Identifying Transition-Age Youth with Disabilities

The transition from youth to adult – and from home to independence - is difficult for many individuals, and youth with disabilities face even more challenges during this period due to issues with accessible environments, health care, and a change from youth to adult-based services. Programs that assist youth with disabilities during these transition years – defined here as ages 16 to 24 – are vital in ensuring their independence. Adequately identifying this population is important in order to assess needs and provide efficient and quality services.

According to a recent study issued by Mathematica Policy Research, a key problem in determining the issues that transition-age youth face is a lack of consistent data: surveys vary in the types of questions used to identify youth with disabilities. Due to this dearth of information, it is difficult not only to adequately identify the population, but also to determine how these youth are faring in transition.

Methods
The study reviewed twelve existing surveys related to disability and presented data from eight of those sources. While several issues make it difficult to consistently count the population of youth with disabilities, the primary challenge is that there is no singular definition of disability used among the surveys. Rather, each survey uses different definitions and asks different questions. The numbers, obviously, then differ depending on which definition is used. Another factor is that most surveys do not specifically target youth with disabilities.

The study presents a framework—defining physical, activity, and participation difficulties, and special need indicators—that can assist in understanding how a survey defines youth with disabilities and why surveys differ.

Changing Disability Definitions from Childhood to Adult
The disability questions that are applied to youth, particularly those who are over age 16, are the ones used for adults. This is an issue because definitions of disability for youth are different than those used for adults in areas such as the kinds of daily activities considered (work is generally used in adult definitions, whereas questions regarding

1 Todd Honeycutt and David Wittenburg, Identifying Transition-Age Youth With Disabilities Using Existing Surveys, Mathematica Policy Research, July 10, 2012. This study was supported by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, through its Rehabilitation Research and Training Center on Disability Statistics and Demographics grant to Hunter College.

2 Data sources are shown from the Survey of Income and Program Participation (SIPP), National Longitudinal Survey of Youth 1997 (NLSY97), American Community Survey (ACS), Current Population Survey (CPS), National Health Interview Survey (NHIS), National Survey of Children’s Health (NSCH), National Longitudinal Transition Survey 2 (NLTS2), and National Survey of SSI Children and Families (NSCF). Other data sources reviewed include the Medical Expenditure Panel Survey (MEPS), Panel Study of Income Dynamics (PSID), National Health and Nutrition Examination Survey (NHANES), and the National Survey of Children with Special Health Care Needs (NS-CSHCN).
school are generally more applicable to youth); certain conditions may be more common among youth than adults, such as learning disabilities and attention-deficit hyperactivity disorder; and youth may have specific needs or youth program indicators such as special education services and cash benefits from Social Security disability programs that differ from those for adults. Youth identified with these types of questions might therefore not be captured by adult definitions of disability.

Among surveys that do specifically target youth, some include statistics on transition-age youth with disabilities as part of the larger population, which allows for comparison of youth with and without disabilities. Others focus just on youth with disabilities and thus provide more in-depth information regarding characteristics or outcomes of a specific group, such as youth in special education programs. Some surveys track individuals over a period of time; others just consider one point in time. Each type of survey has its advantages and disadvantages.

**Prevalence Estimates Range**
The typical categories included in most surveys—physical conditions (sensory, physical, or mental difficulties), activities (difficulties in identified daily activities) and participation (difficulties related to functions such as doing errands or preparing meals; work; school; and other activities such as housework and play) identify only a subset of those with disabilities. As part of its proposed disability framework for youth, the study added special needs indicators (whether an individual participates in special education services or has a special health need), which generally captures a broader population, including those with less severe disabilities. For instance, an individual may participate in a special education program due to a learning disability, but with the proper supports does not experience other difficulties in daily living that would necessitate a response to the survey by the youth as having a disability. It is therefore clear that who is counted as having a disability in a survey depends on what definition is used and whether the definition includes mild, moderate, or severe disabilities.

The range in disability prevalence across surveys—anywhere from 5 to 34 percent of youth have a disability—is largely driven by differences in survey content, structure, and questions used to identify disability. Of particular importance to prevalence is whether a survey includes more youth-based definitions, such as participation issues in school. Some surveys—such as the American Community Survey (ACS), which has a disability prevalence of 5 percent—use very broad definitions and ask very limited questions that may not capture all youth with disabilities and so have lower prevalence rates. Including special education and disability income indicators in the Survey of Income and Program Participation (SIPP) survey data increases the proportion with disabilities from 11 to 14 percent, and the disability prevalence is as high as 34 percent in the National Survey of Children’s Health (NSCH) when including special education and special health need indicators.

Given these factors, and depending on the data need, it would be best to use multiple factors—physical, activity, and participation difficulties as well as special needs indicators—to identify youth with disabilities, and to consider functions that are applicable to transition-age youth—such as school, as opposed to work.

**Institutional Group Facilities**
The study found that most surveys do not include institutional group facilities, which is important because youth with disabilities make up a large proportion of those in
in institutional settings, mainly correctional facilities. Counting them is important and their overrepresentation in such facilities can have significant implications for programs and policies.

**Variance Among States**
The study also found a large difference in numbers across states. There is a threefold difference between the states with the highest rates of transition-age youth with disabilities and those with the lowest rates. This could be due to environmental factors, poverty, and the availability and quality of services provided.

**Conclusions**
These findings provide important guidance for future research. First, disability statistics for youth can vary across definitions, particularly whether a more youth or adult based set of concepts are available. Many of the adult definitions currently used in the literature, including the official disability estimates, do not capture people who might be considered having a disability as a youth because of differences between adult and youth measures (for example, a person with a learning disability). Because of differences between youth and adults, multiple and age-appropriate definitions should be used in identifying transition-age youth with disabilities. It would be useful to study the varied experiences of youth with different kinds of disabilities, and to examine their education and employment outcomes. This could provide valuable information to policymakers regarding programs for transition-age youth with disabilities and what works for different groups. It would also be useful to analyze data on at-risk behavior such as juvenile delinquency in order to determine whether and why youth with disabilities are overrepresented in institutional group settings such as correctional facilities, and how transition programs might reduce risky behavior. Studies should also compare the experiences of youth with disabilities to those of adults with disabilities in order to provide more insight and improve transitions to adulthood. Examining data and programs by state could provide insight into what services are available, which are effective, and which are needed. This research could, in turn, provide critical information for policymakers in determining how to best assist young people with disabilities in the transition from youth to adulthood.