

Identifying Individuals With Intellectual Disability Within a Population Study

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Background: Much remains unknown about the longitudinal health and well-being of individuals with intellectual disability (ID); thus, new methods to identify those with ID within nationally representative population studies are critical for harnessing these data sets to generate new knowledge.

Objective: Our objective was to describe the development of a new method for identifying individuals with ID within large, population-level studies not targeted on ID.

Methods: We used a secondary analysis of the de-identified, restricted-use National Longitudinal Study of Adolescent to Adult Health (Add Health) database representing 20,745 adolescents to develop a method for identifying individuals who meet the criteria of ID. The three criteria of ID (intellectual functioning, adaptive functioning, and disability originating during the developmental period) were derived from the definitions of ID used by the American Psychiatric Association and the American Association on Intellectual and Developmental Disabilities. The ID Indicator was developed from the variables indicative of intellectual and adaptive functioning limitations included in the Add Health database from Waves I to III.

Results: This method identified 441 adolescents who met criteria of ID and had sampling weights. At Wave I, the mean age of this subsample of adolescents with ID was 16.1 years. About half of the adolescents were male and from minority racial groups. Their parents were predominately female, were married, had less than a high school education, and had a median age of 41.62 years. The adolescents' mean maximum abridged Peabody Picture Vocabulary Test standardized score was 69.6, and all demonstrated at least one adaptive functioning limitation.

Discussion: This study demonstrates the development of a data-driven method to identify individuals with ID using commonly available data elements in nationally representative population data sets. By utilizing this method, researchers can leverage existing rich data sets holding potential for answering research questions, guiding policy, and informing interventions to improve the health of the ID population.

Key Words: adolescents • intellectual disability • young adults

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Health disparities researchers, such as nurse scientists, have a mandate to understand the deep structures underlying preventable differences in the burden of health conditions. Significant health disparities exist globally among the estimated 1% of individuals with intellectual disability (ID; Krahn & Fox, 2014; Maulik et al., 2011). Advances in healthcare within the United States have improved survival

rates for those with ID who previously may have died during childhood (Coppus, 2013); however, life expectancy remains 20 years shorter than that of the general population (Lauer & McCallion, 2015). Lower access to quality healthcare perpetuates health disparities (Ervin et al., 2014; Krahn & Fox, 2014) and inferior health outcomes, including higher hospitalization rates and acute care service use (Acharya et al., 2017; Anderson et al., 2013; Krahn & Fox, 2014). These trends are prominent among racial and ethnic minorities (Emerson, 2012; Mandell et al., 2009; Scott & Haverkamp, 2014).

Population-level study of health trajectories of individuals with ID can illuminate health needs and inform interventions. The life course health development framework (Halfon & Forrest, 2018), which explains how health trajectories develop over the life course, guided the conceptualization of this study. The life course health development framework focuses on psychosocial factors contributing to disparities that are present early in life and grow synergistically throughout life. Longitudinal data sets rich in mental and physical health,

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genetic, socioeconomic, and environmental data (Halfon et al., 2014) are effective means in studying life course development. The use of nationally representative longitudinal data sets is an important strategy to understand the health trajectories of individuals with ID as they often participate in these studies, but their unique experiences are left unstudied. A key barrier to knowledge development in this field is the difficulty identifying individuals with ID within population studies not focused on disability.

The terminology used to communicate the diagnosis of ID has evolved from prior stigmatizing terms including *imbecility*, *idiocy*, *mental deficiency*, *feeble-mindedness*, and *mental retardation* (Prabhala, 2007; Schalock et al., 2010). In 2013, the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association [APA], 2013) replaced *mental retardation* with *intellectual disability*, but the stigmatization, lack of recognition, and undertreatment experienced by those with ID persist and contribute to their relative invisibility within nationally representative population studies. This stigma (O'Hara, 2003; Zuckerman et al., 2014) contributes to the reticence to disclose ID (Centers for Disease Control and Prevention/National Center on Birth Defects and Developmental Disabilities Health Surveillance Work Group, 2009; Emerson, 2011). Minority children are less likely to be diagnosed with ID and provided with special education services (Morgan et al., 2017), which contributes to educational and developmental disparities. In addition, 85% of those with ID have mild ID (King et al., 2009) and are a “hidden majority” (Emerson, 2011), increasing their risk of remaining undiagnosed and without formal support.

Studying populations with ID within large, diverse, longitudinal data sets increases generalizability, as large samples are more likely to include minority groups (e.g., racial/ethnic minorities), allowing for testing of within-group differences. Longitudinal designs also allow tracking of patterns of health of the ID population over time. Therefore, studying ID within longitudinal population studies allows the study of their life course development, including those who may not have had access to evaluation services and supports, and the promise of adequate sample sizes to look at within-group differences. Yet, difficulty identifying those with ID has limited our ability to leverage population studies (Fox et al., 2015; Krahn et al., 2010) and understand how their health trajectories compare to those without ID. Health disparities are likely to continue in the absence of our ability to identify those with ID in population studies.

The identification of individuals with ID within nationally representative population studies is often difficult because of lack of a widely agreed upon operational definition of ID (Fox et al., 2015). According to APA (2013) and the American Association on Intellectual and Developmental Disabilities (AAIDD; Schalock et al., 2010), a conceptually valid measure of ID should include both required criteria of

cognitive and adaptive function. In clinical practice, ID is diagnosed through standardized testing of both intelligence (e.g., Stanford-Binet Intelligence Scales) and the ability to perform daily activities known as adaptive functioning (e.g., Vineland Adaptive Behavior Scale). Yet, researchers often use measures of cognitive function as the sole attribute to identify those with ID (e.g., Cheng & Udry, 2005; Halpern et al., 2000; Haydon et al., 2011; Kahn & Halpern, 2018). This unidimensional conceptualization is problematic, as it has been shown to both under- and overestimate the number of individuals with ID in large populations (Haydon et al., 2011; Kahn & Halpern, 2018; Schalock et al., 2010). The objective of this article is to describe a new method for identifying individuals with ID within large, population-level studies by employing an operational definition constructed with commonly available data elements. We explicate this method by identifying individuals who meet criteria for ID (intellectual functioning, adaptive functioning, and disability originating during developmental period) within the National Longitudinal Study of Adolescent to Adult Health (Add Health), a large, nationally representative database.

UTILIZING THE ADD HEALTH DATABASE TO STUDY ID

Add Health is a well-known longitudinal database for studying developmental and health trajectories of adolescents who attended Grades 7–12 in the 1994–1995 school year. The sample of 20,745 adolescents—collected over five waves (1994–2018)—was obtained through a complex, stratified, school-based sampling design (Chen, 2018). Wave I data were collected on 12- to 19-year-olds using a combination of in-school interview, in-home interview, and a parent questionnaire. Subsequent waves continued with in-home interviews and added schooling, education, biomarker, and environmental data. The Add Health database provides a unique opportunity to study health trajectories of individuals with ID within context and to make comparisons to those without ID as diverse subgroups, including individuals with physical disabilities who were oversampled (Chen, 2018).

The Add Health database contains no single variable to identify an individual with ID or measure both intellectual and adaptive limitations consistent with ID. In Wave I, the variable “parent report of ID” asked parents to report if their child was “mentally retarded” (now obsolete language); however, not all individuals had a parent questionnaire. For those who did, accuracy of this variable hinged on access to diagnostic services in the child's school or medical setting, parental knowledge of “mental retardation,” and willingness to disclose it. Given the well-known underreporting of ID and the risk of unrecognized ID (Emerson, 2011; Krahn et al., 2010; Schalock et al., 2010), parental reporting is an insufficient single indicator.

Past studies of the ID population using the Add Health data set used a single proxy variable—the “Add Health Picture Vocabulary Test standardized score”—an abridged Peabody Picture Vocabulary Test (aPPVT; e.g., Cheng & Udry, 2005; Halpern et al., 2000; Haydon et al., 2011; Queirós et al., 2015). In our early exploration of this data set to study health trajectories of individuals with ID, we considered using the aPPVT standardized score of <79 to identify individuals with ID. Importantly, the use of this variable resulted in an unanticipated and implausible number of individuals from racial and ethnic minority groups. Similarly, Kahn and Halpern (2018) used an aPPVT of ≤ 85 to study those with “low cognitive ability” within this data set, resulting in a sample of 33.6% ($n = 742$) non-Hispanic Black, 30.2% ($n = 691$) Hispanic, and 27.9% ($n = 410$) non-Hispanic White, respectively. Results such as these are likely attributed to the aPPVT, representing only one component of intellectual functioning, and likely reflect differences in learning experiences. Using only aPPVT resulted in overrepresentation of racial and ethnic minority groups, raising questions about its validity as a proxy for ID. Thus, a new method of identifying individuals with ID was needed that was inclusive of both intellectual and adaptive functioning to lower the likelihood of misclassification.

METHODS

We conceptualized ID as including disabilities in intellectual and adaptive functioning as well as disability present during adolescence. Add Health contains distinct variables that measure intellectual and adaptive functioning. Most of these variables were measured in Wave I, when participants were adolescents; however, because some variables come from Wave II (13–19 years old) and Wave III (18–26 years old), we refer to the study participants as adolescents and young adults (AYAs). All AYAs within the database with an aPPVT standardized score of ≤ 79 (intellectual functioning) obtained during Wave I and/or Wave III were included. In addition, those missing Wave I sampling weights were excluded as sampling weights, calculated as the inverse of the probability of each individual's selection, and are required to ensure nationally representative estimates (Chen, 2018).

Variables and Procedures

We reviewed the variables collected within each wave of Add Health data to identify those capturing a component of ID conceptually represented by APA (2013) and AAIDD (Schalock et al., 2010) definitions. Table 1 demonstrates the similarities and differences between APA and AAIDD definitions and their specific criteria. The individual variables were then examined for face validity. We sought to develop an indicator of ID that included variables of intellectual functioning (Criterion A) and adaptive functioning (Criterion B) during Wave I (12–18 years old) and Wave II (13–19 years old) to demonstrate that disability was present during the developmental period of

adolescence before 18 years of age (Criterion C). Table 2 demonstrates the Add Health ID indicator criteria and method used to identify those participants with functioning consistent with ID.

Intellectual Functioning A critical component of intellectual functioning is verbal comprehension, defined as the ability to understand spoken language (APA, 2013). Intellectual functioning limitation (Criterion A) for this study was represented by the aPPVT standardized score. The aPPVT, a 87-item abridged version of the Peabody Picture Vocabulary Test-Revised (PPVT-R; Harris et al., 2009), has been shown to be moderately correlated with intelligence measures, including the Wechsler Intelligence Scale for Children and the Stanford-Binet Intelligence Scale (Becker, 2003; Dunn & Dunn, 1981; Wechsler, 2004) and highly correlated (.96) with the entire PPVT-R instrument (Halpern et al., 2000). Age-standardized scores were classified as follows: 90–109 as *average*, 80–89 as *low average*, 70–79 as *borderline* or *very low*, and 69 and below as *extremely low*. Given that the aPPVT does not require reading comprehension skills, it has been identified as a particularly useful cognitive ability measure for those at the lower end of the distribution (Cheng & Udry, 2005).

The aPPVT was assessed during in-home interviews at Wave I and repeated at Wave III. The measurement error for the aPPVT is not known; however, full psychometric tests of intelligence generally use a score of 75 as the cutoff (APA, 2013). Participants with Wave I aPPVT with a standardized score of ≤ 79 (identified as borderline or very low range) were considered for our ID subsample. If they also had a Wave III aPPVT, it must have been ≤ 89 (below average) to demonstrate consistent limitations in intellectual functioning. If a participant did not have an aPPVT completed in Wave I but had a Wave III aPPVT of ≤ 79 , they were also further considered for our ID subsample through analysis of their adaptive functioning.

Adaptive Functioning Adaptive functioning is composed of three domains: conceptual (e.g., reading, math, reasoning, language, problem-solving, memory), social (e.g., communication skills, social judgment, empathy), and practical (e.g., self-management across settings such as personal care, work responsibilities; APA, 2013). To fulfill the diagnostic criteria for ID, an individual must demonstrate a deficit in at least one of these three domains at home, school, work, or in the community, and this deficit must be directly related to their intellectual functioning limitation (Criterion A; APA, 2013). The importance of this relationship between adaptive and intellectual functioning cannot be overstated because physical disability and ID commonly co-occur (APA, 2013). For example, 45% of individuals with a physical disability of cerebral palsy also have ID, but the majority do not (Reid et al., 2018). Because

TABLE 1. Intellectual Disability (ID) Criteria

ID criteria	Definitions	
	APA ^a	AAIDD ^b
Criterion A: Intellectual functioning limitation	“Deficits in intellectual functions such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing” (test score < 75) (p. 33).	“Significant limitations in intellectual functioning” (p. 27), including learning, reasoning, problem solving, etc. IQ standardized test score cutoff approximately two standard deviations from population mean
Criterion B: Adaptive functioning limitation	“Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community” (p.33).	“Significant limitations in adaptive functioning” (p. 27) Composed of limitations in: • conceptual skills • social skills • practical skills Standardized score of adaptive behavior approximately two standard deviations below mean on one type of adaptive skill or overall score of all three skills
Criterion C: Disability during developmental period	Onset of both intellectual and adaptive deficits during the developmental period of childhood or adolescence	Onset before age of 18 years

^aAmerican Psychiatric Association (2013).

^bAmerican Association on Intellectual and Developmental Disabilities (Schalock et al., 2010).

physical disability does commonly co-occur, we recognized the importance of not excluding individuals based on physical disability and of identifying questions that appraise three domains of adaptive functioning among those individuals who have demonstrated Criterion A. We conducted additional analyses to determine how many individuals met criteria of physical disability, met criteria for adaptive functioning limitations based on physical disability alone, or had additional features of Criterion B measured by this ID Indicator.

Adaptive functioning was assessed by the presence of one or more adaptive functioning limitations among individuals who meet Criterion A. Adaptive functioning limitation (Criterion B) was measured by 24 components across three categories: (a) activities of daily living (ADLs), (b) perception/recognition of AYA disability, and (c) special education. Each component was evaluated and given a score of 1 when an adaptive limitation was identified. We developed a total of seven Criterion B components, including parent- and AYA-reported adaptive functioning limitations Wave I, AYA-reported adaptive functioning limitations Wave II, parent- and AYA-reported perception of disability, history of receiving special education, and graduation with special education diploma (see Table 3).

Parent (Wave I) and AYA (Waves I and II)-reported ADLs were used. The in-home parent questionnaire asked parents if their child had difficulty using their hands and arms, or feet and legs. If their answers to both were “no,” skip logic was used, and further disability questions were not asked. If the

parent responded “yes” to either, they were asked if the condition required their child to need help when eating, bathing, dressing, and getting on or off the toilet. Similarly, AYAs who indicated a physical/functional limitation (difficulty using upper or lower extremity, heart problem, asthma or breathing difficulty, or adaptive equipment for ambulation) at Wave I were asked if their condition required help from another person when eating, bathing, dressing, getting on or off the toilet, or shopping. At Wave II, all AYAs were asked if, because of a physical, learning, or emotional condition that had lasted for at least a year, they had (a) any limitations attending school or in their ability to do regular work; (b) difficulty in doing regular household chores, shopping, or errands; (c) limitations in doing strenuous activities such as running, swimming, or other sports; and (d) difficulty with personal care or hygiene, namely, bathing, dressing, eating, or using the toilet. Each ADL component was coded 0 = *no* and 1 = *yes* at both Waves I and II.

In addition to ADLs and questions about extremity function, parents and AYAs were asked about physical conditions. In Wave I, parents were asked, “Are his/her difficulties caused by a physical condition?” whereas AYAs were asked, “Do you consider yourself to have a disability?” and “Do you think other people consider you to have a disability?” In Wave II, AYAs were asked, “Is your condition physical, learning, or emotional in nature?”

To identify individuals not meeting developmental and sociocultural standards, defined as those not meeting social

TABLE 2. Add Health Intellectual Disability (ID) Criteria and Method

ID criteria	Add Health measures	Process
Criterion A: Intellectual functioning limitation	<ul style="list-style-type: none"> ● Abridged Peabody Picture Vocabulary Test (aPPVT) standardized score ≤ 79 	<p>Definition</p> <ul style="list-style-type: none"> ● aPPVT ≤ 79 at Wave I and/or Wave III <p>Procedures</p> <ul style="list-style-type: none"> ● aPPVT ≤ 79 at Wave I ● If aPPVT is also assessed at Wave III, then Wave III aPPVT must be ≤ 89. ● If aPPVT is missing at Wave I, then aPPVT must be ≤ 79 at Wave III.
Criterion B: Adaptive functioning limitation	<ul style="list-style-type: none"> ● Requires assistance with activities of daily life (eating, bathing, dressing, toileting, shopping) ● Physical, learning, or emotional condition (present for >1 year) causing limitations/difficulty with (a) attending school/work; (b) doing household chores, shopping, errands; (c) doing strenuous activities; and (d) personal care ● Perception of disability (parent report): (a) parent considers child disabled, (b) parent thinks others consider child disabled ● Perception of disability (adolescent report): (a) adolescent considers self disabled, (b) adolescent thinks others consider them disabled ● "Mental retardation" ● Learning disability ● Condition physical, learning, or emotional in nature ● Receipt of special education or special education diploma 	<p>Definition</p> <ul style="list-style-type: none"> ● Presence of one or more adaptive functioning limitations, reported by the parent, adolescent, or school transcripts, among those who met Criterion A <p>Procedures</p> <ul style="list-style-type: none"> ● Three categories of adaptive functioning were assessed. Each component of the category was evaluated and given a score of 1 when an adaptive limitation was identified. A total score was determined for each category. Categories and subcategories: ● Activities of daily living (ADLs) ● Parent report of AYAs ADL limitations (Wave I) ● AYA report of AYAs ADL limitations (Waves I & II) ● Perception/recognition of AYA's disability ● Parent perception/recognition that AYA has: <ul style="list-style-type: none"> ● disability (Wave I) ● "mental retardation" (Wave I) ● Learning disability (Wave I) ● AYA perception/recognition: <ul style="list-style-type: none"> ● AYA has disability (Waves I & II) ● Condition physical, learning, or emotional in nature (Wave II) ● Special Education ● Parent report of AYA receiving special education in last 12 months (Wave I) ● Graduated with special education diploma (Wave III) ● The adolescent meeting Criteria A & B during Wave I & Wave II also meets Criterion C as this demonstrates they had disability present during their developmental period
Criterion C: Disability during developmental period		

Note. AYAs = adolescents and young adults; ADLs = activities of daily living.

responsibility and personal independence standards expected of individuals of similar age and sociocultural background (APA, 2013), we identified variables that represent features consistent with ID. These variables include the presence of disability as evidenced by recognized ID (referred to as "mental retardation" in Wave I [1994–1995]), a learning disability, and a perception of a disability according to their parents, others around them, and/or themselves. Seven questions asked parents and AYAs about their perception/recognition of the AYA's disability category. Four questions were asked during the in-home parent questionnaire (coded 0 = no and

1 = yes): "Is (he/she) mentally retarded?" and "Does (he/she) have a specific learning disability, such as difficulties with attention, dyslexia, or other reading, spelling, writing, or math disability?" Parents who indicated that their child had difficulty using their upper and/or lower extremities were also asked, "Do you consider (name of child) to have a disability?" and "Would other people consider (him/her) to have a disability?" We used *parent report of child having learning disability* as a feature of adaptive functioning limitation because it taps the conceptual and practical domains of the AAIDD and DSM criteria. It is important to note that a learning disability (e.g.,

TABLE 3. Characteristics of Intellectual Disability (ID) Criterion Among Adolescents With ID (N = 441)

ID criterion	Unweighted		Weighted	
	N	f	%	SE
Intellectual functioning limitations				
• Maximum aPPVT (Wave I or Wave III)				
○ 0-39	441	22	6.5	2.19
○ 40-59	441	50	14.0	3.59
○ 60-69	441	78	19.7	2.94
○ 70-79	441	229	46.5	5.55
○ 80-89	441	62	13.2	3.75
• aPPVT Wave I				
○ 0-39	424	21	6.9	2.25
○ 40-59	424	55	15.9	3.58
○ 60-69	424	106	25.9	2.12
○ 70-79	424	242	51.3	6.71
• aPPVT Wave III				
○ 0-39	252	15	3.9	2.56
○ 40-59	252	23	13.1	3.48
○ 60-69	252	41	14.0	3.24
○ 70-79	252	111	42.0	5.17
○ 80-89	252	62	27.0	5.09
Adaptive functioning limitations				
• Requires assistance (Wave I parent report)				
○ Eating	423	3	1.7	1.43
○ Bathing	423	6	2.8	1.97
○ Dressing	423	5	2.4	2.06
○ Toileting	423	3	1.7	1.43
• Requires assistance (Wave I AYA report)				
○ Eating	441	4	1.8	1.39
○ Bathing	441	5	2.6	1.92
○ Dressing	441	4	1.9	1.39
○ Toileting	441	5	2.2	1.30
○ Shopping	441	9	3.7	2.32
• Physical, learning, or emotional condition (present for >1 year) causing (Wave II AYA report)				
○ Limitations attending school or work	319	104	33.6	7.07
○ Difficulty doing chores, shopping, or errands	318	42	15.2	6.26
○ Limitations in doing strenuous activities	320	60	19.9	4.12
○ Difficulty with personal care (bathing, dressing, eating, toileting)	320	20	9.1	3.66
• "Mental retardation" (Wave I parent report)	417	104	38.3	13.62
• Learning disability (Wave I parent report)	414	310	80.5	4.85
• Perception of disability (Wave I parent & AYA report)				
○ Parent considers child to be disabled	423	28	8.7	1.59
○ Parent thinks others consider child disabled	420	23	6.8	1.77
○ Adolescent considers self to be disabled	440	13	3.9	2.22
○ Adolescent thinks others consider them disabled	440	13	3.6	1.88
• Condition is (Wave II AYA report)				
○ Physical	316	60	20.4	4.93
○ Learning	316	62	20.6	3.72
○ Emotional	316	27	9.9	4.65
• Received special education in the last 12 months (Wave I parent report)	418	293	79.0	5.91
• Graduated with special education diploma (Wave III school transcripts)	418	4	4.9	3.24

Note. Standardized score. N = unweighted ID sample; f = unweighted frequencies; % = weighted percent after applying Wave 1 sampling weights, stratification, and cluster variables; SE = weighted standard error of the percent (%); aPPVT = abridged Peabody Picture Vocabulary Test; AYAs = adolescents and young adults.

dyslexia) can be present without an ID, but for this sample, all AYAs demonstrated at least one low aPPVT score (≤ 79) and did not have an average or higher aPPVT at either of their aPPVT evaluations. The AYAs' perceptions/recognition of their disabilities were assessed through three questions (coded 0 = *no* and 1 = *yes*): "Do you consider yourself to have a disability?" (Wave I), "Do you think other people consider you to have a disability?" (Wave D), and "Is your condition physical, learning, or emotional in nature?" (Wave II).

Lastly, we used the receipt of special education—indicating the need for support in the school setting—to assess the presence of ID. Special education is a broad umbrella term; it includes education directed to those with ID, but also to those with other impairments (e.g., vision or hearing), emotional disabilities, and specific learning disabilities (Butrymowicz & Mader, 2017). Special education was assessed by asking parents if their child had received any type of special education in the past 12 months (coded 0 = *no* and 1 = *yes*), and the AYAs' high school exit status from their high school transcripts. AYAs receiving special education were given 1 point toward adaptive functioning limitation. Those who received a special education diploma did receive an additional point for adaptive functioning limitation, as it further demonstrated their difficulty in practical and conceptual domains.

Disability During the Developmental Period of Adolescence We identified those meeting Criteria A and B during Waves I and II when the adolescents were 12–19 years of age to demonstrate that their disability was present during the developmental period of adolescence (Criterion C). Each adolescent of this ID subsample demonstrated intellectual and adaptive functioning limitations.

Analytic Strategy

To summarize, we created an operational definition of ID that included limitations in intellectual and adaptive functioning and aligned conceptually with the *DSM-5* and AAIDD ID criteria. Add Health variables that met our criteria for ID—limitations in intellectual and adaptive functioning originating in childhood or adolescence—were used to describe the Add Health subsample with ID and the individual variables that composed the Add Health ID indicator. We applied variance adjustments and the Wave I cross-sectional sampling weights constructed by Add Health investigators to account for the complex survey design, nonrandom sampling, and oversampling of certain subgroups (Chen, 2018). Analyses were conducted using the sampling weights, stratification (region of the country), and cluster (school) variables, which allowed us to produce nationally representative inferences from the Add Health 1994–1995 sample.

RESULTS

Process to Obtain Final Sample

Our consort flow diagram (see Figure 1) demonstrates the progression from the total Add Health sample to the Add Health ID subsample ($N = 441$), including how participants exited. Based on this process, adolescents met Criterion A in one of four ways: (a) Wave I aPPVT missing and Wave III aPPVT ≤ 79 ($n = 76$); (b) Wave I aPPVT ≤ 79 and Wave III aPPVT missing ($n = 668$); (c) Wave I and Wave III aPPVT ≤ 79 ($n = 565$); and (d) Wave I aPPVT ≤ 79 and Wave III aPPVT = 80–89 ($n = 258$). After meeting Criterion A, the remaining 1,567 AYAs were evaluated for Criterion B. Based on Criterion B, 1,048 adolescents who exited lacked a single adaptive functioning limitation. There were 519 AYAs who met Criteria A and B and therefore Criterion C; however, given our aim to make nationally representative inferences, adolescents without sampling weights ($n = 78$), that is, those not part of the original sampling frame who were enrolled in the field (e.g., twin) were exited. This process resulted in a final sample of 441.

Characteristics of ID Subpopulation and ID Criterion

Demographic characteristics of the AYAs ($n = 441$) and parents (one per family) are presented in Table 4. The AYAs' mean age was 16.1 years (range: 12–21 years), and mean maximum aPPVT was 69.6 (range: 7–89). The weighted characteristics of the ID criterion are displayed in Table 3. There were 62 of the 441 participants with an aPPVT at Wave I who scored ≤ 79 and then at Wave III who scored >80 and <89 . Otherwise, those who had a Wave I aPPVT scored ≤ 79 , and if they had a Wave III aPPVT, it also remained ≤ 79 .

The rate of ADL limitation at Wave I, representing adaptive functioning limitations attributed to physical conditions, was low (6.6%). There were six AYAs who had at least one parent-reported adaptive functioning limitation at Wave I; yet, 12 AYAs self-reported having at least one adaptive functioning limitation. Requiring assistance with shopping was the most reported need (3.7%). At Wave II, when the question was not limited to those who reported physical limitations, many more adolescents reported adaptive functioning limitations. There were 137 AYAs who had at least one adaptive functioning limitation at Wave II. Of the 310 AYAs whose parents reported they had a learning disability, 248 had other indicators of adaptive functioning limitation (range: 1–19 indicators). Sixty-two AYAs (20%) who already met the aPPVT criterion met the adaptive functioning criterion based on learning disability alone. When asked about their perception of disability, more parents ($n = 324$) than adolescents ($n = 143$) considered the adolescent disabled.

Additional Characteristics of AYAs With ID

High school transcripts were available for 211 AYAs; 71.8% graduated with a standard high school diploma, 10.7%

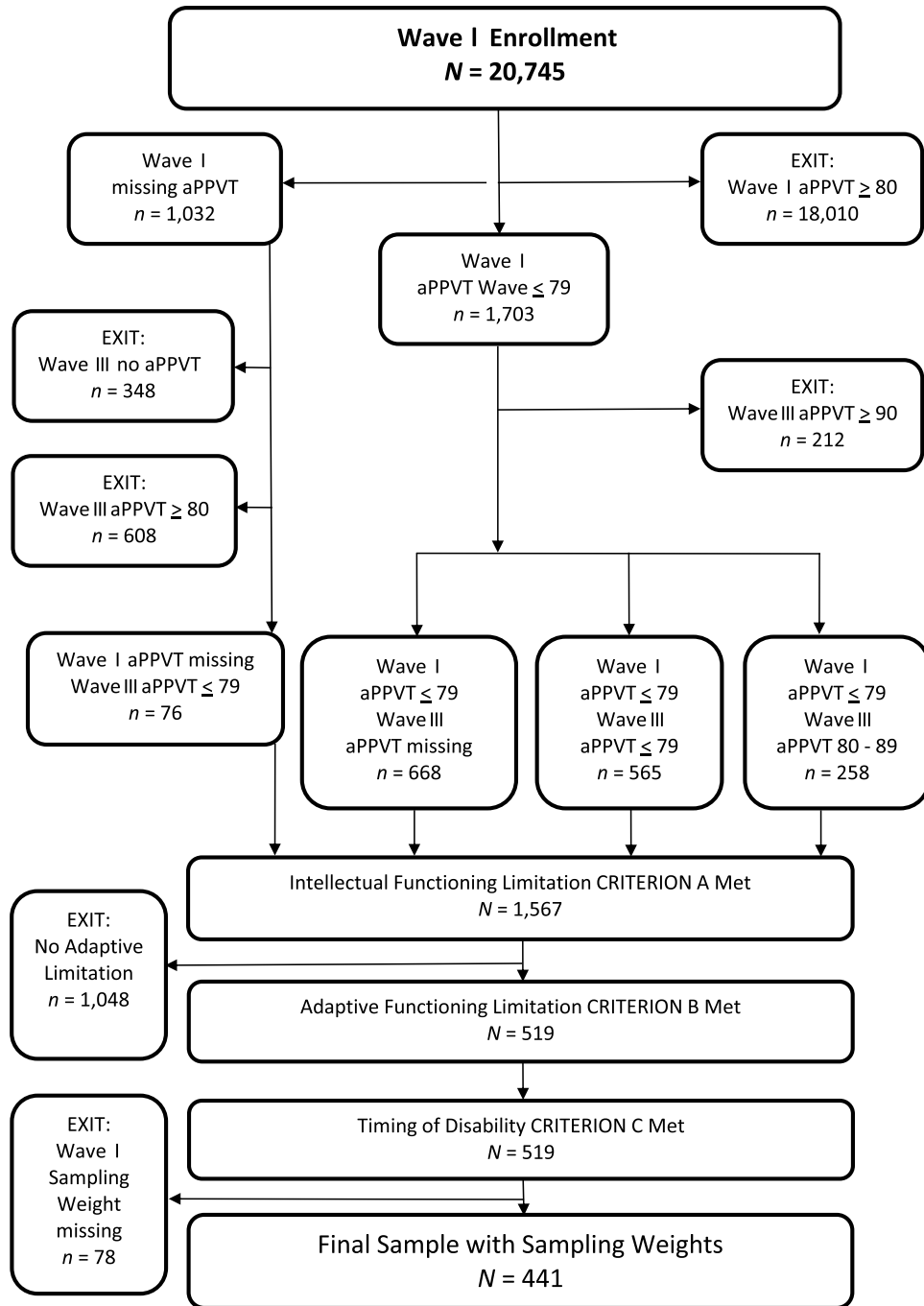


FIGURE 1. Consort diagram demonstrating progression to the final add health intellectual disability subsample.

dropped out, 10.5% were identified as other nongraduate, and 2.1% received a certificate of completion. To measure adolescent self-reported physical disability involving extremities on the in-school questionnaire at Wave I, the original Add Health Study team flagged 589 students from the full sample who self-reported physical disability. Among our subsample, eight AYAs (0.4%) had the Wave I flag. The majority (86.4%) of the 20 parents who attributed their child’s difficulties to their

physical condition indicated that this physical condition was present at birth, whereas 10.8% reported that it was due to an accident.

DISCUSSION

Though there is a critical need to use large population data sets to understand the health needs of individuals with ID, challenges remain in their identification. We present here a

TABLE 4. Demographic Characteristics of Adolescents With Intellectual Disability (ID) and Parents at Wave I (N = 441)

	Unweighted N	Unweighted f	Weighted %	Weighted SE
Adolescents with ID				
Male	441	232	53.1	3.68
Race (may identify 1 or more)				
White	433	175	44.0	3.29
Black/African American	433	164	35.9	5.88
American Indian/Native American	433	13	2.4	1.18
Asian or Pacific Islander	433	29	4.1	1.41
Other	433	65	15.9	3.87
Hispanic/Latinx	437	144	28.0	3.60
Parent characteristics				
Female	403	388	97.6	0.94
Race (may identify 1 or more)				
White	415	181	44.3	5.03
Black/African American	415	158	35.7	5.62
American Indian/Native American	415	14	3.7	1.82
Asian or Pacific Islander	415	24	3.6	1.29
Other	415	54	16.0	2.05
Hispanic/Latinx	414	133	26.2	3.56
Marital status				
Single, never married	414	56	13.0	2.31
Married	414	213	53.2	4.36
Widowed	414	22	4.7	1.51
Divorced	414	72	17.9	2.25
Separated	414	51	11.1	1.89
Highest education completed				
Less than high school	414	200	47.4	4.62
High school graduate/GED	414	111	28.6	2.74
Some college	414	81	19.2	3.10
College graduate	414	15	3.6	1.01
Graduate training	414	7	1.2	0.52
Employed outside home				
Employed full time	406	154	35.5	3.45
Annual household income				
Less than \$14,999	347	150	42.1	4.85
\$15,000–\$34,999	347	111	29.4	2.69
\$35,000–\$49,999	347	52	15.6	3.17
\$50,000–\$74,999	347	21	8.0	2.06
\$75,000–\$99,999	347	7	3.3	1.68
\$100,000 and more	347	6	1.5	0.72

Note. N = unweighted ID sample; f = unweighted frequencies; % = weighted percent after applying Wave sampling weights, stratification, and cluster variables; SE = weighted standard error of the percent (%).

method for identifying individuals who meet conceptually grounded criteria for ID using nationally representative databases. The model can be used to evaluate the presence of similar variables in other data sets and to guide decisions on their usefulness for identifying and studying individuals with ID.

Our method for identifying AYAs meeting criteria for ID was based on the use of leading ID definitions (APA, 2013; Schalock et al., 2010). In order to make nationally representative inferences, we retained 441 AYAs who met the criteria

for ID and had valid sampling weights. We developed the Add Health ID indicator to measure both intellectual and adaptive functioning to prevent the inclusion of an AYA with an aPPVT of ≤ 79 at one time point but with no other features of ID, as could occur in the case of an AYA with low academic opportunity or short-term cause for low aPPVT (e.g., intoxication; Haydon et al., 2011; Kahn & Halpern, 2018).

The intellectual functioning of the majority of AYAs (maximum aPPVT scores) was borderline or very low. This was

expected, as previous literature demonstrates that 85% of those with ID have mild severity (King et al., 2009). Studies using the Peabody Picture Vocabulary Test-4th Edition with samples with ID have found mean standardized scores of 82 (Williams syndrome; Mervis & John, 2010) and 53 (autism; Krasileva et al., 2017). Because the abridged version of the PPVT-R measures receptive vocabulary ability alone rather than all components of intelligence, we are not able to further differentiate among severity based on the aPPVT score.

Features of adaptive functioning limitations—specifically physical disability and learning disability—if taken alone, can present risks to the validity of this ID indicator. Thus, it is important that they be considered in combination with other core domains of ID. A minority of parents (6.6%) attributed their adolescents' difficulties to a physical condition during Wave I. Only 0.4% of the sample were flagged as those AYAs who had self-reported physical disability. This finding reveals that many with physical disability did not demonstrate functioning consistent with ID. Caution is needed in this interpretation as this identification relied on the ability of AYAs to self-report, which may have been difficult for those with significant ID, and may also indicate adolescents' reluctance to report differences or disabilities. In contrast, 80.5% of participants had a learning disability based on parent report. Parents might have been (a) informed that their child had a learning disability when they really had ID, (b) been more comfortable communicating that their child had a learning disability, or (c) been unaware that their child had ID but recognized that their child had difficulty learning.

Implications for Research, Policy, and Nursing Practice

Add Health is an example of a large data set that holds potential to learn more about the health of the ID population. Additional strategies could improve the utility of Add Health and other data sets. Self-report from AYAs with ID is important, but care needs to be taken in assessing the comprehension level of standardized questions. A mixed-method study with primary data collection that includes qualitative interviews with AYAs and parents may help to overcome this challenge and assess questions of validity and reliability for this population. Because of skip logic, parents and AYAs in Wave I were only asked ADL questions if they indicated upper or lower extremity problems or other physical/functional limitations of physical origin. ADLs can be affected by ID and not just by physical disability; thus, it is important to structure studies to ask ADL questions of all individuals. Lastly, interviewer observation-based variables could be leveraged in future waves and within other studies to allow for improved triangulation of data. Other population-based, health-related data sets may contain other variables that allow for operationalizing the three criteria used in this study to identify the ID subpopulation.

The approach developed in this article can be used to identify the strengths and weaknesses of using the best available variables in each data set and to inform a decision on the

usefulness of the data set for studying the ID subpopulation. Future research leveraging other large population-based, health-related data sets and merging data sources is needed to address knowledge gaps of this adolescent to young adulthood period as well as across the life course for the ID population.

Policies to promote effective data exchange across systems (e.g., medical, education) are crucial for understanding life course development and their related effects. For example, intellectual, adaptive, and other types of cognitive testing results are used to determine eligibility for supplemental security income but are not currently accessible to merge with other data sources. The ability to connect this information with data sources, as we have described, could improve tracking of health outcomes, inform policy, and guide efforts to improve the health and well-being of the ID population. Given the need for robust data, the expense of conducting population studies, and the current funding environment, secondary data analysis of existing data and strategies to identify ID subsamples is important to uncover and address disparities, drive clinical improvement, and inform nursing practice.

Limitations

The aPPVT may not be equivalent across cultures, and AYAs with reduced educational opportunities may have poorer performances than those with better opportunities. Second, a limited range of variables were available in Add Health to assess ID. Third, it is possible that our method results in a conservative identification of ID and may result in false negatives given that those without adaptive functioning limitations, but with aPPVT of ≤ 79 , were excluded. Future studies using this method could compare this group to those who exited to see how they differ over time in outcomes and whether they should be further classified.

CONCLUSION

In the absence of appropriate ways to identify and study individuals with ID and their health trajectories in population studies, health disparities are likely to continue unnoticed, untracked, and unaddressed. This study demonstrates a feasible methodology for identifying individuals with ID within a large data set. By doing so, we can learn more about their unique experiences and needs, including those of racial minority and mild ID who are generally underrepresented in clinical studies, and at additional risk due to having multiple minority identities. Our study provides key considerations and approaches that promote the inclusion, retention, and identification of people with ID in population studies. This knowledge is valuable for improving inclusion and addressing health disparities in order to achieve health equity.

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This research study was approved by the Duke University Health System Institutional Review Board (Study Number 00101050). All study activities were conducted according to this approved review and met ethical conduct of research standards.

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