

**Cover Page**

**A Systematic Review of US Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000**

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This paper is a review of published research and does not involve new research on human subjects.

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For Blinded Review

**A Systematic Review of US Studies on the Prevalence of Intellectual or Developmental  
Disabilities Since 2000**

Key Words: Prevalence, Intellectual Disability, Developmental Disability

**Abstract**

This systematic review examined 14 US studies published since 2000 reporting prevalence estimates for intellectual disability (ID) or developmental disability (DD). Prevalence rates for children were between 11.0 and 13.4 per 1,000 for ID and between 45.8 and 69.9 per 1,000 for DD using data from 2010 or later. A 2015 Ohio study of adults yielded a prevalence estimate of 41.0 per 1,000 for DD. The only study of ID in adults and the only study incorporating DD Act definitions used the 1994/1995 NHIS-D yielding prevalence estimates for ID and/or DD of 38.2 per 1,000 for children birth to 5 years, 31.7 for children 6 to 18 years, and 7.9 per 1,000 for adults. Notable differences in prevalence estimates by age and operational definition have important implications for public policy and research. Serious surveillance gaps limit our understanding of service utilization rates, unmet needs, and health and other outcomes for adults with ID or DD.

### **Introduction**

Accurate and timely data on the prevalence of intellectual and/or developmental disability (IDD) and on the characteristics of people with IDD are needed to estimate utilization rates and unmet need for supports and services and to inform research and federal and state disability policy (Bonardi & Lauer, 2011; Havercamp, Krahn, Larson, et al., 2019; Krahn, Walker, & Correa-De Araujo, 2015). Few systematic efforts to understand IDD prevalence across the lifespan exist in the United States (Anderson, et al, 2013; Emerson, Felce & Stancliffe, 2013; Fujiura, Rutkowski-Kmitta, & Owen, 2010; Havercamp, Krahn, & Larson, et al., 2019; Krahn, Fox, Campbell, Ramon & Jesien, 2010). Prevalence estimates must be updated regularly to account for changes in US demographics, advancements in diagnostic practices and medical interventions, and increases in the prevalence of conditions such as ASD. The lack of ongoing nationally representative data collection efforts supporting the identification of adult sample members with ID, DD or related conditions severely limit public health surveillance monitoring for that population (e.g., Piven & Rabins, 2011).

### **Prevalence Study Methodologies**

Several different methodological approaches are used in prevalence studies, each with different foci, strengths, and weaknesses. Common approaches include population-based surveys, public health surveillance, and review of administrative data sets.

***U.S. Population-based Surveys.*** The Center for Disease Control and Prevention (CDC)'s National Center for Health Statistics fields several recurring nationally representative surveys including the *National Health Interview Survey* (NHIS), the *National Health and Nutrition Examination Survey*, the *National Survey of Family Growth*, and the Maternal and Child Health Bureau's *National Survey of Children's Health (NSCH)* among others. The United States Census

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Bureau also fields the annual *American Community Survey* (ACS). These surveys are representative of the US noninstitutionalized population and use consistent sampling, data collection, and management practices across locations and over time. These national surveys include the 50 states and the District of Columbia with the exception of the ACS, which also includes Puerto Rico but exclude the other US territories. They exclude some populations. For example, the NHIS excludes active duty military and people living in institutional group quarters such as nursing homes and other long-term services and supports (LTSS) settings. Annual samples, though large and representative, may not include enough people with relatively uncommon conditions such as ID and DD to allow reliable analyses of those conditions. This limitation can be overcome by combining data from multiple waves or years of data collection.

Several national population-based surveys ask about disabilities. The NHIS and NSCH surveys ask parents if children have conditions such as ID, autism spectrum disorder (ASD) or developmental delays. While earlier versions of the NHIS and the SIPP asked adults if they had IDD or if IDD was the cause of specific limitations, those questions have been dropped from current surveys. The ACS, NHIS, *Survey of Income and Program Participation* (SIPP), and *Current Population Survey* (CPS) ask adults if they have limitations in seeing, hearing, walking or climbing steps, remembering or concentrating, self-care or communicating (understanding or being understood) (Washington Group on Disability Statistics, 2015; US Census Bureau, 2018). However, these questions are not specific enough to differentiate between adults with IDD and those with other conditions. Cognitive limitations causing difficulty remembering, concentrating or making decisions could be caused by a host of conditions other than ID including but not limited to dementia, mental illness or medical conditions for which the treatment causes cognitive side effects. In survey research, disability status is typically determined based on self-

or proxy-reports which may be less reliable than clinical records (Emerson, Felce & Stancliffe, 2013), and which may result in underreporting of stigmatizing conditions.

**Public Health Surveillance.** Public health surveillance is the continuous, systematic collection, analysis, and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice (World Health Organization, 2018). The Autism and Developmental Disabilities Monitoring Network (ADDM) provides annual estimates of the prevalence of Autism Spectrum Disorder (ASD) amongst 4-, 8-, and 16-year-old children in 11 states (Arenson, et al., 2009; CDC, 2017a). Collaborating sites review clinical health and, in some cases, educational records to identify children with ASD and in some cases ID or cerebral palsy. Abstractors use a shared protocol to identify children. However, while this strategy is precise, children with incomplete records, whose disabilities have not been documented or who are not receiving services may be missed. ADDM sites that review both health and educational records report higher prevalence rates than those reviewing only health records (Baio, et al., 2018). Public health surveillance efforts such as ADDM are expensive and limited in geographic scope, which can reduce the generalizability of the findings.

**Administrative Data.** Federal agencies such as the Centers for Medicare and Medicaid, the Social Security Administration (SSI and SSDI), and the Department of Vocational Rehabilitation; and other entities (e.g., insurers) collect administrative data for the purposes of monitoring, reimbursing or regulating funded health or other services (Ward, 2013). Medicaid administrative data can be used to generate treated prevalence estimates for people receiving LTSS through state IDD agencies (e.g., Larson, et al., 2018), and to estimate employment rates for adults with IDD (e.g., Winsor, et al., 2018). Administrative records have also been used to select random samples of service recipients to survey (e.g., the Medicare *Current Beneficiary*

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*Survey*, the Social Security Administration's *National Beneficiary Survey*). Secondary analyses of administrative data sets can be useful to describe service populations and may be less costly than new data collection efforts. However, administrative data are subject to data-entry and coding errors and variations in service utilization across different geographic areas or age groups (Anderson, et al., 2013; Emerson & Glover, 2012; Fujiura, 2003; Ward, 2013). Furthermore, they only include people who participate in or receive services and are not representative of the US population as a whole.

As an example, prevalence estimates for adults (Larson et al., 2001) and children (Zablotsky et al., 2017) were combined with data on the people served by state IDD agencies and the US Bureau of the Census population estimates to estimate that only 17% of people with IDD (1.23 million of an estimated 7.3 million) received services through state IDD agencies in 2016 (Larson et al., 2018). State IDD agencies served 11% of the estimated 5.1 million children with IDD and 41% of the estimated 2.1 million adults with IDD (Larson, 2019). These age differences reflect higher prevalence estimates for children, and higher utilization of state IDD services by adults versus children who have access to a free appropriate public education and may not access (or be eligible for) services through state IDD agencies until they reach adulthood.

### **Identifying People with IDD**

While the phrase “intellectual and developmental disabilities” is commonly used and suggests a singular population, ID and DD have different operational definitions that are not wholly congruent (e.g., Larson, et al., 2001). People can have one condition without having both conditions.

***Intellectual Disability*** is characterized by significant limitations in intellectual functioning and in adaptive behavior evident before the age of 18 years (Schalock, et al, 2010).

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Limitations in intellectual functioning are operationalized as having an IQ of 70 or lower.

Limitations in adaptive behavior occur in activities of daily living such as self-care; instrumental activities of daily living such as shopping, literacy or numeracy; and social and interpersonal skills. Diagnostic criteria for ID are promulgated in the American Association on Intellectual and Developmental Disabilities' *Intellectual Disability: Definition, classification, and systems of support* (Schalock et al., 2010), the American Psychiatric Association's (2013) *Diagnostic and Statistical Manual of Mental Disorder*, and the World Health Organization's (2019) *International Classification of Diseases (ICD-11)*. For health surveillance, people with ID can be identified via direct assessment, self- or proxy-reports, or administrative records documenting the condition(s) treated in a health care encounter or documenting the basis of service eligibility.

***Developmental Disabilities*** are identified in policy and practice based on the presence of and severity of functional limitations. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act; P.L. 106-402) defines DD as a severe, chronic disability manifested before age 22 resulting from mental and/or physical impairments which are likely to continue indefinitely. Substantial functional limitations must be present in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living or economic self-sufficiency. Individuals must need "a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated (14 STAT. 1684)." Children ages 9 years or younger who have "a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria ... if the individual, without

services and supports, has a high probability of meeting those criteria later in life (14 STAT. 1684).”

Eligibility criteria for educational, health or long-term supports and services may use condition-based (e.g., the person has ID or a “related condition” such as Autism Spectrum Disorder or ASD) or functional limitation-based (e.g., based on the DD Act) definitions or a combination of both. The most commonly reported related conditions amongst NHIS-D sample members with ID or DD were cerebral palsy (CP), epilepsy, spina bifida (SB), and ASD (Larson et al., 2001). Eligibility categories for special education include conditions such as ID and ASD, as well as developmental delay for children ages 9 years or younger (as specified in the DD Act).

Of 47 state IDD agencies surveyed in 2008, 16 (34%) based eligibility for services on having ID or a “related condition” (often in conjunction with needing a certain level of supports), while 31 (61%) based eligibility on the number, type and/or severity extent of functional limitations (Zaharia & Moseley, 2008). Of those 31 states, eight defined eligibility based on DD Act criteria while the others used state-specific definitions. The most common conditions mentioned in eligibility criteria were a cognitive or intellectual disability (ID); cerebral palsy (CP); epilepsy; Prader-Willi syndrome; autism, autism spectrum, Asperger’s syndrome or pervasive developmental delay (now ASD); SB, fetal alcohol syndrome, and traumatic brain injury.

This review examines US studies published since 2000 (the year the DD Act and Amendments were last reauthorized) that report prevalence estimates for ID or DD. Research questions include:

- How many people in the United States have ID or DD?

- To what extent do prevalence estimates for ID and DD vary by age and race/ethnicity?

### **Methodology**

The authors worked with a University of Minnesota Biomedical librarian to identify search terms for a review of electronic bibliographic databases (MEDLINE, EMBASE, PsycINFO, and CINAHL) for 2000 through 2018. Search terms included intellectual disabilities, intellectual disability, developmental disabilities, developmental disability, mental retardation [archaic], prevalence, incidence, and epidemiolog\*. Prevalence studies collected by study authors for other projects were also screened.

Studies were abstracted using a modified Joanna Briggs Institute (JBI) Data Extraction Form, which is particularly suited for prevalence studies (Munn, Moola, Lisy, & Rittano, 2014). Data elements abstracted included author name, publication year, article and journal title, disability type, age, study type, sample size, and reported prevalence rate by age and race/ethnicity. Studies were evaluated based on the presence of clear criteria for identifying IDD, sound methodology, and appropriate statistical analyses. For each study, the inclusion/exclusion decision, reason for exclusion, comments, review name, and final inclusion decision were recorded.

Interrater agreement for inclusion/exclusion decisions was tested for 111 articles including 40 articles nominated for inclusion and 71 articles nominated for exclusion. Two authors agreed on 104 studies and disagreed on seven studies in the initial round of reviews. Disagreements were resolved through discussion and the inclusion criteria were clarified.

### **Inclusion Criteria**

To be included, studies must have been published between 2000 and 2018, written in English, and published either in a peer-reviewed journal or by or for a governmental agency. The study had to describe prevalence rates for ID or DD in adults, children or both. Though we did not specifically include search terms for conditions closely related to ID, the search parameters picked up several studies reporting prevalence rates for ASD, CP or Down syndrome.

### **Exclusion Criteria**

Studies of co-occurring conditions in people with IDD such as mental health diagnoses, or other mental or physical conditions were excluded. Also excluded were studies describing the rate of IDD amongst people with other conditions (e.g., studies on rates of ID in children with congenital heart disease). Studies on the prevalence of visual and hearing impairments, traumatic brain injuries, ADHD, or learning disabilities were excluded unless they also reported prevalence rates for ID or DD.

The abstracts of 1,304 articles, including 365 from Pubmed, 362 from Embase, 334 from Psycinfo, 183 from CINAHL, and 14 identified by the study authors, were screened for possible inclusion (See Figure 1). Articles were excluded based on title or abstract if the article did not describe prevalence rates for ID or DD in the US population leaving 111 non-duplicative articles. Based on a review of the full text of those articles by two authors (Anderson & MapelLentz), an additional 98 articles not meeting the inclusion criteria were eliminated. The 40 remaining studies were reviewed and their inclusion was confirmed by the other two authors (Larson & Hall-Lande). This article focuses on the 13 articles reporting prevalence rates for ID or DD identified by the systematic review process. An additional 27 articles reporting prevalence rates for conditions closely related to IDD were also identified (ASD, 16 studies, DS, 5 studies, and CP, 6 studies) but were excluded because the search terms did not specifically include those

conditions. A reviewer of this manuscript identified one additional prevalence study which was added to the 13 identified via the search process resulting in a total of 14 articles.

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Insert Figure 1 about here

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### Results

Fourteen studies published between 2000 and 2018 reported prevalence rates for ID, DD or both (See Table 1). Table 1 lists the last name of the first author, publication year, article title, journal or publication source, disability type, year(s) of data collected, participant age, study type, geographic region, and prevalence rates. Articles are sorted by study type and data year. Prevalence estimates were converted to rates per 1,000 to facilitate comparisons across studies. The studies reported findings from national (7 studies), or state (2 studies) surveys of randomly selected households, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP; 2 studies), administrative records of live births and IDD service recipients (1 study), US Department of Education special education administrative data (1 study) or a national survey of a random sample of Social Security disability recipients (1 study).

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Insert Table 1 about here

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#### Prevalence Rates for Children

Of the 11 studies of children, seven used the NHIS, NSCH, or the *Ohio Medicaid Assessment Survey* (OMAS; RTI, 2015). Four different versions of the NHIS were used (1994/1995 NHIS-D, 1997-2008 NHIS, 2011–2013 NHIS, and 2014-2016 NHIS). Since the studies used different operational definitions of disability and age groupings, prevalence estimates vary and are not directly comparable.

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Two studies used the 1994/1995 NHIS-D (Simpson, Cope & Greenspan, 2003 and Larson et al., 2001). Prevalence estimates for DD in children ages birth to 5 years were 33 per 1,000 for “functional delays” and 34 per 1,000 for “general delays” (Simpson, et al., 2003). Prevalence for children ages birth to 5 years for ID was 4.5 per 1,000 and for ID and/or DD was 38.4 per 1,000 (Larson et al., 2001). Prevalence estimates for children ages 6 to 17 years were 20.3 per 1,000 for ID and 31.7 for ID and/or DD (Larson et al., 2001).

One study using the 1997-2008 NHIS reported prevalence estimates for ID of 5.9 per 1,000 for children 3 to 10 years and 8.4 per 1,000 for children 11 to 17 years (Boyle, et al., 2011). In that study, prevalence estimates for DD (defined as ID, CP, ASD, seizures, stuttering or stammering, moderate to profound hearing loss, blindness, learning disorders and/or other developmental delays) were 117.8 per 1,000 for children ages 3 to 10 years and 162.4 per 1,000 for children ages 11 to 17 years. Prevalence estimates for DD in children ages 3 to 17 years increased significantly from 128.4 to 150.0 per 1,000 between 1997 and 2008 (Boyle, et al., 2011).

Two studies used the 2011 through 2013 NHIS. One study reported prevalence rates for children ages 2 to 17 years of 12.1 per 1,000 for ID (Maenner, et al., 2016). The other reported prevalence rates for children ages 3 to 17 years of 12.7 per 1,000 for ID and 48.4 per 1,000 for other developmental delay (defined as ASD, Down syndrome, CP, muscular dystrophy, cystic fibrosis, sickle cell anemia, diabetes, arthritis, congenital heart condition, and other heart conditions; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). In the 2011 to 2013 NHIS, ASD was subsumed within the category “other developmental delay”. For the 2014 NHIS, a separate question about Autism Spectrum Disorder (ASD) was inserted before the question on “other developmental delay” (Zablotsky, et al., 2015). Between 2014 and 2016, prevalence

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estimates increased from 11.0 to 11.4 per 1,000 for ID, from 35.7 to 45.5 per 1,000 for other DD (excluding ID and ASD), and from 57.6 to 69.9 per 1,000 for ID, ASD or other DD (Zablotsky, Black & Blumberg, 2017).

Six other studies reported prevalence rates for children. One using the 2011 to 2013 NSCH reported prevalence estimates of 12.2 per 1,000 for ID (Maenner et al., 2016). A study using the *Ohio Medicaid Assessment Survey* reported prevalence estimates of 41.0 per 1,000 for DD (defined categorically; Yang, McAdams, Havercamp, & Andridge, 2016a). Prevalence estimates from the Metropolitan Atlanta Developmental Disabilities Surveillance Program for ID in children were 12.0 per 1,000 for 1996 through 2000 (Bhasin, Brockson, Avchen & Braun, 2006) and 13.0 per 1,000 for 1991 through 2010 (Van Naarden Braun, et al., 2015). The number of public school students in the United States receiving categorical special education services for ID decreased from 11.2 per 1,000 in 1999 to 8.57 per 1,000 in 2008 (Larson & Lakin, 2010). Finally, a study of children using birth records and administrative data from California's *Client Development Evaluation Report* (CDER) reported prevalence estimates dropping from 2.88 to 1.95 per 1,000 between 1987 and 1994 for ID of unknown cause (children with ID resulting from chromosomal abnormalities, congenital infections, metabolic or endocrine disorders, accidents or injuries, diseases, anomalies or neoplasms were not counted; Croen, Grether, Hoodstrate, & Selvin, 2001).

### **Studies of Adults or All Ages**

Two studies reported prevalence rates for people of all ages using the 1994/1995 NHIS. One used a categorical definition of ID and a functional definition of DD (based on criteria from the DD Act of 1994) to estimate prevalence rates for people of all ages of 7.8 per 1,000 for ID only, 11.3 per 1,000 for DD only, and 14.6 per 1,000 for ID, DD or both (Larson et al., 2001).

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The other used a categorical definition of ID, and a functional definition of mild intellectual disabilities (defined as an activity limitation or need for formal programmatic supports due to generalized difficulty in learning or the presence of a specific learning disability) to estimate that 12.1 per 1,000 for people of all ages with ID or mild intellectual disabilities (Fujiura, 2003).

One study reported an administrative prevalence rate for ID of 137 per 1,000 within a national sample of Social Security Income or Social Security Disability Income recipients (Livermore, 2017). Two studies reported prevalence rates for adults based on data representative of the general household population. In the NHIS-D study, prevalence estimates for adults were 5.2 per 1,000 for ID, and 7.9 per 1,000 for ID and/or DD in 1994/1995 (Larson et al., 2001). In the OMAS study, the prevalence of DD in adults (defined categorically) was estimated to be 41.0 per 1,000 in 2015 (Yang, Havercamp, & Andridge, 2016b).

### **Prevalence Rates by Race and Ethnicity**

Eight papers reported prevalence rates by race/ethnicity for groups of children with disabilities (See Table 2). None reported prevalence estimates by race/ethnicity for adults. Six studies tested race/ethnicity differences for statistical significance. No significant race/ethnicity differences were detected in three of the studies. One study reported lower prevalence rates for ID in children who were white or other than in children who were black. Two studies reported lower prevalence rates for ID for children who were non-Hispanic white than for children who were non-Hispanic black. Two studies reported prevalence rates for DD by race/ethnicity. One did not test differences for statistical significance. The other reported no differences in the prevalence of functional delays or general delays once gender, age, family structure, poverty level, and parental education were considered (Simpson, Colpe & Greenspan, 2003).

### **Discussion**

Commenting on discrepancies in prevalence estimates available to Congress in 1990, Senator Durenberger said, “This is crazy, that we have this kind of wide variance in our estimates. We ... [need to] look for ways to measure who those people are and where they are so that we can best suit policy to their need” (S. HRG 101-847, p. 3 cited in Larson et al., 2001). Unfortunately, we have made only uneven progress toward this goal in the intervening years. Several recurring national population-based surveys include questions on ID in children from which prevalence estimates are regularly published. However, none currently asks those questions of adults. The 2015 OMAS survey asked about DD categorically for children and or adults. The most recent survey supporting the identification of children or adults with DD using the DD Act definition of DD was the NHIS-D. No national surveys allow identification of DD based on the 2000 DD Act definition.

#### **Differences by Year**

Three studies compared prevalence rates across time for children. In one study, the prevalence of ID (with or without ASD) decreased from 3.14 to 2.44 per 1,000 between 1987 and 1994 (Croen et al., 2002). The second noted a drop in special education students receiving categorical services for ID from 11.2 per 1,000 in 1999 to 5.57 per 1,000 in 2008 (the number receiving categorical services for ASD increased substantially; Larson & Lakin, 2010). Two NHIS studies reported prevalence estimates for ID in children ranging from 11.0 to 13.4 per 1,000 between 2011 and 2016, and for any DD (ID, ASD plus other developmental delays) increasing from 57.6 to 69.9 per 1,000 between 2014 and 2016 (Zablotsky et al., 2017). Despite increasing rates of DD and ASD in children (e.g., MacFarlane & Kanaya, 2009; Zablotsky, et al., 2017; and Van Naarden Braun, et al., 2015), prevalence estimates for ID and DD in adults cannot

be examined in any of the ongoing national population-based surveys leading researchers to call for increased surveillance across the lifespan (Rice et al., 2012).

### **Differences by Age**

Three studies reported prevalence estimates for people in different age groups. One NHIS reported prevalence rates for ID of 5.9 per 1,000 for children ages 3 to 10 years and 8.4 per 1,000 for children 11 to 17 years (Boyle et al., 2011). An NHIS-D study estimated the combined prevalence for ID and/or DD to be 38.4 per 1,000 for children ages birth to 5 years, and 31.7 per 1,000 for ages 6 to 17 years, but only 7.8 per 1,000 for adults (Larson et al., 2001). The same study estimated prevalence rates for ID to be 4.5 per 1,000 for children 0 to 5 years, 20.3 per 1,000 for children 6 to 17 years, and 5.2 per 1,000 for adults. Finally, the prevalence rates for DD in the 2015 OMAS survey were estimated to be 45.8 for children and 41.0 for adults (Yang, et al., 2016a; Yang, et al., 2016b). Lower prevalence estimates for children than for adults in both the NHIS-D and OMAS studies may have reflected, in part a reluctance amongst adults to report having an ID or DD (Tymchuk, Lakin & Luckasson, 2001), or different response patterns for adults who self-reported than for children or adults who had a proxy respondent.

### **Differences by Race or Ethnicity**

Only eight of the thirteen studies on ID or DD reported on race/ethnicity differences (compared to 24 of 27 studies on ASD, CP or Down syndrome). Statistically significant differences by race and/or ethnicity were reported for three of the eight studies, with lower prevalence rates for ID reported for white children than for black children. Five studies reported no differences among children of different race/ethnic backgrounds. None of the studies of IDD or related conditions reported race/ethnicity difference amongst adults. Future prevalence studies should report on race/ethnicity differences for ID and DD in people of all ages.

**Other Comparisons across Studies**

Prevalence estimates for ID in children vary. Prevalence estimates based on birth records and administrative data in California (Croen, et al., 2002) were the lowest by far. The study based on US Department of Education child count data reported prevalence rates of 8.57 per 1,000 for children receiving categorical special education services for ID in 2008 (Larson & Lakin, 2010). Higher but more consistent prevalence estimates for ID in children ages 2 or 3 to 17 years ranging from 11.0 and 13.4 per 1,000 were reported in studies using the 2011 through 2016 NHIS or NSCH (Maenner, et al., 2016; Zablotsky et al., 2015; and Zablotsky et al., 2017). Similar prevalence estimates for 8-year-old children (12.0 and 13.0 per 1,000) were reported in the MADDSP surveillance studies (Bhasin et al., 2006 and Van Naarden Braun, et al., 2015). The convergence of rates across these five studies suggests that the current prevalence of ID in children is between 11.0 and 13.4 per 1,000.

The administrative prevalence of ID amongst working-age adult Social Security Income or Social Security Disability Income recipients (137 per 1,000, Livermore et al., 2017) was dramatically higher than the estimated prevalence of ID in adults in the US general population (5.2 per 1,000, Larson et al., 2001). Prevalence rates for DD in the 2015 OMAS study (41.0 per 1,000) were higher than the estimates for DD and/or ID for adults in the NHIS-D study (7.9 per 1,000). The higher administrative prevalence rate from Social Security's *National Beneficiary Survey* is expected since only the sample frame included only current Social Security recipients. Differences between the OMAS and NHIS-D survey are also not surprising considering that the OMAS survey used a categorical definition for DD while NHIS-D study used the more specific and restrictive DD Act functional limitations criteria. Differences are also likely due in part to differences in the date (the OMAS survey was fielded 20 years after the NHIS-D) and the studies

used different sample frames (Ohio for OMAS versus U.S. noninstitutionalized civilian population for the NHIS-D).

### **Practical Implications and Future Directions**

The health and well-being of the general U.S. population is regularly monitored through national surveys such as the NHIS. However, adults with IDD cannot be easily identified in those surveys (Kats, Payne, Parlier & Piven, 2013). Ensuring that adults with IDD can be identified will support research essential for program planning, tracking health disparities and monitoring other national health goals. The aging of the U.S. population, changing diagnostic practices and prevalence rates for children and continued unmet demand for services/supports across the lifespan make prevalence an important public health issue for people with IDD of all ages (Larson et al., 2018; Piven & Rabins, 2011).

Clear disparities exist in what is known about the prevalence of ID, DD, and related conditions. The literature is much more robust for children than for adults and for ASD than for ID, DD or other related conditions. Remediating these disparities will require changing current national population-based health surveillance surveys to include questions allowing identification of adults with ID and ASD, and of people of all ages with DD as defined by the DD Act of 2000.

Federal investments are needed to fund ongoing research on the prevalence of DD, ID and related conditions such as ASD across the lifespan, characteristics of people with IDD, service utilization and unmet needs for this population. Research is also needed to describe how the increased prevalence of ASD in children may be affecting prevalence rates for ASD, ID, and DD in adults. It is time to remedy the disparity in federal population surveys between the general US populations, people with disabilities generally, and people with ID or DD specifically.

## IDD Prevalence

Both creators of and users of research on prevalence should be aware of how age, race and ethnicity, study type, and operational definition of disability affect prevalence estimates. When prevalence estimates are reported, details about the study methodology, data year, and operational definition must be reported, and differences by age, race, and ethnicity should be tested for statistical significance. Repeated administrations of the same survey are needed to ensure adequate sample sizes to study IDD, and to examine variations in prevalence rates across the lifespan, and especially at important life transitions (entering school, transition from school to adulthood, and transition from employment to retirement).

As federal and state policies and legislation are drafted or reauthorized, careful attention is needed to ensure that eligibility criteria and population definitions are described in ways that can be translated into operational definitions for research and evaluation studies on the impact of those policies. For example, while the DD Act lists seven categories of functional limitations and requires that a person have significant limitations in three of the categories, not all of the categories are equally relevant to young children, youth and adults (e.g., limitations in independent living - such as cooking, cleaning and shopping are much more relevant for adults than for children). In addition, some categories correspond to well-established measures (e.g., self-care can be operationally defined as activities of daily living, which is routinely assessed in national health surveillance programs) while others such as limitations in self-direction are much more difficult to operationally define, particularly in survey research.

### **Study Limitations**

This systematic review examined the prevalence of ID and DD in the US. While 27 additional studies on the prevalence of ASD, CP, and DS were identified, we did not include them because we did not specifically search for those conditions. We also excluded studies

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describing the characteristics of service recipients with ID, DD and ASD (e.g., Hewitt et al., 2017; McDermott et al., 2018; Ticha, et al., 2013), examining characteristics, health status and comorbidities (e.g., Cooper et al., 2015; Fortuna et al., 2016; Traci, Seekins, Szali-Petree & Ravesloot, 2002; Tybor, et al., 2018) reporting prevalence rates in other countries (e.g., Brugha, et al., 2011), or published after this review was prepared (e.g., Phillips, Houtenville & Reichard, 2018). While we pointed out the difference in prevalence rates that may be associated with variation in inclusion criteria or operational definition, participant age, and study type, we did not use statistical tests to examine those differences. Further, some of the studies that reported differences across groups did not test those differences for statistical significance.

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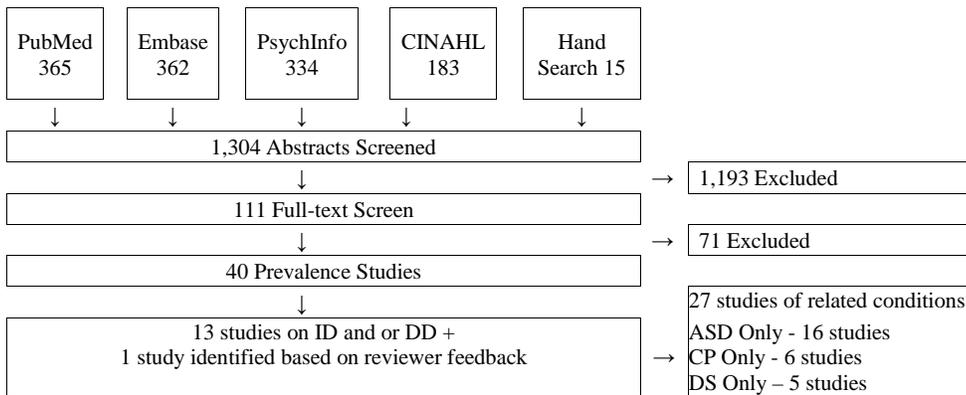
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**Figure 1 Flow Chart for Systematic Review of Prevalence of Intellectual or Developmental Disability  
Source and Number of Articles Identified**



IDD Prevalence

| Table 1 Prevalence Studies Reporting Rates for Intellectual Disabilities, Developmental Disabilities or Both since 2000 |      |  |  |                                 |              |  |                            |                  |                   |   |
|---|------|--|--|---------------------------------|--------------|--|----------------------------|------------------|-------------------|---|
| First Author  | Year | Article Title  | Journal                                | Disability                      | Data Year(s) | Age  | Data Source                | Sample Size      | Geographic Region | Prevalence (per 1,000) <sup>1</sup>   |
| <b>Household Surveys</b>  |      |  |  |                                 |              |  |                            |                  |                   |   |
| Simpson   | 2003 | Measuring functional developmental delay in infants and young children: prevalence rates from the NHIS-D.  | Pediatric Perinatal Epidemiology       | Developmental Delay             | 1994-1995    | 4-59 months  | National Survey (NHIS-D)   | 15,291           | National          | 33.0 Functional Delays<br>34.0 General Delays   |
| Fujiura   | 2003 | Continuum of Intellectual Disability: Demographic Evidence for the "Forgotten Generation"  | Mental Retardation                     | ID + Learning disabilities      | 1994-1995    | All ages   | National Survey (NHIS-D)   | 202,560          | National          | 12.7 ID+LD  |
| Larson  | 2001 | Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. | American Journal on Mental Retardation | ID<br>DD<br>ID and/or DD        | 1994-1995    | Birth to 5 years; 6 to 17 years; 18 years or older | National Survey (NHIS-D)   | 202,560          | National          | <u>ID</u><br>4.5 0 to 5 yrs.<br>20.3 6-17 yrs.<br>5.2 18+ yrs.<br>7.8 All ages<br><u>DD</u><br>38.4 0 to 5 yrs.<br>19.5 6 to 17 yrs.<br>5.8 18+ yrs.<br>11.3 All ages<br><u>ID and/or DD</u><br>38.4 0 to 5 yrs.<br>31.7 6 to 17 yrs.<br>7.9 18+ years<br>14.9 All ages |
| Boyle   | 2011 | Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008   | Pediatrics                             | ID                              | 1997 - 2008  | 3-17 years   | National Survey (NHIS)     | 119,367          | National          | <u>ID</u><br>5.9 3-10 yr.<br>8.4 11-17 yr.<br><u>Any DD</u><br>117.8 3-10 yrs.<br>128.4 11-17 yrs.  |
| Maenner   | 2016 | Prevalence of cerebral palsy and intellectual disability among children identified in two U.S. National Surveys  | Annals of Epidemiology                 | ID                              | 2011 - 2013  | 2-17 years   | National Survey NSCH, NHIS | 85,637<br>34,503 | National          | <u>ID</u><br>12.2 NSCH<br>12.1 NHIS   |
| Zablotsky   | 2015 | Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey       | National Health Statistics Reports     | ID<br>Other Developmental Delay | 2011-2013    | 3-17 years   | National Survey (NHIS)     | 43,283           | National          | 12.7 ID<br>12.5 ASD<br>48.4 Other Developmental Delay   |

IDD Prevalence

| Table 1 Prevalence Studies Reporting Rates for Intellectual Disabilities, Developmental Disabilities or Both since 2000 |       |  |   |   |              |                   |  |                       |                   |  |
|---|-------|--|---|---|--------------|-------------------|--|-----------------------|-------------------|--|
| First Author  | Year  | Article Title  | Journal                                       | Disability  | Data Year(s) | Age               | Data Source                                    | Sample Size           | Geographic Region | Prevalence (per 1,000) <sup>1</sup>  |
| Zablotsky   | 2017  | Estimated Prevalence of Children With Diagnosed Developmental Disabilities in the United States, 2014–2016   | NCHS Data Brief                               | ID<br><br>Other Developmental Delay<br><br>Any DD (ID+ASD+ other developmental delay) | 2014-2016    | 3-17 years        | National Survey (NHIS)                         | ns                    | National          | <u>ID</u><br>2014 11.0<br>2015 13.4<br>2016 11.4<br><u>Other DD</u><br>2014 35.7<br>2015 35.6<br>2016 45.5<br><u>Any DD</u><br>2014 57.6<br>2015 60.4<br>2016 69.9 |
| Yang <sup>2</sup>   | 2016a | Ohio Children with Developmental Disabilities and Special Health Care Needs: 2015 OMAS Health and Health Care Findings   | Ohio Colleges of Medicine                     | DD  | 2015         | Birth to 18 years | State Survey (Ohio Medicaid Assessment Survey) | 10,122                | State (Ohio)      | 45.8 DD  |
| Yang  | 2016b | Ohio Adults with Developmental Disabilities and Special Health Care Needs: 2015 OMAS Health and Health Care Findings   | Ohio Colleges of Medicine                     | DD  | 2015         | 19 years or older | State Survey (Ohio Medicaid Assessment Survey) | 43,876 <sup>3</sup>   | State (Ohio)      | 41.0 DD  |
| <b>Surveillance Studies</b>   |       |  |   |   |              |                   |  |                       |                   |  |
| Bhasin  | 2006  | Prevalence of Four Developmental Disabilities Among Children Aged 8 Years --- Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996 and 2000    | Morbidity and Mortality Weekly Report         | ID  | 1996-2000    | 8 years           | Surveillance (MADDSP)                          | 43,593                | 1 site (Atlanta)  | 12.0 ID  |
| Van Naarden Braun   | 2015  | Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991-2010. | Public Library of Science (PLOS One)          | ID  | 1991-2010    | 8 years           | Surveillance (MADDSP)                          | 5,590                 | 1 site (Atlanta)  | 13.0 ID  |
| <b>Administrative Prevalence</b>  |       |  |   |   |              |                   |  |                       |                   |  |
| Croen   | 2002  | The changing face of autism in California  | Journal of Autism and Developmental Disorders | ID  | 1987-1994    | Birth cohorts     | Birth records and Administrative data (CDER)   | 4,590,333 live births | California        | <u>ID no ASD</u><br>1987 2.88<br>1994 1.95<br><u>ID and ASD</u><br>1987 0.26<br>1994 0.49  |

IDD Prevalence

| Table 1 Prevalence Studies Reporting Rates for Intellectual Disabilities, Developmental Disabilities or Both since 2000 |      |   |   |                  |                              |                                    |  |  |                   |  |
|---|------|---|---|------------------|------------------------------|------------------------------------|--|--|-------------------|--|
| First Author  | Year | Article Title   | Journal                                     | Disability       | Data Year(s)                 | Age                                | Data Source  | Sample Size                              | Geographic Region | Prevalence (per 1,000) <sup>1</sup>                                  |
| Larson  | 2010 | Changes in the Primary Diagnosis of Students With Intellectual or Developmental Disabilities Ages 6 to 21 Receiving Special Education Services 1999 to 2008 | Intellectual and Developmental Disabilities | ID<br>Dev. Delay | 1999-2008                    | 6 to 21 years (Students)           | Administrative Data (US Dept. of Education)                  | 1999<br>52,875,000<br>2008<br>55,500,000 | National          | ID<br>1999 11.2<br>2008 8.57<br>Dev. Delay<br>1999 0.37<br>2008 1.75 |
| Livermore   | 2017 | Supplemental Security Income and Social Security Disability Insurance Beneficiaries with Intellectual Disability  | Social Security Bulletin                    | ID               | 2004<br>2005<br>2006<br>2010 | 18 to 64 (SSI and SSDI recipients) | National Beneficiary Survey (Social Security Administration) | 16,190                                   | National          | ID 137   |

MADDSP Metro Atlanta Developmental Disabilities Surveillance Program; ID Intellectual Disabilities, DD developmental disabilities, Dev. Delay Developmental Delays; LD severe learning disabilities; NHIS National Health Interview Survey; NHIS-D NHIS – Disability supplement; NSCH National Survey of Children’s Health. <sup>1</sup>If more than one study reported the same data the result is shown for the most recent article. <sup>2</sup>Study added based on reviewer feedback to manuscript. <sup>3</sup>RTI International (2015)

## IDD Prevalence

| Table 2 Race/Ethnicity Differences in Prevalence Rates for ID, DD in Children   |          |                        |                         |  |
|---|----------|------------------------|-------------------------|--|
| First Author  | Pub Year | Data Year <sup>1</sup> | Significant Differences | Details  |
| <b>Intellectual Disabilities</b>  |          |                        |                         |  |
| Bhasin  | 2006     | 2000                   | w,o < b                 | Prevalence lower for w and o than for b  |
| Van Naarden Braun   | 2015     | 2010                   | nhw < nhb               | Prevalence lower for nhw than for nhb  |
| Maenner   | 2016     | 2012                   | nhw < nhb               | Prevalence lower for nhw than for nhb (NSCH)   |
| Boyle   | 2011     | 2008                   |                         | no differences   |
| Maenner   | 2016     | 2013                   |                         | no differences (NHIS)  |
| Zablotsky   | 2017     | 2016                   |                         | no differences   |
| <b>Developmental Disabilities</b>   |          |                        |                         |  |
| Simpson   | 2003     | 1995                   |                         | No differences for functional delays or general delays once gender, age, family structure, poverty level, and parental education were considered |
| Yang  | 2016     | 2015                   |                         | differences not tested   |
| nhw – non-Hispanic white; nhb non-Hispanic black; nho non-Hispanic other, h Hispanic, w white, b black, api Asian/Pacific islander; < less than; > greater than |          |                        |                         |  |

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