding and reorganizing to make this MCH resource portal comprehensive and user-friendly

Chapin Hall

www.chapinhall.org

Chapin Hall is an applied research center at the University of Chicago dedicated to conducting and actively disseminating rigorous research that serves children and youth, their families, and the communities in which they live. The work is driven by the conviction that our society cannot afford to write off a single child, and that policy and programs designed to help children and adolescents—especially the most vulnerable—must be based on facts, not ideology or anecdote. Chapin Hall is committed to building knowledge about the state of our young people—and the nature, extent, and consequences of the challenges they face—and sharing what is learned about how our society is faring in addressing those challenges. Also included are studies of adult functioning of former foster children. A series of reports evaluates select independent living programs for youth who age out of foster care.

Child and Adolescent Health Measurement Initiative (CAHMI)

www.cahmi.org

CAHMI developed and maintains a number of quality measurement tools and strategies that assess the quality of care provided to children and young adults. CAHMI is a national collaboration to develop and implement a comprehensive set of consumer-centered quality measurement tools. CAHMI involves consumer organizations, federal and state policymakers, health care purchasers, researchers, practitioners and others that influence health care delivery, quality measurement and reporting to develop, test and deploy consumer-centered quality measures

- **The Children With Special Health Care Needs (CSHCN) Screener ©**

<http://www.cahmi.org/pages/Sections.aspx?section=10>

The CSHCN screener is a five item parent survey-based tool that is used to identify children with special health care needs.

- **Young Adult Health Care Survey (YAHCS) Version 2.0**

<http://www.cahmi.org/pages/Sections.aspx?section=9>

The Young Adult Health Care Survey (YAHCS) is designed to capture information about the quality of preventive health care provided to adolescents. This is the YAHCS for a mail administration.

- **A Portrait of Adolescents in America, 2001**

<http://www.cahmi.org/ViewDocument.aspx?DocumentID=88>

http://www.markle.org/resources/facct/doclibFiles/documentFile_522.pdf

This report explores the health and health care experiences of 2,000 adolescents, ages 13 to 17, surveyed online in May 2001. The Robert Wood Johnson Foundation, in collaboration with FACCT, conducted this survey to learn from teens about their physical, mental and social well-being and the perceptions and behaviors that promote or threaten their health.

- **Data Resource Center for Child and Adolescent Health**

<http://www.childhealthdata.org>

This site provides tips and tools for interacting with the data from the National Survey of Children's Health (2003 and 2007) and the National Survey of Children with Special Health Care Needs (2001 and 2005/2006). Users can view and compare state, regional and nationwide findings from these surveys. Educational materials about the survey as well as state profiles on key indicators are also available.

Child Trends

<http://www.childtrends.org/>

Child Trends is a nonprofit, nonpartisan research center that studies children at all stages of development. Our mission is to improve outcomes for children by providing research, data, and analysis to the people and institutions whose decisions and actions affect children, including program providers, the policy community, researchers and educators, and the media. Youth development and health are areas of focus.

Child Trends Databank

<http://www.childtrends.databank.org/>

Child Trends Databank is a one-stop shop for the latest national trends and research on over 100 key indicators of child and youth well-being, with new indicators added each month. *A Statistical Portrait of Well Being in Early Adulthood, 2004*, summarizes status of transition of young people in the US can be found at:

<http://www.childtrends.databank.org/PDF/Young%20Adults%20Brief.pdf>

Children's Defense Fund

www.childrensdefense.org

CDF is the foremost national proponent of policies and programs that provide children with the resources they need to succeed. We champion policies that will lift children out of poverty; protect them from abuse and neglect; and ensure their access to health care, quality education, and a moral and spiritual foundation. Current strategic plan includes promoting health insurance coverage for all children and developing youth leaders who will become the next generation of child advocates. Website offers links to data sources.

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. Health insurance for young adults is a focus.

- *Rite of Passage? Why Young Adults Become Uninsured and How New Policies Can Help, 2009.* Nicholson JL, Collins SR, Mahato B, Gould E, Schoen C & Rustgi SD, 2009 Update, The Commonwealth Fund, August 6, 2009 | Volume 64
<http://www.commonwealthfund.org/Content/Publications/Issue-Briefs/2009/Aug/Rite-of-Passage-Why-Young-Adults-Become-Uninsured-and-How-New-Policies-Can-Help-2009-Update.aspx>
- *Testimony--Young and Vulnerable: The Growing Problem of Uninsured Young Adults and How New Policies Can Help* April 23, 2009, Sara R. Collins, PhD:
<http://www.commonwealthfund.org/Content/Publications/Testimonies/2009/Apr/Testimony-Young-and-Vulnerable.aspx>
- *Aiming Higher: Results from the 2009 State Scorecard on Health System Performance.* The report ranks states on 38 indicators in the areas of access, prevention/treatment quality, avoidable hospital use and costs, healthy lives, and equity:
<http://www.commonwealthfund.org/Content/Publications/Fund-Reports/2009/Oct/2009-State-Scorecard.aspx>

Forum for Youth Investment

<http://www.forumfyi.org>

Forum for Youth Investment is a nonprofit, nonpartisan "action tank" dedicated to helping communities and the nation make sure all young people are Ready by 21™: ready for college, work and life. Informed by rigorous research and practical experience, the Forum forges innovative ideas, strategies and partners to strengthen solutions for young people and those who care about them. A trusted resource for policy makers, advocates, researchers and program professionals, the Forum provides youth and adult leaders with the information, connections and tools they need to create greater opportunities and outcomes for young people.

4-H Study of Positive Youth Development

<http://www.fourh.umn.edu/evaluation/4hpydstudy.html>

<http://ase.tufts.edu/iaryd/research.htm>

This six year study, conducted by researchers at Tufts University and Boston College and funded by the National 4-H Council, is aimed at assessing across the early years of adolescence the key characteristics of healthy, positive youth development. Building on a strong theoretical base, the researchers define these characteristics by what they term *the “5 C’s”—competence, confidence, character, connection, and caring (or compassion)—which is believed to ultimately lead to the 6th C, contribution.* The research evaluates the impact on positive youth development of key ecological assets—families, communities and, in particular, community-based programs for youth.

The Future of Children

<http://www.futureofchildren.org/>

The Future of Children is a collaboration of the Woodrow Wilson School of Public and International Affairs at Princeton University and the Brookings Institution. The mission of *The Future of Children* is to translate the best social science research about children and youth into information that is useful to policymakers, practitioners, grant-makers, advocates, the media, and students of public policy. The project publishes two journals and policy briefs each year, and provides various short summaries of our work. Topics range widely -- from income policy to family issues to education and health – with children’s policy as the unifying element. The senior editorial team is diverse, representing two institutions and multiple disciplines

- **Transition of Immigrant Children, 2004**

<http://www.princeton.edu/futureofchildren/publications/journals/article/index.xml?journalid=39&articleid=128>

This article focuses on the extent to which diverse adolescents are prepared for adulthood according to these three critical developmental outcomes. It finds that, in general, adolescents from Latino and African American backgrounds appear to be less prepared to become healthy, productive, and successful adults than their peers.

Horatio Alger Association

www.horatioalger.org

“*The State of Our Nation’s Youth*” 2008-2009 is at <http://www.horatioalger.com/pdfs/0708SONY.pdf>

Since 1996 the Horatio Alger Association of Distinguished Americans has conducted a survey of young people between the ages of 13 and 19 to ascertain the issues and feelings of American youth. The report offers valuable insight into the lives of teens across the country and what effect our nation’s government, culture and their own relationships have on their lives.

Kaiser Family Foundation

State Health Facts

<http://www.statehealthfacts.org/>

This resource contains the latest state-level data on demographics, health, and health policy, including health coverage, access, financing, and state legislation.

KIDS COUNT

www.kidscount.org

<http://www.aecf.org/MajorInitiatives/KIDSCOUNT.aspx>

www.aecf.org/kidscount/

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.

Maternal and Child Health Library at Georgetown University

<http://www.mchlibrary.info/>

Providing accurate, timely information including the weekly newsletter MCH Alert, resource guides, full text publications, databases, and links to essential MCH resources. Knowledge paths points to resources that analyze data, describe effective programs, and report on policy and research aimed at developing systems of care. The 2009 knowledge path for children and youth with special health care needs promotes systems that are family-centered, community-based, coordinated, and culturally competent. Separate sections address specific aspects of care and development, such as early intervention and special education, financing services, rehabilitation, screening, and transition. The knowledge path is designed for health professionals, program administrators, policymakers, educators, researchers, and families.

- The CYSHCN knowledge path is available at http://www.mchlibrary.info/KnowledgePaths/kp_CSHCN.html.
- An adolescent health resource brief is available at <http://mchlibrary.info/guides/adolescent.html>
- Knowledge paths on other maternal and child health (MCH) topics are available at <http://mchlibrary.info/KnowledgePaths/index.html>.

MacArthur Foundation Network on Transitions to Adulthood

<http://www.transad.pop.upenn.edu/>

In the span of a few generations, significant cultural, economic, and demographic changes have altered the path that many young adults follow as they strive for the traditional milestones of adulthood. The Network is both documenting these significant shifts and exploring how young adults, their families, government, and social institutions might adapt to better meet the needs of young adults in the 21st century. Website has chapter summaries for *On the Frontier of Adulthood: Theory, Research, and Public Policy 2005* and many downloadable reports.

- *Adolescence and the Transition to Adulthood: Rethinking Public Policy for a New Century*, a two-day conference held in Chicago in November 2004, assembled a diverse set of researchers, practitioners, and policymakers to mark the centennial of psychologist G. Stanley Hall's landmark study on the needs of adolescents. The two-day conference, cosponsored by Chapin Hall Center for Children and the MacArthur Research Network on Transitions to Adulthood and Public Policy, discussed current research and practice and what it suggests about how well our major social institutions have adapted to support young people as they make the transition to adulthood in the twenty-first century. Conference summary can be found at http://www.transad.pop.upenn.edu/downloads/Conference_Summary_Final.pdf

Monitoring the Future

www.monitoringthefuture.org

Monitoring the Future is an ongoing study of the behaviors, attitudes, and values of American secondary school students, college students, and young adults. Each year, a total of approximately 50,000 8th, 10th and 12th grade students are surveyed (12th graders since 1975, and 8th and 10th graders since 1991). In addition, annual follow-up questionnaires are mailed to a sample of each graduating class for a number of years after their initial participation. Study is funded under a series of research grants from the National Institute on Drug Abuse at the University of Michigan.

National Longitudinal Study of Adolescent Health (Add Health)

<http://www.cpc.unc.edu/projects/addhealth/>

Add Health is a longitudinal study of a nationally representative sample of adolescents in grades 7-12 in the United States during the 1994-95 school year. The Add Health cohort has been followed into young adulthood with four in-home interviews, the most recent in 2008, when the sample was aged 24-32. Add Health combines longitudinal survey data on respondents' social, economic, psychological and physical well-being with contextual data on the family, neighborhood, community, school, friendships, peer groups, and romantic relationships, providing unique opportunities to study how social environments and

behaviors in adolescence are linked to health and achievement outcomes in young adulthood. The fourth wave of interviews expanded the collection of biological data in Add Health to understand the social, behavioral, and biological linkages in health trajectories as the Add Health cohort ages through adulthood. See <http://www.icpsr.umich.edu/DSDR/addhealth/index.html>

National Adolescent Health Information Center (NAHIC)

<http://nahic.ucsf.edu/>

The goals of NAHIC are to serve as a national resource for adolescent health information and research; and to assure the integration, synthesis, coordination and dissemination of adolescent health-related information. NAHIC was established in 1993 with funding from the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services. It is based within the University of California, San Francisco's Division of Adolescent Medicine, Department of Pediatrics and Institute for Health Policy Studies. Downloadable papers and data briefs including *Trends in Adolescent and Young Adult Health in the United States, 2009*.

Panel Study of Income Dynamics, University of Michigan

<http://psidonline.isr.umich.edu/CDS/TA05-Overview.pdf>

In 2005, the PSID began a new study called "*Transition into Adulthood*". This study was designed to collect information from all children who had participated in the Child Development Supplement who had turned age 18 and had completed high school and had families still active in PSID. The study collects data on young adult developmental pathways and outcomes, filling a gap between the detailed information about development from early and middle childhood through adolescence (as measured in CDS-I, CDS-II, and CDS-III), and the detailed information on adulthood once these youth assume the role of economic independence and become PSID heads and wives. For more information on the PSID, see <http://psidonline.isr.umich.edu/>

Public Agenda

<http://www.publicagenda.org/>

PublicAgenda.org is set up to provide both citizens and leaders with the tools they need to tackle tough problems. Get documented facts, consider the choices and current public opinion, and learn about new ways of working together on fundamental problems facing the country.

Life After High School: Young People Talk about Their Hopes and Prospects, 2005

http://www.publicagenda.org/files/pdf/life_after_high_school.pdf

This survey of young adults examines the decisions they make about work or college. The vast majority of young adults, of all races, strongly believe in the value of higher education. But the study raises questions about the shortage of high school counselors and the economic pressures felt by many young adults, especially minorities. The study also portrays the hit-or-miss career path experienced by those who enter the work force with a college or technical degree. Funding provided by The College Board, GE Foundation, the George Gund Foundation, W.K. Kellogg Foundation and KnowledgeWorks Foundation.

Public Policy Analysis and Education Center for Middle Childhood, Adolescent and Young Adult Health

<http://policy.ucsf.edu/>

The goal of the Policy Center is to identify and analyze the effects of public policies on the health and well-being of young people and their families. This is achieved through the objectives: to examine the relationship between the health status of young people and service delivery systems, and to examine the environmental determinants of health and development. Website had many downloadable papers including *A Federal Monitoring System for Early Adult Health*

The Urban Institute Health Policy Center

<http://www.urban.org/content/PolicyCenters/HealthPolicy/Overview.htm>

<http://www.urban.org/adolescents/index.cfm>

The Urban Institute studies health, insurance, disability, aging, family health and produces reports that monitor health issues in the US. The Urban Institute gathers data, conducts research, evaluates programs, offers technical assistance overseas, and educates Americans on social and economic issues — to foster sound public policy and effective government.

- *Vulnerable Youth and Transition to Adulthood*: <http://www.urban.org/publications/411948.html>

FOSTER CARE

National Youth in Transition Database (NYTD)

<http://www.acf.hhs.gov/programs/cb/systems/index.htm>

NYTD collects case-level information on youth in care including the services paid for or provided by the State agencies that administer the Chafee Foster Care Independence Program (CFCIP), as well as the outcome information on youth who are in or who have aged out of foster care. Powerpoint describing the project is at <http://www.nga.org/Files/pdf/0704YOUTHWORKSHOPNYTD.PDF>

The National Resource Center for Family-Centered Practice and Permanency Planning

http://www.hunter.cuny.edu/socwork/nrcfcpp/info_services/independent-living.html

This National Resource Center focuses on increasing the capacity and resources of State, Tribal, and other publicly supported child welfare agencies to promote family-centered practices that contribute to the safety, permanency, and well-being of children while meeting the needs of their families. The NRCFCPPP helps States and Tribes to implement strategies to expand knowledge, increase competencies, and change attitudes of child welfare professionals at all levels, with the goal of infusing family-centered principles and practices in their work with children, youth and families who enter the child welfare system. This site gives resources for supporting young people.

INTERNATIONAL STUDIES OF YOUTH

International Health Behavior of School-Aged Children Study (HBSC)

<http://www.hbsc.org/>

Questionnaires are completed by 11, 13, and 15 year olds in schools every 4 years. Studies were initiated in 2002. In 2008, 43 countries are participating. Website has many downloadable reports and charts.

Canada's Youth in Transition Study (YITS)

[http://www.statcan.ca/cgi-](http://www.statcan.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=4435&lang=en&db=IMDB&dbg=f&adm=8&dis=2)

[bin/imdb/p2SV.pl?Function=getSurvey&SDDS=4435&lang=en&db=IMDB&dbg=f&adm=8&dis=2](http://www.statcan.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=4435&lang=en&db=IMDB&dbg=f&adm=8&dis=2)

or <http://www.pisa.gc.ca/yits.shtml>

YITS is designed to examine the patterns of, and influences on, major transitions in young people's lives, particularly with respect to education, training and work. Human Resources and Skills Development Canada and Statistics Canada have been developing the YITS in consultation with provincial and territorial ministries and departments of labour and education. Content includes measurement of major transitions in young people's lives including virtually all formal educational experiences and most about-market experiences, achievement, aspirations and expectations, and employment experiences. The implementation plan encompasses a longitudinal survey of each of two cohorts, ages 15 and 18-20, to be surveyed every two years. Study started in 2000 and data for 2006-7 (Cycle 5) was released in July 2009.

Resources on Youth and Young Adults with Disabilities

Disability☆gov - Connecting the Disability Community to Information and Opportunities

www.disability.gov

Disability.gov is an award-winning federal Web site that contains disability-related resources on programs, services, laws and regulations to help people with disabilities lead full, independent lives. With just a few clicks, visitors can find critical information on a variety of topics, including benefits, civil rights, community life, education, emergency preparedness, employment, housing, health, technology and transportation. Click on "Health" on the left side to find health information; one category is Research and Statistics.

US CENSUS - Disability Statistics

www.census.gov/hhes/www/disability/disability.html

Census Bureau data on disability with links to related sites

- **American Community Survey – Disability statistics**
<http://www.census.gov/acs/www/SBasics/Information/disability.htm>

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

- National Center on Birth Defects and Developmental Disabilities
<http://www.cdc.gov/ncbddd/index.html>
Center is dedicated to helping people live to the fullest. Much of our work focuses on protecting people who are especially vulnerable to health risks - babies, children, people with blood disorders, and people with disabilities.
- DisAbility and Health: <http://www.cdc.gov/ncbddd/dh/default.htm>
Focus is promoting the health of people who are living with disabilities. Available are: *At-A-Glance: Disability and Health: Promoting Health and Well-being of People with Disabilities 2005* and the *2006 Disability and Health Chartbook*.

HRSA/ MCHB – TITLE V SYSTEMS INFORMATION DATA

State Data Forms: <https://perfdata.hrsa.gov/mchb/mchreports/forms.asp>

Block Grant Reports: https://perfdata.hrsa.gov/mchb/mchreports/states_Narrative.asp

NOTE: New key word search function allows users to identify state Block Grant Reports by specific activities/terms.

Data from 59 US States, Territories, and Jurisdictions are from the States' annual Block Grant applications and reports. Data on MCH programs and number of children and youth with special health care needs served by State Title V Programs. Block Grant report and status on progress to meet performance measures.

MCHB National Resource Centers for the CYSHCN Block Grant Performance Measures

- **Screening: National Newborn Screening and Genetics Resource Center:**
<http://genes-r-us.uthscsa.edu/>
- **Screening: Early Hearing Detection and Intervention (EHDI): National Center for Hearing Assessment and Management at Utah State University:** <http://www.infanthearing.org/>
- **Participation in Decision Making: National Center for Family and Professional Partnerships at Family Voices:** www.familyvoices.org

- **National Center for Cultural Competence:**
<http://www11.georgetown.edu/research/gucchd/nccc/>
- **Medical Home: National Center of Medical Home Initiatives for Children with Special Needs at the American Academy of Pediatrics:** www.medicalhomeinfo.org
- **Insurance: Catalyst Center for Improving Financing of Care for Children and Youth with Special Health Care Needs:** <http://www.hdwg.org/catalyst/>
- **Community Based Systems of Care: Champions for Inclusive Communities:**
www.championsinc.org
- **Transition to Adulthood: Healthy & Ready to Work National Resource Center:**
www.hrtw.org
Focus is on data related to health and other transitions of youth with disabilities from the MCHB HRTW projects and other sources. Links to websites about transition issues.

NATIONAL SURVEY OF CSHCN, 2001 and 2005-6

<http://www.cdc.gov/nchs/slaits/cshcn.htm>

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 these surveys through the State and Local Area Integrated Telephone Survey (SLAITS). More than 3,000 households with children were screened to identify 750 CSHCN in each State and DC. 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. This survey looks at CSHCN ages birth – 17; questions about transition were asked of families with children ages 12 – 17. Transition questions were expanded for the 2005-6 survey. In the 2005-6 round, a national referent sample of approximately 5,000 children *without special health care needs* was also selected, so that characteristics of CSHCN may be compared with characteristics of children without special health care needs. This website has survey forms, methodology and reports for both rounds of the NS-CSHCN; for interactive use of the data, go to www.childhealthdata.org

DEPARTMENT OF EDUCATION OFFICE OF SPECIAL EDUCATION AND REHABILITATION (OSERS)

www.ed.gov

Information and statistics about special education and special education students
Annual Reports: <http://www.ed.gov/about/reports/annual/otherplanrpts.html>

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

www.ideadata.org

Site provides public access to the most recent data about children with disabilities served under IDEA. These data are collected annually by the US Department of Education, Office of Special Education Programs in accordance with Section 618 of EDEA. They are provided in the form of tables produced for the Annual Reports to Congress.

INTERAGENCY COMMITTEE ON DISABILITY RESEARCH (ICDR)

www.icdr.us/

ICDR facilitates the effective exchange of information on disability and rehabilitation research activities among its member agencies. ICDR coordinates activities that span the areas of assistive technology and universal design; medical rehabilitation; data and statistics; employment; and community participation. The ICDR collects input from stakeholders to inform planning; identifies emerging research areas; assesses gaps and duplications in existing research; and makes recommendations to strengthen the federal research agenda.

NATIONAL CENTER ON EDUCATIONAL OUTCOMES

<http://education.umn.edu/nceo/>

National Center on Educational Outcomes at the University of Minnesota provides national leadership in designing and building educational assessments and accountability systems that appropriately monitor educational results for all students, including students with disabilities and students with limited English proficiency.

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH (NIDRR)

<http://www.ed.gov/about/offices/list/osers/nidrr/>

NIDRR provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. All 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 are available. Chartbooks on disability in US are at: www.infouse.com/disabilitydata

- **Disability Statistics Center**

www.dsc.ucsf.edu

The Disability Statistics Center 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. The Center is based at the Institute for Health and Aging at the University of California, San Francisco (UCSF). It receives funding from the National Institute on Disability and Rehabilitation Research (NIDRR). A wide variety of statistical information about people with disabilities is available including: *Disability Statistics Report and Disability Abstracts*

- **National Center for the Dissemination of Disability Research (NCDDR)**

www.ncddr.org/

NCDDR's scope of work focuses on knowledge translation of NIDRR-sponsored research and development results into evidence-based instruments and systematic reviews. NCDDR is developing systems for applying rigorous standards of evidence in describing, assessing, and disseminating research and development outcomes. NCDDR is based at SEDL, a private, nonprofit education research, development, and dissemination corporation based in Austin, Texas. Improving teaching and learning has been at the heart of SEDL's work for more than 40 years (formerly the Southwest Educational Development Laboratory).

- **Research and Training Center on Disability in Rural Communities (RTC:Rural)**

<http://rtc.ruralinstitute.umt.edu/geography/datasources.htm>

RTC:Rural was established in 1988 as part of the Rural Institute at the University of Montana.

RTC:Rural is funded by the National Institute on Rehabilitation Research to improve the ability of persons with disabilities to live independently in rural America.

NATIONAL CENTER FOR SECONDARY EDUCATION AND TRANSITION (NCSET)

www.ncset.org

NCSET coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures. NCSET is headquartered at the Institute on Community Integration in the University of Minnesota's College of Education and Human Development.

NATIONAL COUNCIL ON DISABILITY (NCD)

www.ncd.gov

NCD is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. On the website are reports focusing on transitioning people from social security income to work, long term supports and services, the impact of the Americans

with Disabilities Act, and financial incentives related to employment and living independently. See publications: <http://www.ncd.gov/newsroom/publications/index.htm>

- Current State of Health Care for People with Disabilities, September 2009

The National Council on Disability (NCD) recently a report calling for immediate health care reform for people with disabilities. The report provides a road map for eliminating the pervasive barriers to health care for people with disabilities, which will improve the quality of life, productivity, and well-being of greater numbers of Americans as the population ages. The complete report can be downloaded in PDF or Word formats:

<http://www.ncd.gov/newsroom/publications/2009/pdf/HealthCare.pdf>

<http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html>

- *The Rehabilitation Act: Outcomes for Transition-Age Youth, October 2008*

Keeping Track: National Disability Status and Program Performance Indicators, April 2008, This report is the result of a year-long effort by NCD to identify valid federal data and to describe the status of the U.S. population of Americans with disabilities:

http://www.ncd.gov/newsroom/publications/2008/Indicators_Report.html

NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES (NICHCY)

www.nichcy.org

NICHCY serves the nation as a central source of information on: disabilities in infants, toddlers, children, and youth; IDEA, which is the law authorizing special education; No Child Left Behind (as it relates to children with disabilities); and research-based information on effective educational practices. Find NICHCY state pages at <http://www.nichcy.org/Pages/StateSpecificInfo.aspx>

NATIONAL LONGITUDINAL TRANSITION STUDY (NLTS) and NLTS-2

www.nlts2.org and <http://www.sri.com/policy/cehs/dispolicy/>

NLTS2 is funded by the U.S. Department of Education to document the experiences of a national sample of 12,000 special education students ages 13-16 in 2000 as they move from high school into adult roles. NLTS2 is focusing on a wide range of important topics, such as high school coursework, extracurricular activities, academic performance, postsecondary education and training, employment, independent living, and community participation. NLTS2 is producing information of interest to many audiences, including state and local education agencies, the U.S. Congress, the U.S. Department of Education, parents, teachers, researchers, advocates, and policy-makers. The NLTS2, commissioned by the U.S. Department of Education, Institute of Education Sciences (IES), is a follow-up of the original National Longitudinal Transition Study (NLTS) designed and conducted by SRI International for OSEP from 1985 through 1993. Reports accessed through this website compare results from the 2 surveys. See recent reports: *The Post-High School Outcomes of Youth with Disabilities up to 4 Years After High School* (April 2009) and *Perceptions and Expectations of Youth with Disabilities* (August 2007); and *Fact Sheet: Substance Use Among Young Adults With Disabilities* (March 2008)

NATIONAL SECONDARY TRANSITION TECHNICAL ASSISTANCE CENTER (NSTTAC)

www.nsttac.org/

NSTTAC's objectives are to assist state education agencies with collecting data on IDEA Part B State Performance Plan Indicator 13 and using these data to improve transition services (Indicator 13: Percent of youth aged 16 and above with an IEP that includes coordinated, measurable, annual IEP goals and transition services that will reasonably enable the child to meet the post-secondary goals. [20 U.S.C. 1416(a)(3)(B)]); generate knowledge that provides a foundation for states to improve transition services that enhance post-school outcomes; build capacity of states and local educational agencies to implement effective transition education and services that improve post-school outcomes; and disseminate information to state personnel, practitioners, researchers, parents, and students regarding effective transition education and services that improve post-school outcomes.

REHABILITATION SERVICES ADMINISTRATION (RSA)

Research and Statistics

<http://www.ed.gov/about/offices/list/osers/rsa/research.html>

For the purposes of improving program management and effectiveness, RSA evaluates all programs authorized by the Rehabilitation Act of 1973, as amended. For example, to assess linkages between vocational rehabilitation (VR) services and economic and non-economic outcomes, RSA is conducting a longitudinal study of a national sample of VR consumers. RSA may also disseminate information on exemplary practices concerning vocational rehabilitation.

DEPARTMENT OF LABOR

- **Disability Statistics**

www.dol.gov

<http://www.dol.gov/dol/topic/disability/statistics.htm>

Statistics on people with disabilities in the workforce. Detailed employment statistics on the overall American workforce can be found at the Department of Labor's Bureau of Labor Statistics:

www.bls.gov

- **New monthly data series on the employment status of people with a disability**

<http://www.bls.gov/cps/cpsdisability.htm>

In June 2008, questions were added to the Current Population Survey (CPS) to identify persons with a disability in the civilian noninstitutional population age 16 and older. The addition of these questions allowed BLS to begin releasing monthly labor force data from the CPS for persons with a disability.

- **Office of Disability Employment Policy (ODEP)**

<http://www.dol.gov/odep>

ODEP is the arm of the U.S. Department of Labor tasked with ensuring people with disabilities are fully integrated into today's work force. ODEP develops disability employment policies, builds collaborative partnerships, and provides data on employment of people with disabilities. ODEP is a considerable resource for both employees and employers who are looking for statistics or research, or links to external resources that provide information on technical assistance, job accommodations, telecommuting and other best practices. ODEP is working on a work-force development case study to track and report impact evaluation and customer satisfaction of sites that have Workforce Investment Act-assisted programs, for which two summary reports are available. Additionally, ODEP evaluates disability-employment policy programs to identify best practices and continually figure out ways to improve the programs funded to build capacity and change the workplace for people with disabilities. ODEP also provides a survey report on employer perspectives on the employment of people with disabilities. This national survey compares employer perspectives across 12 industries and varying company sizes. One of the more interesting future undertakings is ODEP's work to develop a process to accurately track the disability employment rate.

<http://www.dol.gov/odep/pubs/fact/data.htm>

Who are people with disabilities? What do we know about people with disabilities? How many individuals with disabilities use assistive devices? How many people with disabilities are working? What are people with disabilities' demographics? These are just a few of the questions that are asked every day as we develop and implement programs and strategies to combat the high unemployment rate of persons with disabilities. Numerous resources are available to provide statistical data to answer these questions and provide information on other disability related topics. Many resources now post their information on Web sites, which makes researching disability data readily accessible and fast. This site gives list of these websites.

SOCIAL SECURITY ADMINISTRATION

www.ssa.gov or www.socialsecurity.gov

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

NON-GOVERNMENTAL AGENCIES AND PROGRAMS

American Foundation for the Blind

<http://www.afb.org/Section.asp?SectionID=15&DocumentID=2417>

The primary focus of the American Foundation for the Blind's Public Policy Center is programs affecting education and rehabilitation of persons with vision loss, as well as laws that relate to economic status and civil rights. However, policy advocates often require information about disability policy concerns in general. This page is intended to provide advocates with tools and information in the larger disability policy arena.

Chicago Healthy Adolescents Transition Study (C.H.A.T.S.)

<http://www.luc.edu/psychology/chats/res.htm>

Dr. Grayson Holmbeck, a clinical psychologist and professor at Loyola University Chicago, is the principal investigator of CHATS. For the past ten years, Dr. Holmbeck and his research team have been visiting families who have children with spina bifida, a congenital birth defect that affects neurological, urological, orthopedic, and educational functioning. Though this study is no longer open to new participants, this website is open to everyone. Specifically, this website contains information about the research study, spina bifida, adolescence, weblinks, and much more.

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

<http://www.ilr.cornell.edu/edi/> and <http://www.ilr.cornell.edu/edi/p-srrtc.cfm>
and www.disabilitystatistics.org and <http://www.ilr.cornell.edu/edi/disabilitystatistics/sources.cfm>

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 Center website offers disability statistics and policy briefs on transitions with special focus on work. The Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC) bridges the divide between the sources of disability data and the users of disability statistics. The goal of the StatsRRTC is assisting those collecting data to answer such questions and to help users find the answers to such questions. High quality disability-related data and statistics are needed to support the needs of policymakers, service providers, researchers, educators, the media, and people with disabilities and their families.

Cornucopia of Disability Information, School of Public Health, University at Buffalo, The State University of New York

<http://codi.buffalo.edu/>

CODI serves as a community resource for consumers and professionals by providing disability information in a wide variety of areas. It consists of both an Internet Directory of Disability Information and a repository of electronic disability documents, dating back to the early 1990s. Many of the documents on CODI are publicly available nowhere else on the Internet.

Institute for Community Inclusion

<http://www.statedata.info/>

ICI at the University of Massachusetts, Boston, and Children's Hospital, Boston, offers training, clinical, and employment services, conducts research, and provides assistance to organizations to promote inclusion of people with disabilities in school, work, and community activities. The ICI StateData.info website offers ready access to descriptive information on services and outcomes for state agencies that provide employment supports to individuals with disabilities. The target audiences include state agency personnel, policymakers, and advocates. The website automatically creates fully accessible graphics from underlying data. This website generates customized charts of state, national, and individual disability data. Accessible text versions are automatically created by the charting software.

KASA (Kids As Self-Advocates)

www.fvkasa.org/

Kids As Self Advocates (KASA) is a national, grassroots project created by youth with disabilities for youth and sponsored by Family Voices. We are teens and young adults with disabilities speaking out. KASA knows youth can make choices and advocate for themselves if they have the information and support they need. Website has resources, links, and documents created by youth including a *Youth As Leaders Manual*.

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/>

M&M states have strengthened their measurement capacity via data warehousing, data integration, development of interagency surveys, and simply sharing data results that pertain to the broader population of CSHCN. EIRI has ongoing research on youth.

National Alliance on Mental Illness (NAMI)

www.nami.org

From its inception in 1979, NAMI has been dedicated to improving the lives of individuals and families affected by mental illness. Dedication, steadfast commitment and unceasing belief in NAMI's mission by grassroots advocates have produced profound changes. NAMI's greatest strength is the dedication of our grassroots leaders and members. We are the families, friends and individuals that serve to strengthen communities across the country.

- [Grading the States 2009: A Report on America's Health Care System for Adults with Serious Mental Illness](#)

National Collaborative on Workforce and Disability for Youth

www.ncwd-youth.info

NCWD/Youth is a source for information about employment and youth with disabilities. The partners — experts in disability, education, employment, and workforce development — strive to ensure the highest quality, most relevant information available.

National Organization on Disability/Harris Survey of Americans with Disabilities

www.nod.org

Results of on-line and telephone surveys of people with disabilities compared with people without disabilities on a variety of quality of life indicators since 1986. The NOD/Harris Poll information for 2004 is available with comparisons to previous surveys. Click on Information and Resources.

National Youth Leadership Network (NYLN)

<http://www.nyln.org/newsroom/index.html>

NYLN is dedicated to advancing the next generation of disability leaders. The NYLN promotes leadership development, education, employment, independent living, and health and wellness among young leaders representing the diversity of race, ethnicity and disability in the United States; fosters the inclusion of young leaders with disabilities into all aspects of society at national, state and local levels; and communicates about issues important to youth with disabilities and the policies and practices that affect their lives. The website lists a variety of resources for and by youth and young adults

PACER Center

www.pacer.org

The mission of PACER Center in Minneapolis, Minnesota, is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents. Website offers variety of resources and links. A survey of over 1100 youth with SHCN ages 14-25 asked what they needed to be successful in adulthood. They clearly stated that the most important was jobs and job training with independent living skills with college and vocational

counseling close behind. Lower on the list was finding and paying for medical care. Transition-specific materials are at: <http://www.pacer.org/publications/transition.asp>

Research and Training Center on Family Support and Children's Mental Health at Portland State University

www.rtc.pdx.edu

The Center's website reports research and information on mental health issues for children, youth and young adults. *Focal Point* publications online are excellent. Transition-related examples are: Transition (Spring, 2001) including best practices in mental health; Resilience and Recovery (Summer, 2005), Strengthening Social Support (Winter, 2006), Workforce (Winter, 2008); and Youth Empowerment and Participation in Mental Health Care (Summer, 2009).

INTERNATIONAL DATA ON DISABILITIES

INTERNATIONAL CENTER FOR DISABILITY INFORMATION (ICDI)

www.icdi.wvu.edu/disability/tables.html

The International Center for Disability Information is a department of the College of Human Resources and Education at the West Virginia University that organizes disability data obtained from various sources and presents them in this link. The disability data are organized into various tables by US states, US totals, and for the world.

UNITED NATIONS DISABILITY STATISTICS

<http://unstats.un.org/unsd/demographic/sconcerns/disability/>

The UN Statistics Division Disability web page.

Reference guide to standards and methods:

<http://unstats.un.org/unsd/demographic/sconcerns/disability/disab3.htm>

Data on functioning and disability:

<http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp>

WORLD BANK

<http://www.worldbank.org>

The World Bank is a vital source of financial and technical assistance to developing countries around the world. We are not a bank in the common sense. We are made up of two unique development institutions owned by 186 member countries.

- *Beyond DALYs: Developing Indicators to Assess the Impact of Public Health Interventions on the Lives of People with Disabilities, May 2008*
<http://siteresources.worldbank.org/SOCIALPROTECTION/Resources/SP-Discussion-papers/Disability-DP/0815.pdf>
- *Measuring Disability Prevalence, 2007*
<http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf>

This paper reviews what is meant by disability and puts forth a way of measuring disability suitable for internationally comparable prevalence rates. The basic trend in this regard is to measure functional limitations, rather than disability, and then use different severity thresholds for defining disability based on the purpose of measurement.