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Child and adult disability in the 2000 census: Disability is a household affair

Carrie L. Shandra, Ph.D.^{a,*}, Roger C. Avery, Ph.D.^b, Dennis P. Hogan, Ph.D.^b, and Michael E. Msall, M.D.^c

^aHofstra University, Department of Sociology, Hempstead NY 11749, United States

^bBrown University, Population Studies and Training Center, Providence RI 02912, United States

^cUniversity of Chicago, Pritzker School of Medicine, JP Kennedy Research Center on Intellectual and Developmental Disabilities, Section of Developmental and Behavioral Pediatrics, Comer and LaRabida Children's Hospitals, Chicago IL 60637, United States

Abstract

Background—Survey data indicate that individuals with disabilities in the United States often experience less advantageous economic and social resources than individuals without disabilities. Furthermore, they often reside with other individuals with disabilities in the same household. However, less is known about resource availability when multiple child and adult household members have a disability.

Objective—We use child-level data from the 2000 Census to examine the relationship between aggregation of disability in households with children and education, labor force participation, poverty level, and inadequate housing.

Methods—We utilize tabular analysis and Kruskal–Wallis tests to examine how resources in education, employment, income, and housing adequacy compare for children with disabilities who are the only member of their household with a disability, children with disabilities who live in a household with at least one other member with a disability, children without disabilities who live in a household where no other member has a disability, and children without disabilities who live in a household where at least one other member has a disability.

Results—Among children without a disability, 86% live in a household in which no other member has a disability. Among children with a disability, 53% live in a household in which no other adult or child has a disability. Poverty, inadequate housing, and low adult education were more two times more likely – and adult unemployment over five times more likely – in households with multiple members with disability versus households without disability.

Conclusion—There is a high prevalence of aggregation of adults and children with disability in households of children with disability. These households have substantially fewer resources than households who do not have disabilities.

Keywords

Child disability; Adult disability; Households; Health disparities; Children with special health care needs

Introduction

A recent fact sheet published by the United Nations called persons with disabilities “the world’s largest minority.”¹ In the United States, the latest *Americans with Disabilities* report² using Survey of Income and Program Participation data estimates 18.7% of the civilian noninstitutionalized population has some level of disability. As individuals with disabilities often experience less advantageous health,³ economic,^{4,5} and educational² outcomes, understanding the prevalence of disability at the population level is crucial for addressing social disparities and quantifying service and support needs.⁶

However, most of the population-based literature examines social disparities between persons with and without disabilities at the individual level – despite evidence that nine percent of families in the United States have multiple members with disabilities, and that the likelihood of living in poverty increases with the number of members with a disability.⁷ The challenges faced by households with multiple members with disabilities are consequential for children, as childhood poverty and social disadvantages are factors that adversely relate to children’s health, development, and educational well-being.^{8–10} Children with disabilities may be particularly affected by living in an underprivileged household, as they often require greater care needs and incur significantly higher average health expenditures than children without disabilities.¹¹ In sum, it is important to understand how the aggregation of disability at the household level affects children’s access to household-level resources – especially if a child also has a disability.

Our purpose was to address two questions that were underdeveloped in prior research studies: 1) Among households with children ages 5–17 years, what percentage of children with and without disability in motor, sensory-communicative, and/or self-care skills live in households with other children or adults with disabilities? 2) How do household resources in education, employment, income, and housing adequacy compare between children with disability who do not live with other children or adults with a disability compared to those who do live with another household member with a disability? Such descriptive findings involving a large representative U.S. population will contribute to our knowledge of household resources for child development and highlight the additional supports required for children with disabilities.

Data and methods

The 2000 Census of the United States was specifically designed to reflect not only traditional measures of household composition, housing, and economic well-being, but was also the only census with questions about child, as well as adult, disability in functioning.¹² This information is included in the Census’ long form, which was administered to roughly 1 out of every 6 housing units in the United States. While the full population data is not made publicly available to protect confidentiality, a 5% sample is available from this long-form data as the Integrated Public Use Microdata Series (IPUMS).¹³ These data reflect a 1-in-20 national random sample of the population and are weighted to take into account nonresponse and the differential probability of selection of households in rural versus urban areas.

We define disability as an area in which a child or adult has functional limitations in mobility, sensory-communicative, and self-care daily living skills compared to peers.^{14–16}

These questions are asked only of household members ages 5 and older in the 2000 Census; therefore we restrict our sample to children ages 5–17 and adults ages 18 and over. In this study, adult disability is characterized using the same functional disability questions asked of children. We utilize data from all children in the sample, and weight the final analysis such that it is representative of all children ages 5–17 living in households with an adult in the United States in the year 2000. Therefore, this is a child-level analysis representing children's experiences with household resources by the aggregation of disability among other household members.^d

The 2000 Census offers a unique opportunity to examine the relationship between disability prevalence and household resources because it is the last decennial Census to utilize the long form. The long form was essentially replaced in 2005 by the American Community Survey (ACS), and while this shift in data collection techniques now provides data annually, it also comes with a significant reduction in the number of annually sampled individuals and a corresponding increase in the sampling error.¹⁷ The ACS is not a “point in time” survey like the decennial census and therefore does not provide a snapshot of the United States Population in a given year. Instead, data are released as one-year, three-year, and five-year period estimates – with five-year estimates providing the greatest statistical reliability for small population subgroups. Our child-level analysis of disability aggregation requires accurate estimates of small populations, as less than 3% of children experience several of the combinations of child and household disability presented in Fig. 1. Changes to the disability items in the ACS between 2002–2003 and again in 2007–2008 prevent full comparability of annually pooled measures required for multiyear estimates.^{18,19} Therefore, the most precise estimates of disability subpopulations in the ACS can be attained when the wording and structure of the disability questionnaire becomes consistent with future releases of multi-year period estimates.

Disability

In the 2000 Census of the United States, three survey questions addressed the disability status of children ages 5 and older and adults. The first focused on sensory-communicative functioning and queried: “Does this person have any of the following long-lasting conditions: Blindness, deafness, or a severe vision or hearing impairment?” The second focused on motor functioning and asked, “Does this person have any of the following long-lasting conditions: A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?” The third question focused on self-care functioning and asked, “Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: dressing, bathing, or getting around inside the house?” It is important to note that the design of the census questions on disability in motor, sensory-communicative, and self-care functioning does not allow attribution to specific etiological diagnosis, the proportion of persons receiving federal aid specifically for disability, or validation of census respondent reports.^e

^dChild-level data is advantageous for understanding child-level phenomena. While this means that some households are represented more than once in the analysis, overall results are robust when examining similar analyzes at the household level. Household resources are less advantageous in households where either an adult or a child has a disability – when compared to households without disability. Households with both child disability and adult disability have the least advantageous household resources. Results are available from the first author upon request.

^eThe goal of this study is to provide child-level estimates of the relationship between household resource constraint and disability aggregation. While we recognize that different combinations of child and adult disability are likely to be associated with different household resource constraints (as implied by the household-level analyzes discussed in note 1), an examination of those other combinations would require further disaggregation of the sample to control for family composition (and ideally, school enrollment for children and employment status and work disability for adults). This is a lucrative avenue for future research, but it is not the objective of this study.

Household resources

To assess the aggregation of disability in the household, we first examine the presence of disability impacting on functioning in mobility, sensory-communicative, or self care skills in children ages 5–17. We define aggregation of disability as the presence of additional child (aged 5–17) or adult (aged 18 or older) disability among other people living in the same household. A household's social resources are measured by the highest level of educational attainment of adults in the household (less than high school, high school graduate or GED/some college, and at least a college degree) and the highest level of employment among parents and the household head (none, part time, 35 or more hours per week). Measures of economic resources are indicated by level of household income (income of less than the poverty level, 1–3 times the poverty level, and higher than three times the poverty level) as well as quality of housing. More specifically, a household is defined as “inadequate” if it is substandard on any one of the housing quality indicators, including crowding (if the number of persons per room in the house, apartment, or mobile home is greater than or equal to 1.5, with rooms not counting bathrooms, porches, balconies, foyers, halls, or half-rooms per the Census questionnaire), the presence of a separate kitchen (“Do you have complete kitchen facilities in this house, apartment, or mobile home; that is, 1) a sink with piped water, 2) a range or stove, and 3) a refrigerator”), working plumbing (“Do you have complete plumbing facilities in this house, apartment, or mobile home; that is, 1) hot and cold piped water, 2) a flush toilet, and 3) a bathtub or shower”), and telephone access (“Is there telephone service available in this house, apartment, or mobile home from which you can both make and receive calls?”). In 2000, the federal poverty level (FPL) for a family with 1 adult and 1 child was \$11,250, 1 adult and two children was \$14,150, and 2 adults and 2 children was \$17,050.²⁰ In examining the resources for a household, it is useful to consider three times the FPL as a definition of a living wage to raise children and to meet needs for housing, transportation, health insurance, and basic expenses.²¹

Analysis

Tabular analysis of census data was used to address two questions: 1) Among households with children ages 5–17 years, what percentage of children with and without disability in motor, sensory-communicative, and/or self-care skills live in households with other children or adults with disabilities? 2) How do resources in education, employment, income, and housing adequacy compare between children with disability who do not live with other children or adults with a disability compared to those who do live with another household member with a disability? We utilize the Kruskal–Wallis test to compare the social and economic resources of four types of children's households: (a) children without disability who live in a household without other persons (children or adults) with disability, (b) children without disability who live in a household with another person with a disability, (c) children with disability who live in a household without another person with a disability, and (d) children with disability who live in a household with another person with a disability. Kruskal–Wallis is a non-parametric statistical test that can compare ordinal-level variables among two or more independent samples.²² All results shown are statistically significant at $p < .001$. After using the Census-provided person weights, the total number of children represented in the analysis is 52,784,357; of these, 37,491,015 live in households with another child aged 5–17 and 15,293,342 live in households where they are the only child aged 5–17.

Results

Fig. 1 displays the prevalence of child disability in all households with more than one child aged 5–17. The categories of “other child disability”, “adult disability”, and “child and adult disability in the household” are not mutually exclusive in order to provide estimates of

overall disability prevalence (for example, children who live in households with both child and adult disability will also be counted in the “other child disability” and “adult disability” categories). Among children *without* disability living in a household that includes at least one other child ages 5–17, 14.3% live in a household where at least one other member has a disability (Fig. 1). In contrast, among children *with* a disability, 46.8% live in a household where another adult or child has a disability. The likelihood of children living with an adult with a disability is 2.9 (36.0% vs. 12.6%) times higher among children with a disability compared to children without a disability. Children with disability are also 8.6 times more likely (25.5% vs. 3.0%) to live in a household in which another child has a disability. However, the greatest difference between children with a disability and children without a disability lies in the percentage of children who live with both an adult and another child with a disability (14.7% vs. 0.9%), a likelihood that is over 16 times greater for children with a disability than for children without disability.

Fig. 2 displays the prevalence of child disability in households with only one child age 5–17. These results also demonstrate that adult disability occurs significantly more frequently when a child has a disability. Over 14.2% of these children without a disability live with an adult with a disability. In contrast, 37.6% of these children with a disability live with an adult with disability.

Table 1 compares the highest level of adult educational attainment in all households with children (using all children from Figs. 1 and 2) by the child’s disability status and by the disability status of all other household members. In households without any children or adults with disability, 1 in 3 (32.4%) have an adult who is a college graduate. In contrast, among households where both children and other household members have a disability, only 13.3% live in a household with an adult who is a college graduate and 1 in 4 (24.7%) live in a household where all adults have less than a high school education. In every comparison, children growing up in households in which another member has a disability have significantly less access to adult postsecondary education, regardless of their own disability status.

Table 2 presents results for the highest level of adult labor force participation in the household, an indicator of access to additional information and contacts the household can use to increase its social resources, as well as access to a job that may provide health insurance coverage. In almost 90% of households where a child does not have a disability and no other household members have a disability, there is at least one adult (parent or household head) who works full-time. This number is somewhat lower (82.9%) for children with disabilities in households where no other members have a disability. However, only two-thirds (65.1%) of households with a child *and* another member with a disability have a full-time adult wage-earner. In these households the likelihood that an adult will not be working at all is more than 5 times greater (25%) than in households without child or adult disability (4.8%). Our data highlight that, for many children with disability, health insurance through full-time employment of an adult care-giver may not be an option.

Table 3 compares the poverty status of the households of children with and without disability in functioning by the disability status of other household members. Children with disabilities in functioning are much more likely to live in a household in poverty. Strikingly, among children with disabilities living in a household with another household member with a disability, 37.9% reside in poverty and only 17.8% reside in a household that enjoys economic security (i.e., greater than 3 times the federal poverty level). This compares to children without disabilities who reside in households without any child or adult disability, in which 14.3% experience poverty and 44.1% experience economic security.

Table 4 compares the adequacy of housing (including crowding, the presence of a separate kitchen, working plumbing, and telephone access) for children by their disability status and the disability status of others in their household. When no other person in the household has a disability, child disability status does not alter a child's risk for experiencing inadequate housing. Specifically, 11% of children without disability live in households with inadequate housing versus 14.4% of children with disability. However, children are more likely to live in inadequate housing when they live with another household member with a disability. Among children who live with another household member with a disability, 18.2% of children without disability and one-quarter (25.1%) of those with disability reside in inadequate housing. These data suggest children living in households where another member has a disability have less access than children living in households where another member does not have a disability to environments that may prevent the chance of illness, injury, and developmental delay. Our data also support that access to adequate housing is a significant problem when both the child and another household member has a disability.

Discussion

The purpose of this study was to address two questions that were underdeveloped in prior research: 1) Among households with children ages 5–17 years, what percentage of children with and without disability in motor, sensory-communicative, and/or self-care skills live in households with other children or adults with disabilities? 2) How do household resources in education, employment, income, and housing adequacy compare between children with disability who do not live with other children or adults with a disability compared to those who do live with another household member with a disability? Our analyses utilize nationally representative data of the U.S. population to provide a greater understanding of the household resources available to children with disabilities.

Results from the examination of our first question demonstrate that there is a disproportionately higher prevalence of adult and child disability in households with a child who has a disability. Results from the examination of our second question demonstrate that a higher occurrence of disability is associated with less advantageous household resources.

This study is unique in focusing on child-level experiences and considering households as contexts for child development. The strengths of our analysis are the large population available through the 2000 United States Census and our ability to standardize the indicators of functional limitations for both children and adults.

Our study provides clear evidence for the aggregation of child and adult disabilities in households in the United States. This study builds on previous research that used survey methods to measure disability among children and adults.^{5,23–25} These studies were able to link measures of disability status to children and adult's mental health, as well as to children's school attendance, and use of medical and rehabilitative resources. We also add to existing literature that suggests disability is clustered in families⁷ and that parents with disabilities are more likely than parents without disabilities to have children with disabilities.²⁶ Despite its prevalence, this phenomenon is typically unrecognized in the current literature on the experiences of children with disabilities.

Our study also extends research that suggests children with disabilities disproportionately encounter poverty, inadequate housing, and live in households with adult unemployment²³ by demonstrating that household resource constraint increases with the number of household members with disabilities. These constraints are particularly consequential given the financial liability associated with having a disability in the United States. Children with disabilities incur significantly higher average health expenditures than children without

disabilities,¹¹ and the combination of disability and poverty is doubly deleterious for a household's financial security. For example, analysis of the Medical Expenditure Panel Survey indicates that total medical expenses comprise 91% of income for families below the poverty line with at least one member with chronic disease. This compares with 61% for families below the poverty line without chronic disease and 8% for financially secure families with chronic disease.²⁷ Our results reveal that households with multiple disabilities have fewer social resources in addition to their lower financial resources. This is particularly detrimental for children with disabilities, as advantages such as adequate housing and access to education^{28,29} protect against health disparities.

These findings have major implications for applied researchers, health professionals, and policy makers. When a physician or another health care specialist, special education specialist, or other professional who administers programs that provide assistance to families encounters a child with disability, it is also important to consider the disability status of the child's household members.

One important consideration involves health insurance coverage in households with lower levels of employment. Specifically, children with disabilities disproportionately live with adults who do not participate in full time paid work and therefore will not have access to private health insurance through an employer. Prior to the current economic downturn, access to SCHIP or Medicaid waivers was especially important for families working part time and having a child with disability.³⁰ These programs are additionally important during periods of economic downturn when employment opportunities and job security are even more sporadic. Research on previous economic downturns suggests that federal support is important in maintaining access to these programs.³¹ Even in early 2008 – before the current financial crisis – thirteen states facing balanced budget requirements and other fiscal pressures had proposed Medicaid and SCHIP cuts.³² Restriction of CHIP enrollment could further exacerbate gaps in health care coverage.

Another important consideration is that parents of children with disabilities face higher caretaking demands,^{33,34} which are negatively associated with parental employment.^{35,36} Parents of children with disabilities often face unpredictable care needs and must coordinate complex medical obligations – both of which are often incompatible with traditional employment schedules.³⁷ These constraints may be compounded when multiple householders have disabilities. More generous family support systems for the coordination of care^{38,39} and more generous work-family supports such as schedule control and family-care policies^{40,41} are necessary to address these challenges.

Lastly, the combination of poverty, unemployment, and inadequate housing in households in which both children and adults have disabilities may make these households vulnerable to homelessness.⁴² These results are reflective of the period prior to the housing foreclosure crisis; however, current economic conditions may further challenge the housing security of households with children with disabilities. A 2006 analysis of homeowners in California, Florida, Illinois and New Jersey suggests that medical disruptions – including illness or injury, unmanageable medical bills, lost work due to a medical problem, or caring for sick family members – were a major contributor to mortgage default.⁴³ More recently, results from the 2007 and 2009 Panel Study of Income Dynamics⁴⁴ indicate that adults with work disabilities were more likely than those without work disabilities to experience a mortgage default – net of demographic, socioeconomic, and mortgage characteristics. Less is known about the relationship between a child's disability and housing distress; however, these studies call attention to the broader implications of disability on financial and social well-being. It is imperative that housing assistance be available and accessible to households with disability. However, greater financial protection via reduction of medical costs and an

increase in employment flexibility are likely to buffer struggling households before housing situations become precarious.

There are several limitations to our study. First, our indicators cannot account for learning and behavioral disability in children or adults. These domains of functioning cannot be easily captured in one or two survey questions across all developmental stages of the school-age or the adult population. Second, our data do not include medically diagnostic reports of etiology or the supports and services required for disability management. This would require linking of data to electronic medical records and a methodology for collecting information about services and supports across health, education, and social service providers. This is not the goal of the Census. Finally, our results focus on the experiences of children with and without disability in all households, and do not further disaggregate households to examine resource constraint where the second person with a disability is a child versus an adult. We recognize that these children may experience different household situations. Future research should consider how different combinations of disability aggregation affect resource constraint across different types of households.

In conclusion, our study indicates that children with disabilities in functioning disproportionately experience home situations characterized by more limited household resources than children without disabilities. They disproportionately lack adequate housing. Furthermore, children with disabilities have less access to adults with full-time employment and thus are less likely to access private and supplemental health insurance. This research demonstrates that child disability needs to be considered in context with other household members' limiting conditions and socioeconomic constraints.

If the United States is to achieve its goal of lessening health disparities in children, more coordination and delivery of resources will be necessary to address the functional challenges and barriers to participation among children with disabilities. Implementing a child safety net for comprehensive health, housing, transportation, education, and income support is required to help all children, especially those with disability in functioning.^{44,46} Furthermore, interventions which decrease the socioeconomic constraints associated with the aggregation of disability in households may also be crucial for reducing health disparities.

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Fig. 1.

Child disability in households with other children. ^a Source: 2000 Census of the United States; weighted. ^b Does not add to 100% because some households have both other children and adults with disability. ^c Number of children without a disability: 36659998. Number of children with disability: 831017.

Fig. 2.

Child disability in households without other children. ^a Source: 2000 Census of the United States; weighted. ^b Number of children without a disability: 14939540. Number of children with disability: 353802.

Table 1

Highest level of adult education by disability status.

	Less than high school	High school	College	Percent of children	Number of children
<i>Children without a disability</i>					
No other person with a disability in the household	9.64	58.01	32.35	100	44095109
Other person with a disability in the household	15.26	65.32	19.43	100	7504429
<i>Children with a disability</i>					
No other person with a disability in the household	14.66	62.54	22.80	100	663118
Other person with a disability in the household	24.71	61.98	13.31	100	521701

^aSource: 2000 Census of the United States; weighted.

^bData shown are percentages unless otherwise indicated.

Table 2

Labor force participation by disability status.

	None	Part-time	Full-time	Percent of children	Number of children
<i>Children without a disability</i>					
No other person with a disability in the household	4.76	5.39	89.85	100	44095109
Other person with a disability in the household	18.18	8.11	73.30	100	7504429
<i>Children with a disability</i>					
No other person with a disability in the household	9.28	7.85	82.86	100	663118
Other person with a disability in the household	24.95	10.00	65.06	100	521701

^aSource: 2000 Census of the United States; weighted.

^bData shown are percentages unless otherwise indicated.

Table 3

Poverty level by disability status.

	Below FPL	1–3 times FPL	Greater than 3 times FPL	Percent of children	Number of children
<i>Children without a disability</i>					
No other person with a disability in the household	14.32	41.57	44.11	100	44095109
Other person with a disability in the household	26.06	46.76	27.18	100	7504429
<i>Children with a disability</i>					
No other person with a disability in the household	22.78	45.31	31.92	100	663118
Other person with a disability in the household	37.85	44.32	17.83	100	521701

^aSource: 2000 Census of the United States; weighted.^bData shown are percentages unless otherwise indicated.

Table 4

Inadequate housing by disability status.

	Inadequate housing	Adequate housing	Percent of children	Number of children
<i>Children without a disability</i>				
No other person with a disability in the household	10.99	89.01	100	44095109
Other person with a disability in the household	18.23	81.77	100	7504429
<i>Children with a disability</i>				
No other person with a disability in the household	14.37	85.63	100	663118
Other person with a disability in the household	25.14	74.86	100	521701

^aSource: 2000 Census of the United States; weighted.^bData shown are percentages unless otherwise indicated.