

WorkingPAPER

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Transition Counts: Identifying Transition-Age Youth with Disabilities Using Public Surveys

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ABSTRACT

This paper provides a framework to categorize disability definitions for the purpose of interpreting disability prevalence estimates of transition-age youth (ages 16 to 24) with disabilities. We apply this framework to compare disability prevalence estimates within four disability definitions (impairment, activity limitation, participation limitation, and special needs/program indicators) across eight surveys. Prevalence estimates for transition-age youth vary based upon the number of disability questions asked, the inclusion of disability questions that capture disability severity status (low, moderate, or severe), the proportion of youth- versus adult-specific disability questions asked (such as special education versus work limitation), and the area of focus of the survey (health versus employment). The findings have important implications in examining disability statistics for young adults.

Keywords: transition-age youth, disability definitions, disability prevalence, special needs indicators

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I. INTRODUCTION

Many policies attempt to improve outcomes of transition-age youth (ages 16 to 24) with disabilities, though limited systematic information exists on their characteristics and outcomes. In part, this reflects the complexity of defining disability for this age group, particularly as youth move from school- to adult-based definitions of disability. But another challenge is that multiple data sources exist to track outcomes of youth, and the disability-related measures contained in these data sources vary. Hence, there is a need to develop a conceptual framework that can categorize disability prevalence measures so that disability prevalence, characteristics, and outcome statistics for youth with disabilities can be compared and interpreted across data sources.

This paper provides a conceptual framework for interpreting disability prevalence and identifying commonalities in disability definitions across eight publicly available and commonly used surveys. We first develop a framework for interpreting disability statistics based on a theoretical approach to disability. This approach includes four definitions used in previous literature to identify youth with disabilities. We then use that framework to calculate each survey's disability prevalence for the disability definitions and to compare the definition's prevalence estimate across each source.

Our findings illustrate that disability prevalence estimates for youth with disabilities are sensitive to the disability measures available in each survey (e.g., the types of questions available to identify disability status). One important issue is whether surveys include youth-based measures, such as limitations in school participation. For example, surveys limited to adult-based measures, such as work limitations, tend to produce lower estimates of disability prevalence than surveys that include youth-based measures. Our findings indicate that many people with youth-based reports of disability (such as limitation in school) do not report an adult-based measure of disability (such as limitation in work). Second, the number of questions available to measure disability in each survey has direct implications for prevalence. All else equal, surveys with more questions related to adult and/or child disability measures tend to have higher prevalence relative to surveys that include only a limited number of questions on these topics.

Differences in disability prevalence rates between child and adult measures are important because they reflect the challenges of defining disability as youth move from childhood to adulthood. Additionally, these differences have long-term implications in measuring adult disability status, given that many adults who had school-based limitations, such as learning disabilities, continue to have these disabilities as adults, even though the adult-based measures do not capture those limitations.

The rest of this paper is structured as follows. We begin by reviewing the disability content available in several major surveys used in the previous literature. We then summarize our analytical approach, including a framework to understand disability status using survey data. We use this framework to examine disability prevalence for each of our definitions and across eight data sources that vary substantially in disability content and target populations. We conclude by summarizing our findings.

II. BACKGROUND

Two challenges in summarizing statistics on youth with disabilities are the use of different definitions within a survey and a lack of consistent disability questions across surveys. Both issues lead to wide variations in prevalence estimates. A recent review of disability prevalence across 10 data sources for youth 18 years and younger found specific childhood disability rates ranging from 1 to 13%, depending on the source, the measure used, and the age range (Halfon, Houtrow, Larson, & Newacheck, 2012). Use of a narrow definition of disability can generate a low prevalence rate. For example, the prevalence rate of work limitations using data from the Survey of Income and Program Participation (SIPP) is approximately 3% for youth ages 18 to 24 (Wittenburg & Nelson, 2006). However, the prevalence rate triples (to about 9%) when disability status relies on an instrumental activities of daily living definition. Prevalence rates are especially sensitive to the inclusion of a youth's special health care needs, which represent a youth's ongoing need for more than routine services because of a health condition. For example, one study found that the prevalence of special health care needs for youth ages 12 to 17 was from 16 to 24% depending on the data source (Bethell, Read, Blumberg, & Newacheck, 2008), which is substantially higher than the prevalence estimates noted earlier.¹

Framework for Producing Disability Statistics

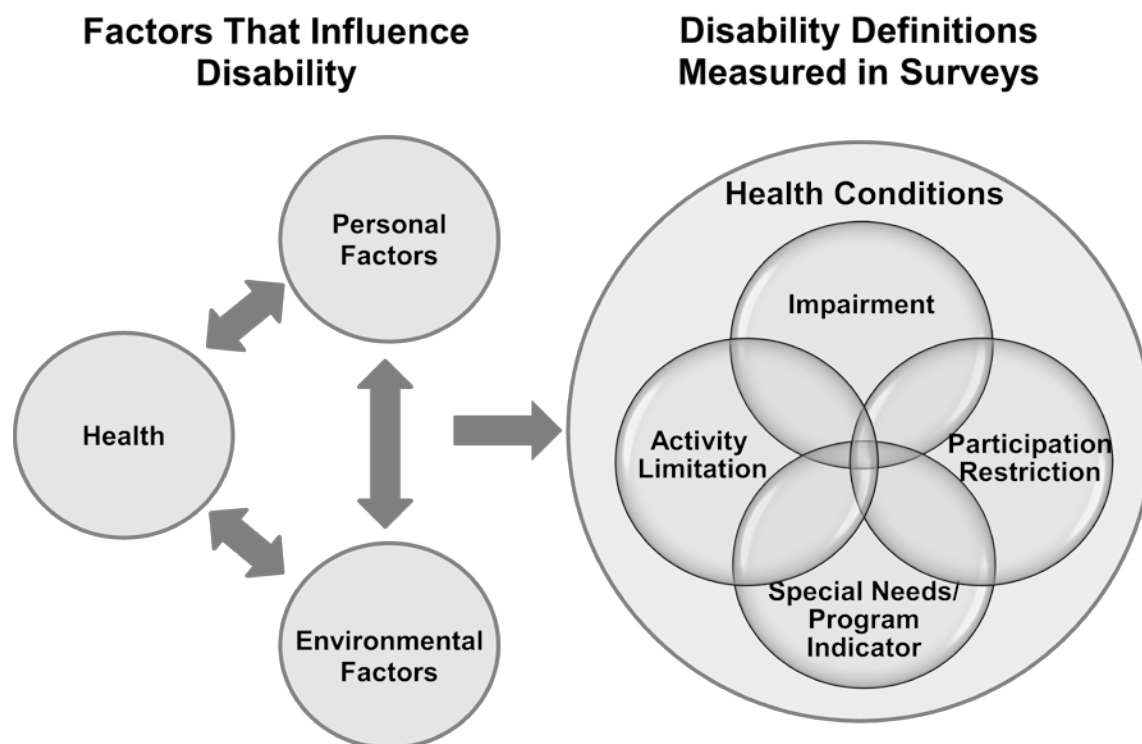
To conceptualize youth disability measures, we developed a framework that is consistent with the theoretical model of disability developed in the International Classification of Functioning, Disability and Health (ICF) model (Figure 1).² The ICF model posits that disability is a function of one's health, environment, and personal factors (see the left portion of Figure 1) (World Health Organization, 2001). Specifically, a health condition may result in a disability through an *impairment* that affects one's body structure or function, an *activity limitation* that affects one's ability to take care of oneself, or a *participation limitation* that affects one's ability to engage socially. We present prevalence rates for these three definitions, recognizing that many individuals might identify with one or more of them.

Though the framework attempts to closely follow the ICF model, we added a fourth definition, a special needs indicator that cuts across the other three definitions. The special needs indicator identifies whether a youth received a special service or support based on his or her disability. This fourth definition enables us to identify another dimension of disability status based on a need for service rather than a limitation. A major advantage of this addition is it helps us to identify an additional group of youth with service needs based on a set of questions asked in child health-related questionnaires.

¹ The two data sources included the National Survey of Children with Special Health Care Needs (NS-CSHCN) and Medical Expenditures Panel Survey (MEPS).

² This framework shares many similarities with the one recently developed by Halfon, Houtrow, Larson, and Newacheck (2012) to identify data collection needs to measure statistics for youth with disabilities. They defined *disability* as "an environmentally contextualized health-related limitation in a child's existing or emergent capacity to perform developmentally appropriate activities and participate, as desired in society" (p. 32). The definitions we propose here share similarities with the Halfon, Houtrow, Larson, and Newacheck (2012) definition, though ours seek to use current definitions based on specific survey concepts to examine the potential sources of variation across surveys.

Figure 1: Theoretical Model of Disability for Transition-Age Youth



Our disability framework includes the following definitions:

- *Impairment* captures whether a youth has a sensory, physical, mental, or other impairment.
- *Activity limitation* captures whether a person is limited in a daily self-care activity, such as eating.
- *Participation limitation* captures whether a youth has (1) a functional limitation, such as difficulty doing errands outside the home; (2) a work limitation; (3) a school limitation; or (4) other participation limitations, such as housework or play.
- *Special needs/program indicator* captures whether a youth has a specific health need (for example, use of a service) or participates in an education or income support program, such as special education or Supplemental Security Income (SSI).

This framework is similar to the one originally developed by Weathers (2009) to categorize disability statistics for adults, though we modified it to incorporate youth-specific conditions and youth special needs indicators to account for age-specific functioning issues (right side of Figure 1).

The major advantage of classifying the definitions this way is that we can compare disability prevalence rates both within and across surveys using a common framework. This framework enables us to compare how prevalence rates change based on both measure and data source.

Using this framework, we answer four research questions. First, how does disability prevalence vary within disability definitions? Answers to this question will demonstrate how

data sources vary in their prevalence rates and the reasons for that variation. Second, how does disability prevalence vary for youth with special needs indicators? Disability prevalence that includes or excludes youth with special needs indicators will have systematic variation in the population captured; answers to this question will document the types of youth who will be affected. Third, how does disability prevalence affect demographic and other characteristics? Disability definitions can influence the characteristics of youth included in the prevalence rates, with subsequent effects on results drawn from who is examined. Fourth, how do youth-specific disability definitions overlap with adult-specific definitions? To the extent that the two definitions capture unique youth, research that uses only adult-based measures might exclude a significant portion of youth with disabilities.

III. METHOD

We present prevalence estimates and selected characteristics from eight surveys.³ As a starting point, we selected the American Community Survey (ACS), Current Population Survey (CPS), National Health Interview Survey (NHIS), and SIPP, all of which have been commonly used to produce prevalence estimates for adults (see Weathers, 2009). We also included four data sources commonly used in studies of youth with and without disabilities: the 1997 National Longitudinal Survey of Youth (NLSY97), the second National Longitudinal Transition Study (NLTS-2), National Survey of SSI Children and Families (NSCF), and the National Survey of Children's Health (NSCH). For the NLSY97, we generated our own estimates for prevalence rates, whereas we used information from existing reports to generate estimates for the NHIS, NLTS-2, and NSCF (NHIS: Centers for Disease Control and Prevention, 2011; NLTS-2: Wagner et al., 2003a; Wagner et al., 2003b; Wagner, Newman, Cameto, & Levine, 2006; and NSCF: Wittenburg & Loprest, 2007). We made the decision to use statistics from these existing reports primarily because the available statistics were similar to those we would have produced ourselves for the analysis, though a secondary concern was maximizing the resources we had available.

As shown in Table 1, the type of disability content varies across surveys, which has important implications for disability prevalence. For example, the ACS includes a small set of questions on impairments for a wide age range (16–24), but lacks detailed information to construct other disability definitions, such as special needs. By comparison, the NSCH includes detailed questions that cut across all four concepts in our framework, but it covers youth only up to age 17.

Additionally, the periodicity of data collection varies by survey. For example, the NHIS includes several cross-sections that can be used to analyze historical trends, but it does not include longitudinal data to track outcomes, such as disability onset. Conversely, the NLSY97 tracks a longitudinal panel but does not allow for the tracking of trends across cohorts.

³ We also considered three other surveys: the MEPS, the Panel Study of Income Dynamics (PSID), and the National Health and Nutritional Expenditures Survey (NHANES). However, we did not include content from these surveys here because their samples of transition-age youth were either limited (PSID) and/or they included a limited set of information on specific outcomes (MEPS and NHANES).

Table 1. Advantages and Limitations of Publicly Available Surveys for Research on Transition-Age Youth with Disabilities

Survey	Advantages	Limitations
Longitudinal Surveys		
NLSY97	Detailed annual data for cohort of transition-age youth followed for multiple years, with general impairments and participations restriction questions for selected years	Disability and health questions limited to specific years
SIPP	Up to four years of data per person Detailed disability questions on general impairments, activity limitations, participation restrictions, and program indicators	Detailed disability questions asked only in some topical modules; information on program indicators undercount participation
Cross-Sectional Surveys		
ACS	State-level estimates Some questions on general impairments	Very limited information on transition-specific indicators, especially functional limitations, participation restrictions, and special needs indicators Limited information in areas other than employment and education
CPS	Official source for employment statistics for working-age adults with disabilities Recent addition of more detailed limitation questions that mirror ACS Detailed labor variables State-level estimates	Disability measures included work limitations only before June 2008
NHIS	Detailed impairment, activity limitation, and participation restriction questions State-level estimates	Limited employment and education indicators
NSCH	Official source of special health care needs Very detailed information on specific impairments, activity limitations, and participations restrictions State-level estimates	Limited to youth ages 17 and younger
Disability-Specific Surveys		
NLTS-2	Nine-year observation of special education students Large sample population	Limited to youth in special education No comparisons to youth without disabilities
NSCF	Large sample of SSI recipients Detailed information on youth receiving SSI not available from administrative data	No comparisons to youth without disabilities

We focus on youth ages 16 to 24, though for some surveys we are limited in producing estimates for all ages. For the CPS, SIPP, and ACS, we included youth in the full age range. For the NHIS, we restricted our analysis to published statistics on those ages 18 to 24.⁴ For the NLSY97, the available age range is 17 to 22, reflecting the ages of the sample available for a specific follow-up interview (wave 6) that included self-reported disability questions for young adults within our selected age range. Finally, we restricted our analysis to those younger than 18

⁴ The NHIS includes information on people of all ages, but the published results we used included statistics only for those 18 and older.

for child-specific surveys (the NSCH, NLTS-2, and NSCF).⁵ The years covered by the surveys range from 2001 to 2010, though when multiple years were available, we used the most recent one.

Using Framework to Interpret Disability Statistics

To compare prevalence estimates across these eight surveys, we matched the definitions of disability in our model to measures in each data source. For the *impairment* definition, we identified three categories: sensory (such as having difficulty seeing or hearing), physical (such as having difficulty walking or climbing stairs), and mental. We divided mental impairments into two groups: broad measures, such as having difficulty concentrating or remembering, and specific conditions, such as having a learning disability or depression. The *activity limitation* definition included activities of daily living, such as difficulty dressing, bathing, or moving around inside one's home. For *participation limitation*, we included several categories: functional limitations (such as difficulty going outside one's home, preparing meals, or taking medicine); having a work limitation; having a school limitation; and other limitations (such as making friends, doing housework, or participating in organized activities such as sports or clubs). Finally, for *special health needs*, we included four categories that have been used previously in the literature categories: (1) youth with special health care needs (based on five questions: needing more health care or education services than other children; taking medicine; being limited because of a health condition; receiving special therapy; and getting treatment for emotional, developmental, or behavioral problems); (2) youth receipt of special education services; (3) youth receipt of SSI benefits; and (4) youth receipt of Social Security Disability Insurance (SSDI) benefits. As we will show, this addition has important implications when comparing prevalence estimates across surveys.⁶ Tables showing the questions from each survey matched to the disability definition are available from the corresponding author.

For each disability definition and category, we show the prevalence rates at a point in time. For all results, we used weights to generate nationally representative estimates.

IV. RESULTS

Differences in National Estimates of Youth Disability Prevalence

We begin by comparing prevalence estimates of the four disability definitions (impairments, activity limitations, participation limitations, and special needs indicators) across six nationally representative surveys that collect information on youth with and without disabilities (Table 2).

⁵ The maximum age for youth in the NSCH is 17, so that the sample available includes only 16- and 17-year-olds. Because we use previously released reports for the NLTS-2 sample, we have disability data only for youth during the first wave of data collection (2002), when they were ages 13 to 17. The NSCF contains two age cohorts; we selected youth ages 13 to 17, corresponding to those who were SSI beneficiaries in December 2000 (Wittenburg & Loprest, 2007).

⁶ For example, many youth have asthma, but that condition need not result in disability if youth have access to the appropriate supports, such as inhalers. Similarly, youth receiving special education most commonly have learning disorders, which might not greatly interfere in activities or social interactions outside school.

Table 2. Disability Prevalence for Transition-Age Youth from Six National Surveys

	ACS	CPS	NHIS	NLSY97	SIPP	NSCH		
						Mild, Moderate, or Severe Impairment	Moderate or Severe Impairment	Severe Impairment
Population	Households and group quarters	Households	Households	Households	Households	Households	Households	Households
Age Range	16–24	16–24	18–24	17–22	16–24	16–17	16–17	16–17
Year	2009	2009–2010	2009	2002	2005	2007	2007	2007
Sample Size	342,511	51,270	Not available	7,888	11,483	13,672	13,672	13,672
Weighted Sample Size	39,021,000	37,735,000	Not available	19,364,000	36,612,000	8,460,231	8,460,231	8,460,231
Impairment								
Sensory	1.6 (±0.0)	0.9 (±0.1)	No data	10.6 (±0.6)	1.8 (±0.1)	5.7 (±0.3)	3.0 (±0.2)	1.2 (±0.2)
Physical	1.1 (±0.0)	0.7 (±0.1)	14.0 (±1.7)	12.6 (±0.7)	3.5 (±0.2)	14.2 (±0.5)	5.6 (±0.3)	1.5 (±0.2)
Mental (broad measure)	3.9 (±0.1)	2.5 (±0.2)	2.4 (±0.3)	5.3 (±0.4)	No data	6.6 (±0.4)	6.6 (±0.4)	6.6 (±0.4)
Mental (specific condition)	No data	No data	No data	No data	5.3 (±0.2)	17.8 (±0.5)	9.0 (±0.4)	2.5 (±0.2)
Activity Limitation	0.8 (±0.0)	0.5 (±0.1)	0.5 (±0.2)	No data	0.6 (±0.1)	4.2 (±0.4)	4.2 (±0.4)	4.2 (±0.4)
Participation Limitation								
Functional limitation	2.0 (±0.1)	1.1 (±0.1)	0.9 (±0.2)	2.5 (±0.3)	1.4 (±0.1)	No data	No data	No data
Work limitation	No data	2.7 (±0.2)	No data	No data	5.8 (±0.3)	No data	No data	No data
School limitation	No data	No data	No data	No data	8.0 ^a (±0.2)	3.4 (±0.3)	3.4 (±0.3)	3.4 (±0.3)
Housework limitation	No data	No data	No data	No data	2.0 (±0.1)	No data	No data	No data
Organized activities limitation	No data	No data	No data	No data	No data	4.9 (±0.3)	4.9 (±0.3)	4.9 (±0.3)
Make friends limitation	No data	No data	No data	No data	No data	2.6 (±0.2)	2.6 (±0.2)	2.6 (±0.2)
Special Needs/ Program Indicator								
Supplemental Security Income	0.9 (±0.0)	1.1 (±0.1)	No data	0.5 (±0.1) ^c	2.2 (±0.2)	No data	No data	No data
Social Security Disability Income	1.1 (±0.0)	0.6 (±0.1)	No data	No data	0.6 (±0.1)	No data	No data	No data
Special education	No data	No data	No data	No data	9.7 ^b (±0.5)	11.2 (±0.4)	11.2 (±0.4)	11.2 (±0.4)
Children with special health needs screener questions	No data	No data	No data	No data	No data	22.5 (±0.6)	22.5 (±0.6)	22.5 (±0.6)
Any Disability	6.3 (±0.1)	5.3 (±0.3)	Not available	24.0 (±0.9)	13.8 (±0.4)	34.4 (±0.7)	27.0 (±0.6)	23.5 (±0.6)

Table 2 (*continued*)

Note: Authors' calculations for ACS, 2009; CPS, 2009 and 2010; NSCH, 2007; NLSY97, wave 6; and SIPP, 2004, wave 5. NHIS estimates as reported in CDC 2011. Table shows prevalence of disability concepts across six surveys, with 90 percent margin of error estimates in parentheses. Margins of error less than 0.05 are shown as 0.0 due to rounding. Although similarities generally exist across surveys in the question asked about each concept, there is some significant variation in the severity of the concept for sensory and physical impairments. The NHIS and NLSY97 include very modest definitions of these impairments; other surveys use more severe restrictions to define these categories. These variations result in large prevalence differences across surveys and contribute to the particularly high prevalence rate of any disability from the NLSY97. Additionally, the SIPP generally includes more information across all concepts. Given these differences across surveys, caution should be used in making comparisons of "any disability" measures across surveys.

^a Youth ages 16 and 17 only.

^b Youth ages 16 to 19 only.

^c Household indicator of "other welfare," which includes SSI.

These surveys provide an important starting point because many studies compare the outcomes of those with and without disabilities.

Impairment. Prevalence rates of impairment varied substantially by survey, in part reflecting the number of questions available in each survey to capture this definition. The CPS and ACS include very general questions on impairment type (sensory, physical, and mental), which resulted in generally low prevalence estimates (less than 4% for any specific type of sensory, physical, or mental condition). The SIPP estimates had higher prevalence rates than the ACS and the CPS for physical impairments (3.5 vs. 1% in the other surveys), which likely reflects the larger battery of questions available to identify physical impairments in the SIPP (10 questions) compared with the ACS and CPS (only one question). In addition, the SIPP study asked about specific mental health conditions (such as having a learning or developmental disability) rather than using more general language. The NHIS, which used a similar battery of questions as the SIPP, had high prevalence rates for physical impairments. The higher prevalence rate in the NHIS relative to the SIPP is consistent with findings for adults. We speculate that health-related surveys, which focus respondents' attention on health questions, tend to result in respondents answering more affirmatively when asked about potential issues. Finally, results from the NLSY97 indicate that more than one in 10 youth ages 17 to 22 had a sensory or physical impairment. Unlike other surveys, the NLSY97 has questions that assess severity and allow youth who have mild limitations to report an impairment. For example, the NLSY97 asked about "ever having trouble seeing, hearing, or speaking," which reflects having difficulty at any time before the survey. By comparison, other surveys, such as the SIPP, ask whether an interviewee has a "serious difficulty" at the time of the survey.

The NSCH includes questions that enable researchers to assess the severity of impairment, though, as noted earlier, a limitation is that data are available only for youth younger than 18 (final three columns of Table 2). A major advantage of the NSCH is that it asks about specific conditions for sensory (hearing, vision, or speech problem); physical (such as asthma and diabetes); and mental (such as learning disability and depression) impairments, as well as the severity of each condition (mild, moderate, or severe). The first data column in Table 2 for the NSCH shows responses for having any condition; the rates for each condition are high when compared with the impairment rates from the ACS, CPS, and SIPP and closer to the NHIS (for physical impairments) and NLSY97 (for sensory and physical impairments). For example, 17.8% of youth reported any mental impairment and 14.2% reported any physical impairment. This high overall prevalence illustrates how broadly stated identifiers capture samples of youth who might have conditions that are not severe. However, the prevalence is attenuated when counting only moderate or severe impairments (the second NSCH data column) or when the definition is limited to severe impairments (the third NSCH data column). For example, only 2.5% of youth reported a severe mental impairment and only 1.5% reported a severe physical condition. The decision to use mild, moderate, or severe impairments for disability identification therefore has important implications for the youth who is counted as having an impairment.

Activity limitation. Activity limitations for youth were relatively rare, in part because they likely capture relatively severe physical functional limitations. Prevalence was consistently less than 1%, with the exception of the NSCH, which includes higher prevalence rates for all measures (4.2%). The generally low prevalence rates in all surveys indicate that relatively few youth have impairments that limit daily self-care activities.

Participation limitation. Estimates for functional limitations related to daily activities were generally low across all surveys (roughly 2%). The ACS, CPS, and NHIS had only one [related?] question (focused on going outside the home). Among the surveys with content on participation restrictions, the NLSY97 had the most questions related to participation restrictions, though prevalence was 2.5%.⁷

Two surveys (CPS and SIPP) included information on work limitations, which both had higher prevalence rates than the functional limitations definitions. Despite using similar wording, the prevalence of work limitations in the SIPP was higher than the CPS (5.8 vs. 2.7%). The relatively higher prevalence rate in the SIPP in comparison to the CPS is consistent with trends reported for older adults. Weathers (2009) speculated these higher rates might reflect the SIPP's heavier focus on disability-related content relative to the CPS, which might increase the likelihood of self-reported work limitations.

The SIPP and the NSCH included participation limitation questions related to school and housework. Perhaps not surprisingly, the prevalence rates for school limitations were higher relative to other participation restrictions. For example, the prevalence rate of school limitations for youth younger than 18 was 8% in the SIPP and 3% in the NSCH. Additionally, as with the other participation restriction questions, the prevalence of housework limitations was relatively limited in the SIPP for youth ages 16 to 17 (2%) and in the NSCH for a limitation in participation in sports, clubs, or other organized activities (5%) and a limitation in making friends (3%).

Special needs/program indicators. Four special needs/program indicators were included in the surveys listed in Table 2. The first category of program indicators—SSDI and SSI—capture the relatively narrow population of transition-age youth who receive these benefits. Relatively few youth—no more than 2%—reported receiving either SSI or SSDI regardless of the survey. Rates were somewhat higher for SSI than SSDI in most cases; this result is expected given that those younger than 18 will not have a sufficient work history to qualify for SSDI (although some might qualify for other reasons, such as being a dependent).

The prevalence of youth involved in special education was higher in comparison to the SSI and SSDI program definitions, and generally had similar prevalence rates in the two surveys that included special education questions. About one in 10 youth ages 16 to 19 had ever “received special education services,” according to the SIPP. The NSCH identified special education students as youth who had an individualized education program. At 11%, the prevalence rates in the NSCH for 16- to 17-year-olds were similar to the SIPP.

Finally, one survey—the NSCH—included several questions that identified whether a youth had a special health need or used a special service. A large proportion of youth (22.5%) had a special health care need based on these measures, reflecting the broad range of potential special

⁷ The NSCH had no questions addressing the functional limitation category. The NLSY97 included questions regarding whether sensory, physical, or mental impairments limited the ability of respondents to participate in activities. We identified those whose impairments limited their participation a lot as having a functional limitation. This approach to functional limitations with the NLSY97 is somewhat broad and vague and, hence, fewer individuals might have responded affirmatively to the more specific functional limitation question contained in other surveys.

health care needs and services. For instance, items that identify youth with special health care needs include taking medicine regularly; using health care more than other youth; and getting treatment or counseling for any kind of emotional, developmental, or behavioral problem. These measures can therefore capture a population not typically identified through traditional disability definitions (that is, impairment, activity limitations, and participation limitations) or capture a broader population that identifies as having a health need and has access to services.

Any disability. In the last row of Table 2, we estimated the proportion of youth who reported any of the four disability definitions, which shows how disability prevalence varies broadly across several measures. The overarching finding is that the surveys with more disability-related content not surprisingly produced higher prevalence rate estimates. The ACS and the CPS had the lowest overall disability prevalence rates among the data sources included in Table 2, which reflects their relatively limited set of measures corresponding to the various aspects of the disability definition framework. The overall disability prevalence for the ACS was slightly higher than that for the CPS (6.3 vs. 5.3%), largely because the prevalence rate of impairments was higher in the ACS. The SIPP estimates, at 13.8%, were more than twice as high as those from the ACS and CPS; the main drivers of this difference were the addition of school limitations, the higher proportion of youth reporting work limitations, and the inclusion of special education and disability income as special needs indicators. The overall disability prevalence from the NLSY97 exceeded that of the CPS, ACS, and the SIPP, with one in five transition-age youth having a disability; this frequency reflected the large number of youth reporting sensory and physical impairments with a very broad definition of severity. Finally, the prevalence rates from the NSCH ranged from 24 to 34%, depending on the level of impairment severity. The overall disability prevalence from this data source reflected the inclusion of special needs indicators, particularly children with special health needs.

Variation in Disability Definition Prevalence for Youth with Special Needs Indicators

In Table 3, we examine disability measures within two select groups of youth with disabilities, special education students and SSI youth from the NLTS and NSCF, respectively. Unlike the general population surveys, the disability prevalence rates in selected samples of youth with disabilities reflect characteristics of specific populations that meet a set of program criteria. The special education population (at 1.8 million youth) was much larger than the SSI population (at 192,000 youth), reflecting the differing eligibility requirements and target populations for these services. Both the SSI and special education samples included a large portion of youth with mental impairments, compared with special education students. However, not surprisingly, youth receiving SSI benefits had more severe disabilities, as noted by the higher prevalence of activity and functional limitations. For example, 26% of child SSI recipients reported an activity limitation; only 1.3% of special education youth did. Additionally, 91% of child SSI recipients reported a special health need (for example, help with routine needs). This finding is not unexpected given that the medical criteria that a youth must satisfy to become eligible for SSI distinguish these youth from others who might have reported some other limitation in a survey or who received special education services. Finally, the overlap between receipt of special education services and SSI was quite high. About one in eight special education students received SSI, and most SSI youth—about three in four—had been involved in special education.

Table 3. Disability Prevalence for Youth Younger than 18 with Special Education and SSI

	NLTS-2	NSCF
Population	Special education students	SSI recipients
Age Range	13–17	14–17
Year	2002	2001–2002
Sample Size	9,230	895
Weighted Sample Size	1,839,000	192,000
Impairment		
Sensory	6.0 (NA)	10.0 (NA) ^a
Physical	7.9 (NA)	14.3 (NA) ^a
Mental	86.3 (NA)	75.7 (NA) ^a
Activity Limitation	1.3 (±0.4)	25.7 (2.6)
Participation Limitation		
Functional limitation	8.1 (±1.3)	79.3 (±5.2) (age 17 only)
Work limitation	No data	No data
School limitation	No data	No data
Special Needs/Program Indicator		
Children with special health needs screener questions	No data	90.6 (±1.7)
Special education	100.0 (NA)	72.4 (±3.4)
Supplemental Security Income	13.3 (±1.1)	100.0 (NA)
Social Security Disability Income	No data	20.5 (±2.1) ^b
Any Disability	100.0 (NA)	100.0 (NA)

Note: NLTS-2 as reported in Wagner, Newman, Cameto, and Levine (2006) and Wagner et al. (2003a, b); NSCF as reported in Wittenburg and Loprest (2007). Table shows prevalence of disability concepts across two surveys, with 90 percent margin of error estimates in parentheses.

^a Diagnostic information not available in the public-use NSCF files. Data show diagnostic information from SSA administrative reports.

^b Household indicator of “other SSA benefits,” which could be SSDI, survivors, or retirement insurance for any household member.

NA = margin of error not applicable, because statistic is based on administrative data or categorical inclusion.

Disability Prevalence and Demographic or Other Characteristics

Perhaps not surprisingly given the difference in the prevalence of disability noted in Tables 1 through 3, there were key differences in demographic and other characteristics across disability definitions. Understanding these differences is important because they likely have strong effects on reporting a variety of outcomes, such as employment, for subgroups within the disability population.

Substantial variation in disability prevalence existed within demographic characteristics across the disability concepts, particularly in comparing the more general definitions (for example, participation restrictions) with the special needs definition (that is, SSI and special education) (Table 4). In general, the gender composition was evenly split for youth ages 16 to 24, youth with any impairment, and youth who reported work limitations. However, special education and SSI participants differed in that approximately two-thirds of both groups were male. Special education and SSI participants were also less likely to be white relative to the groups with impairments and work limitations. Table 4 also shows the distribution of impairment types for the various groups of youth. The prevalence of mental impairments was very high

among the general impairment group as well as in the two special needs groups (SSI and special education). However, fewer than half of youth with work limitations had a mental impairment, indicating that a survey that used questions only about work limitations might not capture those with mental disorders who are identified in other measures.

Table 4. Comparison of Selected Demographic and Impairment Characteristics of Youth, by Selected Disability Definition and Survey

	All Youth	Impairment	Participation Limitation	Special Needs/Program Indicator	
		Youth with Sensory, Physical, or Mental Impairments	Youth with a Work Limitation	Special Education Students	SSI Recipients
Source	SIPP	SIPP	SIPP	NLTS-2	NSCF
Age Range	16–24	16–24	16–24	13–17	14–17
Sample Size	11,483	1,046	705	9,230	895
Weighted Sample Size	36,612,000	3,099,000	2,121,000	1,838,848	191,759
Male	50.3	49.4	51.1	65.8	62.8
White	78.0	75.1	72.8	62.1	47.8
Impairment					
Sensory	1.8	21.6	18.5	6.0	10.0a
Physical	3.5	40.8	32.1	7.9	14.3 ^a
Mental	5.3	62.3	43.1	86.3	75.7 ^a

Note: Authors' calculations for SIPP 2004, wave 5. NLTS-2: as reported in Wagner et al. (2003a); NSCF: as reported in Wittenburg and Loprest (2007).

^a Diagnostic information is not available in the public-use NSCF files. Data show diagnostic information from SSA administrative reports.

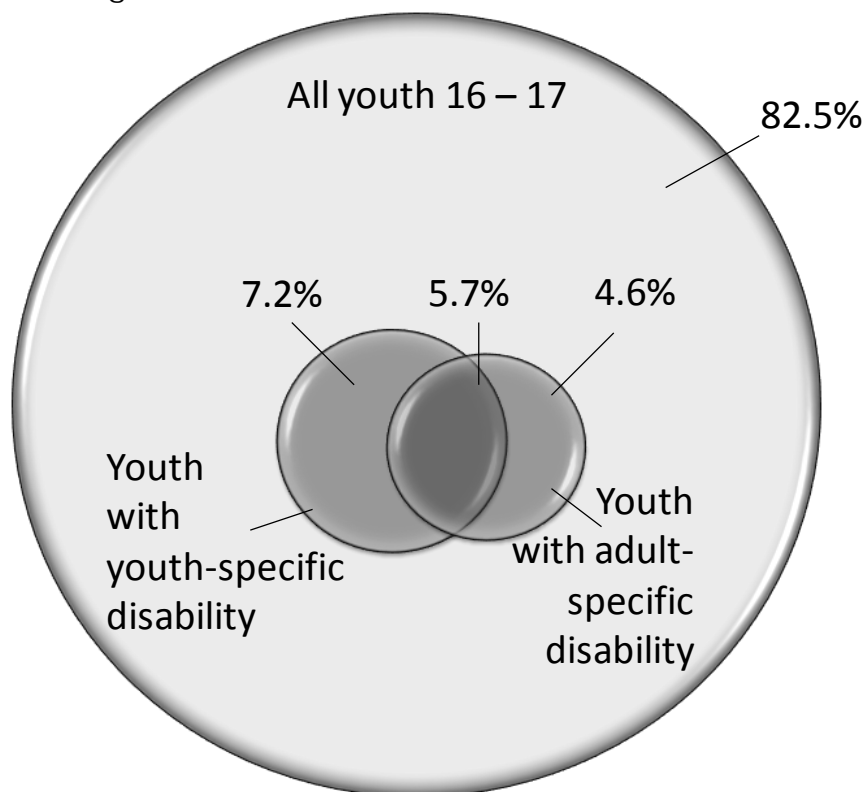
Comparison of Youth- and Adult-Specific Definitions

We mapped selected disability definitions in the SIPP for those age 16 to 17 to illustrate the overlaps across the definitions for youth and those for adults in one survey. We were particularly interested in mapping how school- and youth-based categories affected disability prevalence for transition-age youth because of the implications as they move into the years beyond high school. Presumably, youth with limitations in school might retain these limitations into adulthood when they enter work, but the limitations might no longer be measured. For this reason, we measured the interaction between these definitions before age 18, when we can observe impairment, work limitation, and school limitation interactions. In addition to being an important transitional overlap, impairments and work limitation definitions are commonly used in the literature to identify youth and adults with disabilities.

In Figure 2, we grouped conditions into adult- and youth-based criteria to illustrate their overlap. We defined adult-based criteria as those questions asked of everyone in our sample (that is, those older and younger than 18): a physical, sensory, or mental impairment; an activity limitation; and a participation restriction through either a functional limitation or a work

limitation.⁸ We defined a youth-specific definition as questions asked of those younger than 18: having a school limitation or ever receiving special education services. Overall, 17.5% of youth ages 16 and 17 had a disability under either a youth or adult definition; 10.3% had an adult-based disability and 12.9% had a youth-based disability. There was a 5.7 percentage point overlap in youth reporting both types of disability. Although our categories are not precise, the limited overlap illustrates the changing nature of how disability is viewed at this important transition point and underscores that transition-age statistics on youth are highly sensitive to the chosen disability measures. Further, it indicates that adult-based disability measures, as typically used in research, do not necessarily capture youth-based disabilities. As youth age, the focus on their limitations (such as school limitations) can change, particularly as they move into the workplace, but the youth-based issues might not go away. Hence, youth-related disabilities could often go unmeasured by studies that use certain adult-based definitions.

Figure 2: Prevalence of Youth- and Adult-Specific Disability Definitions Among Youth Ages 16 and 17, from the 2004 SIPP



Note: SIPP 2004, wave 5. N = 2,967 (all youth ages 16 and 17); 329 (youth ages 16 and 17 with any adult disability impairment); and 404 (youth ages 16 and 17 with any youth-specific disability). The larger circle represents youth ages 16 and 17. The small shaded circles show the overlap between youth with youth-specific disabilities (a school limitation or receipt of special education services) and youth with adult-criteria disabilities (impairment, activity limitation, participation limitation, or work limitation). The 7.2 percent estimate represents youth with youth-specific disabilities, but no adult-criteria disabilities. The 5.7 percent estimate represents youth with youth-specific and adult-criteria disabilities. Finally, the 4.6 percent estimate represents youth with adult-criteria disabilities only. The figure is drawn roughly to scale.

⁸ The SIPP impairment questions include categories such as sensory (such as difficulty seeing or hearing), physical (such as difficulty with walking or reaching), and mental (having a specific condition, such as a learning or intellectual disability, or any other mental health or emotional disorder).

V. DISCUSSION

In this paper, we presented a framework that can be used to organize and contrast disability measures of transition-age youth from public surveys. We used this framework to illustrate both the variation in prevalence rates across measures and surveys and the changes in those measures from youth to adulthood.

Before summarizing the results and their implications, we note two important caveats in using this framework. First, the questions used in each survey for each disability definition vary in their wording, which may drive part of the differences observed across surveys. We have identified key features of many of these differences (such as questions that ask about current condition versus ever having a condition), though survey design issues (for example, question wording and order of appearance in the survey) might still influence prevalence. Nonetheless, our framework presents an overarching approach to contrasting the measures and definitions across surveys. Second, we used age 18 as a demarcation between youth and adults, but this criterion is arbitrary, as many youth, particularly those with significant disabilities, can continue to be enrolled in secondary education until age 21. Surveys, however, typically use age 18 as the cutoff point for either their samples or the types of questions asked (the NSCH, for example, does not include anyone over 17 in its sample), thereby limiting the questions that can be included and compared across all ages of transition-age youth.

Disability prevalence varied across surveys, with higher rates generally in surveys that had more inclusive definitions of disability severity or more questions related to functional limitations. Although prevalence varied across definitions, disability definitions and categories overlapped substantially. Our findings are particularly sensitive to the inclusion of special needs or program indicators, such as special education enrollment and/or special health care needs indicators, from our disability framework. A challenge in measuring disability status for youth is that several surveys do not include information on special needs questions.

Disability prevalence changed substantially based on specific measures for adults (for example, work limitations) and youth (such as school limitations and learning disabilities). This change has important implications for measuring disability status as youth transition into adulthood. Presumably, a youth's childhood disability will remain, though most adult disability metrics would not capture childhood limitations. These differences also reflect the uniqueness of the youth's situation, which influences the higher overlap in measures that relate to age-specific activities, such as schooling (for example, school limitations and special education). For instance, youth with school limitations were more often involved in special education than were youth with work limitations, and youth with school limitations did not necessarily have limitations in other social spheres, such as work. In addition to affecting disability measurement in adult surveys, the differences for youth- and adult-specific definitions have implications for adult service access, as well. As youth with disabilities transition into adulthood, many of them find that they no longer meet the disability criteria for adult-based services, and so are at a disadvantage in obtaining supports that would benefit their social and economic situations. One example is with SSI, for which the disability definitions is different for those under and over age 18.

Our framework provides a new mechanism for interpreting the large differences in disability prevalence rates for alternative measures and data sources that are directly relevant for research

on transition-age youth. First, we show that prevalence rates for impairment and special needs indicators tend to be much higher relative to functional and activity limitation indicators for this population. Not including such measures in research on youth with disabilities could therefore bias the results presented on their activities and outcomes. Second, the choice of youth- or adult-based measures, particularly participation limitation measures, has important implications for who is observed as having a disability. Of particular importance is that many child-based definitions have limited overlaps with adult-based measures. Even though a youth might age into adulthood, presumably these childhood limitations persist. For example, a youth with a learning disability might not necessarily report a work limitation, though it is likely that having a learning disability has important implications for the youth's long-term opportunities in the labor market.

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