

Developing an Operational Definition of Intellectual Disability for the Purpose of National Health Surveillance

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The opinions in this document reflect the author's work and the recommendations of those contributing to the report. They are not intended to reflect the official position of the CDC, AUCD, or the University of Massachusetts Medical School.

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EXECUTIVE SUMMARY

When compared to the general population, people with an intellectual disability experience disparities in health outcomes and in access to health services both in the United States and internationally. While there is a growing body of research demonstrating health disparity in this population, the public health response has not risen to meet the evidence.

Efforts to improve surveillance of this population are underway, with a major effort initiated in 2009 by the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) in collaboration with the Association of University Centers on Disability (AUCD). Building on two international meetings, a Research Topic of Interest (RTOI): *Health Surveillance of Adults with Intellectual Disability* was developed and funded for a one year project to lay foundational work towards enhanced surveillance in this population.

Public health surveillance serves an essential function in identifying health disparities and monitoring progress in our efforts to improve health or reduce health disparities in a defined population. One major challenge in monitoring the population with intellectual disability has been the variable means by which the population definition is operationalized. This population may be defined in a variety of ways, including clinical definitions, functional definitions, definitions used to establish eligibility for federal support programs such as SSI, SSDI, or housing support programs, as well as the range of definitions applied for State-specific support programs.

This report summarizes recommendations that were developed to establish a more consistent approach to operationalizing the case definition for the purpose of public health surveillance among adults with intellectual disability in the United States. The approach included consideration of well established conceptual definitions, such as in the International Classification of Disability, Health, and Function (ICF), and the most recent version of the definition established by the American Association on Intellectual Disability (AAIDD). Additionally, the definitions used in current national and state level major data collection efforts, as well as those used in targeted research studies were considered, with a recognition that these sources are likely to remain the foundation upon which a national surveillance system will be built, and that any recommended definition must accommodate or ‘fit over’ those used in current data collection.

A panel of national experts was convened to assist in this review and develop recommendations through participation in a one-day summit and follow up discussions. To facilitate review and organize the output, the project team structured the consideration of the components of the definition into the following domains, based on the multidimensional definition proposed by AAIDD:

Intellectual Abilities; Adaptive Behavior; Health; Participation ; Context; Age of onset; Support needs.

Recommendations for an operational definition of intellectual disability

The population of adults with intellectual disability includes people who:

1. Have intellectual limitations* that significantly limit the person's ability to successfully participate in normal day-to-day activities such as self care, communication, work, or going to school, **and**
2. Developed the intellectual limitation during the 'developmental period' (before approximately age 22), **and**
3. Have an intellectual limitation that is anticipated to result in long-term adaptive or functional support needs, **and/or**
4. Are eligible for State or Federal public support programs because they have been diagnosed as having an intellectual disability.

* The World Health Organization's International Classification of Diseases and Related Health Problems (ICD), defines four levels of intellectual limitations, based on IQ score: mild (IQ of 50-70), moderate (IQ of 35-49), severe (IQ of 20-34) and profound (IQ of under 20).

By definition, the population does not include:

- People who have a related condition such as Autism Spectrum Disorder (ASD) or severe and persistent mental illness but no evidence of significant intellectual limitations.
- People who develop a cognitive limitation due to injury, illness, or dementia after becoming adults.

The project team developed a set of recommendations for operationalizing the definition based on review by the expert panel, including input from self advocates (adults with an intellectual disability) and other stakeholders. Recommendations include a 'conceptual definition', aligned with an 'operational definition', and a 'Pathways' approach that may be used in identifying the population. This approach was designed to allow for researchers and analysts to build sample frames from existing data, and to recognize where they may be 'missing' a given population. It also can be used to inform the development of targeted survey questions.

The definition, as proposed is not intended to alter or supplant eligibility rules, rather it is intended to use as a structured means to understand the population under review, and to guide future efforts to ensure a representative population is included in surveillance efforts.

There is much work yet to do. The recent adoption by HHS of disability data standards is an area in which the current guidance for an operational definition may be applied to further enhance data collection. Best practices in the use of the recommended operational definition must be developed in a range of surveillance applications. Survey questions that accurately identify a population through functional and clinical coding questions must be developed.

Introduction

People with an intellectual disability experience disparities in health outcomes and in access to health services both in the United States and internationally (Horowitz et al., 2000; Van Schroyen Lantman-de Valk, 2005; Oulette-Kuntz, 2005; Krahn et al., 2010). While there is a growing body of research demonstrating health disparity in the population, the public health response has not risen to meet the evidence. Despite an estimated prevalence of approximately 2.5 - 4 million adults in the United States with an intellectual disability (Larson et al., 2001; Fujiura, 2003), the health of this population is not monitored in any routine or consistent manner (CDC, 2009).

The development of a clear, operational definition of intellectual disability is an essential step in establishing national health surveillance for this population (Krahn et al., 2010). Both in the United States and internationally, variation in how the population is defined and in how researchers operationalize the existing definitions has presented a significant challenge to consistent, sustainable health surveillance (Linehan et al., 2009; Fujiura, Rutkowski-Kmitta & Owen, 2010; WHO, 2011). As a population within the broader 'disability' population, adults with intellectual disability are all but invisible in national health surveillance (Scheepers et al., 2005).

Defining this heterogeneous population presents challenges due to the multiple social and environmental influences on a person's life experience, combined with the wide range of etiological causes. While complex social phenomena such as disability are necessarily defined using multiple dimensions (AAIDD, 2010), case definition used in research are often established on available measured outcomes (Altman, 2001). In the absence of a consistent definition of intellectual disability for health research, researchers have applied a range of methods to operationalize the conceptual definition based on inclusion criteria derived from eligibility criteria (Zaharia and Moseley, 2008), self-identification (Rimmer & Hsieh, undated), or a combination of data fields thought to be most likely to capture the population (Larson et al., 2000; Fujiura, 2003; Slayter, 2010; Reichard, Stolze, and Fox, 2011). The source of data often serves as the driver of the definition and differences in format and terminology. The reason and method of data collection create significant limitations in data comparability (Emerson et al., 2010; Krahn et al., 2010).

In 2009, the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDDDS), in collaboration with the Association of University Centers on Disabilities (AUCD) convened a meeting of researchers and analysts to consider the feasibility of conducting population-based surveillance of the health status of adults with intellectual disability (ID). The informal theme of that meeting was 'What is there?'. The gathering of researchers and stakeholders from the United States, Canada, and other countries resulted in recognition of the challenges in current data, a summary of domains that might be considered for a minimum dataset, and a 5-step action plan.¹

¹ White paper available online at

A larger meeting was held in early 2010 to further explore the possibility of moving towards enhanced national surveillance of the population and included researchers, government agency representatives and multiple stakeholders. The informal theme of that meeting was 'Is there the will to do this?'. The result was a statement that "Federal agencies, advocates, and researchers are ready to work together to document and ameliorate the poor health of people with IDs", and that "documenting the problem through improved surveillance and subsequent analyses are the first steps toward change." (CDC, 2010).

Based on the findings of the first meeting and spurred on by the broad stakeholder interest in national surveillance of the population with ID, the NCBDDDS and AUCD established the solicitation for a 2010 Research Topic of Interest (RTOI) entitled "Health Surveillance of Adults with Intellectual Disability". The intended outcomes of the RTOI were to:

1. Develop a recommendation for an operational definition for the purpose of health surveillance.
2. Develop an inventory and summary of information on health of people with intellectual disability that can inform understanding at the population level.
3. Provide a critical overview of research and surveillance approaches that examine the health of people with intellectual disability by level of disability.
4. Develop sound methodologies for identifying a representative sample of the affected population on whom health variables can be measured.

This report summarizes the progress towards the first objective: detailing an operational definition for the purpose of national health surveillance. It includes an overview of current definitions and major contextual issues, a summary of the process used to gather expert and key stakeholder input, and the resultant proposed definition, along with a proposal for a step-wise approach to case identification for future research that leads towards a sustainable system of surveillance.

This activity was funded by a NCBDDDS/AUCD cooperative agreement, Research Topic of Interest 2010: Health Surveillance of Adults with Intellectual Disability.

Population Health and Intellectual Disability

Health surveillance, defined as the ongoing, systematic use of routinely collected health data to guide public health action in a timely fashion (Thacker & Berkelman, 1988) is a core public health activity. The goals of public health surveillance are to protect and promote health in the population under review and to inform interventions that prevent injury, (secondary) disability, and death. Adequate public health surveillance supports the framing of research questions and ‘problems’ for policy makers, a necessary step for public health to serve as an agent of positive change.

Disability in public health has undergone a paradigm shift in which the presence of a disability is not only seen as a health outcome but is used to define a population that may experience unique health outcomes (Rimmer, 2011). Functional limitations, environmental influences, and prevention of secondary outcomes are gaining increased recognition as important measures of health in the population with disability, including those with intellectual disability (Lollar & Crews, 2003; Krahn & Campbell, 2011).

Specific Challenges in Defining the Population with ID for Health Surveillance in the United States

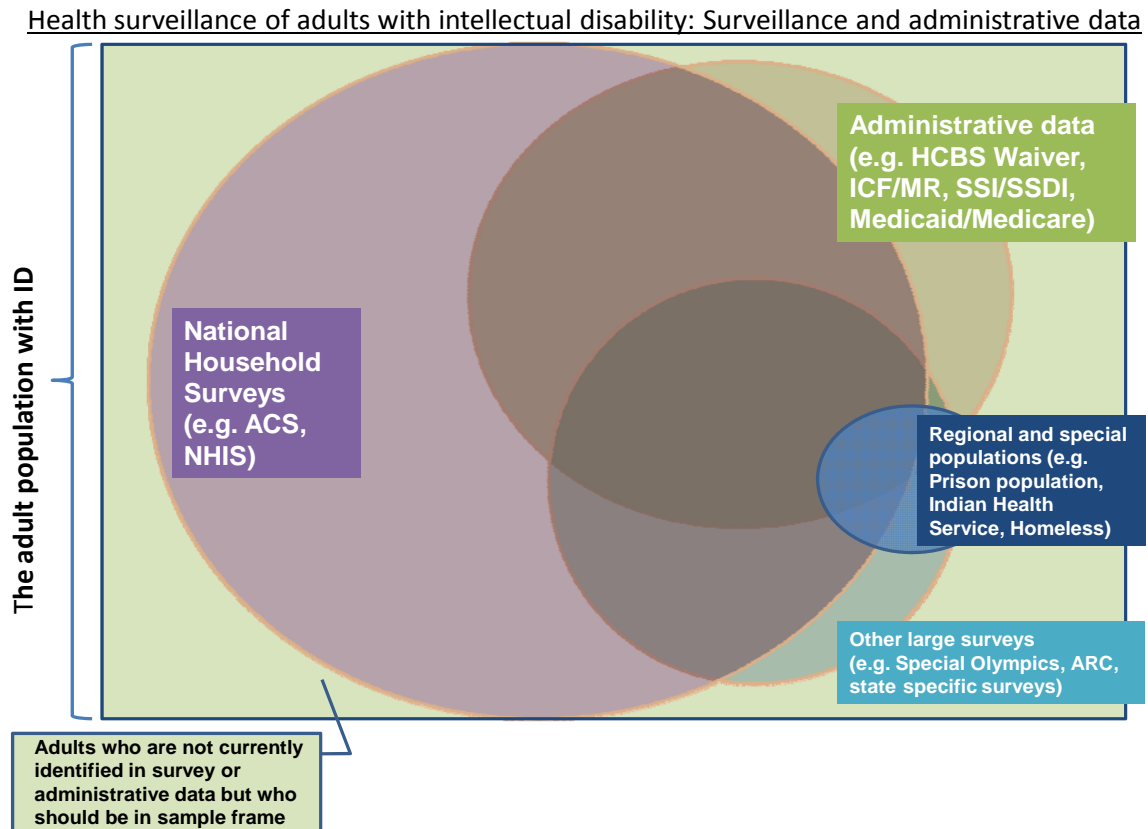
In the case of intellectual disability, health surveillance as a public health function is hampered in several ways. National surveillance efforts in the United States query for the presence of disability through functional means or by diagnostic categories but do not allow for clear distinction of either type of disability or the sub-population with intellectual disability.

Livermore and She (2007) describe the extensive data collections that query for or identify people with disabilities in the United States, both from national surveys such as the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey (NHIS) and from data collected in the administration of major disability support programs at the state and federal level. In the United States, hundreds of data sources may include information from individuals with disabilities, yet the quality of data and information that may be gleaned from them is often compromised by limited ability to identify this subpopulation and to overcome inconsistencies in the definition of disability.

Improving health surveillance will require government and researchers to establish means to use both administrative and survey data to identify the national population with intellectual disability and routinely monitor health outcomes (Krahn et al., 2010). The following figure depicts a model of the incomplete but overlapping populations captured by National Household Surveys, administrative data, large scale surveys of the ID-specific population, and other surveys and administrative data in sub-populations in which people with ID who are not identified elsewhere may be identified. Of note in this model is the population that is not included in any of the ovals or sample frames: those who are not identified in national or specific surveys or in administrative data. There is likely a portion of the

population with ID who are not routinely included in surveys due to difficulty with communication, variable use of proxy responses, or stigma resulting in reluctance to identify self or others with an ID.

Figure 1: Adults with ID in major data sources



Current data collection at the national level demonstrates ongoing challenges. For example, an analysis of data collected in the National Health Interview Survey (NHIS) determined that approaches to estimate the prevalence of intellectual disability with the definitions used in analyses of the *ad hoc* National Health Interview Survey on Disability (NHIS-D, 1994-1995) estimated a population prevalence with intellectual disability that was only one third of that estimated by the detailed NHIS-D (Hendershot et al., 2005). The NHIS, which includes questions about functional and diagnostic health issues, clearly does not effectively capture and identify people with intellectual disability at the national level.

In response to requirements of Section 4203 of the Affordable Care Act of 2010, the US Department of Health and Human Services developed draft standards for data collection on race, ethnicity, sex, primary language and disability status (US HHS 2011). The draft standards on disability status were promulgated in July 2011 for public review and ultimately adopted for use in national data collection such as the CPS and ACS in October 2011 are as follows:

- 1. Are you deaf or do you have serious difficulty hearing?**
- 2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?**
- 3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)**
- 4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)**
- 5. Do you have difficulty dressing or bathing? (5 years old or older)**
- 6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)**

These questions are in use by the Current Population Survey (CPS) and the American Community Survey (ACS), two of the largest and most important federal government surveys used nationally by both academics and policy-makers.

The law requires the use of data collection standards for health and disability measures, to the extent practicable, in all national population health surveys. This is a basic requirement, with optional additions for any survey. The proposed data standards do not however improve the ability of the national surveillance system to distinguish between individuals who have intellectual or developmental disabilities, a cognitive disability that was developed later in life or resulted from injury, or cognitive limitations secondary to a psychiatric condition. While a standards-based approach is essential in disability surveillance, the population with intellectual disability will not be served in any specific or helpful manner from the questions as proposed. Scheepers et al (2005) argued strongly against simply including people with intellectual disability within the broader 'disability' group in national and international health data collection efforts with the following assertions:

- Persons with ID should not be subsumed into a broad "disability population" definition, because additional factors, which may affect health outcomes, play significant roles that require specific attention to the needs of people with a range of syndromes, but having in common cognitive difficulties.
- Surveys and data systems should identify persons with ID, as recognition can then be used to facilitate measurement of all aspects of health and reduce health disparities.
[Scheepers et al 2005, page 250]

International Disability Data Standards

The Washington Group on Disability Statistics (WG), a group sponsored by the United Nations Statistics Division, has developed questions that are recommended for inclusion in national surveys. These questions are similar to those adopted by HHS (above) but allow for a distinction in level of difficulty the person experiences. The six questions query functional difficulties in a range of areas including communication, mobility, self care, sensory issues, concentration and memory, with four possible responses possible for each: No – no difficulty; Yes – some difficulty; Yes – a lot of difficulty; Cannot do at all. The Washington Group proposed set of 6 questions are as follows.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

These questions are proposed as a means to identify those in the population at greatest risk of a participation restriction because of disability, health surveillance is not the identified goal. In terms of population identification, the Washington Group clearly identifies the population with intellectual disability as being unlikely to be captured in a representative fashion. (Washington Group, 2009a).

National and Consensus Definitions of Intellectual Disability

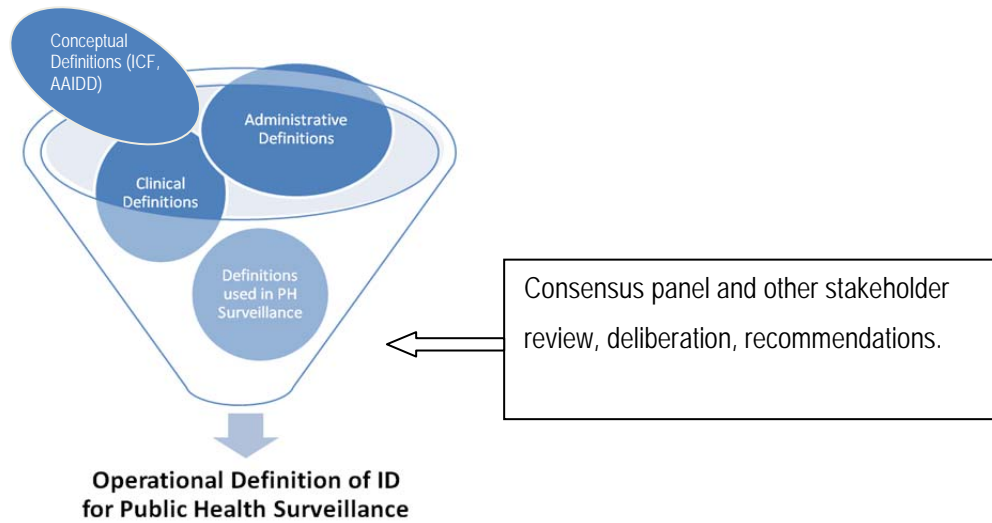
The definition of intellectual disability (and the previously used term ‘mental retardation’) has been the subject of intense discussion for more than 50 years. Efforts to align it with a shifting view of disability, changing social and clinical approaches to intellectual disability, and advances in measurement theory have necessitated multiple revisions in how this population is defined (Schalock, R. et al., 2007). National definitions do exist, yet they remain closer to a conceptual schema and are not consistently operationalized or applied in current data collection efforts that might be useful for health surveillance.

Method

To reach a feasible recommendation for a definition that may be used for national health surveillance, input from a wide range of sources needed to be considered. The project team reviewed nationally and internationally accepted clinical and conceptual definitions, and considered how the population definitions of those with ‘intellectual disability’, ‘developmental disability’, ‘cognitive disability’ and ‘disability’ are being applied in major research efforts. Recognizing that surveillance questions could be addressed through a combination of both administrative and existing public health surveillance data sources, the project needed to consider definitions used in each of these sources, as well as existing conceptual definitions.

The project team proposed a process that would use conceptual definitions of intellectual disability to drive toward a consensus definition of intellectual disability (deductive approach), taking into consideration the definitions that currently are in use (inductive approach). The following figure depicts an (over) simplified model the project team used to conceptualize and describe the desired inputs.

Figure 2: Schematic view of inputs for definition



A National Summit meeting to develop recommendations for an operational definition of the adult population with intellectual disability for national health surveillance.

A consensus panel approach was used. National experts including researchers, self advocates and family members, representatives of national advocacy organizations, and government agencies were convened in a one day summit to review existing definitions, define the population that should be included for health surveillance, and provide recommendations for operationalizing the definition. The input of people with intellectual disability themselves was included both through participation in the consensus panel and in follow-up communications with the national organization Self Advocates Becoming Empowered (SABE). Appendix A includes the participant list (page31).

Prior to the meeting, the project team developed a review of definitions used in major data collection and/or survey efforts and in eligibility for state I/DD services. For discussion with the summit attendees, the multiple elements of each definition were organized into 'domains'. These domains are based on the 'multiple dimensional framework for understanding intellectual disability' proposed by the American Association on Intellectual and Developmental Disability (AAIDD, 2010). Their relationship with the International Classification of Function, Disability and Health (ICF) is outlined in the following table.

Table 1: Crosswalk of domains associated with AAIDD definition and ICF

		International Classification of Functioning, Disability, and Health (ICF)				
		Health Conditions (ICD)	Body Functions and Structures ¹	Activities and Participation	Environmental Factors	Personal Factors
Dimensions of the AAIDD conceptual framework of human functioning (2010)	Intellectual Abilities		■			■
	Adaptive Behavior (skills that are learned and performed in everyday life)			■		
	Health (Mental and physical health issues)	■	■			■
	Participation (Performance in roles that are expected in home, work, education, leisure, spiritual, and cultural setting)			■		
	Context (The immediate social setting, the community, and the overarching cultural, societal, policy influence.)				■	
Modified crosswalk from W. Buntinx in 'What is Mental Retardation?' (Switsky and Greenspan, 2006) (p.319) AAIDD domains updated to 2010 from the 2002 AAMR definition used in the original crosswalk.						
¹ The ICF classification scheme includes mental or intellectual functioning as part of "Body Functions and Structures". The classification code 'b117' includes "general mental functions, required to understand and constructively integrate the various mental functions, including all cognitive functions and their development over the lifespan". Included is: functions of intellectual growth, intellectual retardation, mental retardation, and dementia. Excluded is: memory functions (b144), thought functions (b160); higher level cognitive functions (b164)						

Table 2 illustrates the domains that were considered, in order to structure deliberations, in a crosswalk with the current major definitions used for legal, clinical, research, and eligibility purposes. The eligibility for state ID/D services were included in this crosswalk as the definitions are very relevant to the ultimate goal of population identification and surveillance, but it should be noted that state-level definitions are variable and based on the other definitions in the crosswalk. It should also be noted that 'Context' is included in the AAIDD framework. This is an important domain in the current conceptualization of disability as described in the ICF, yet current definitions have not successfully

incorporated language that describes the person’s interaction with their environment, or the context in which they live.

Two additional, more specific, domains were added for discussion by summit participants: ‘age of onset’ and ‘support needs’. These were not specified in the multidimensional framework proposed by AAIDD, but were included as specific domains to consider by the summit participants because they are specified in several definitions and would likely be used to operationalize the population definition.

Table 2: Domains applied to major definitions

DOMAIN	AAIDD	DD Act	SSI/SSDI	State ID/D Services ¹	ICD-10	DSM-V
1. Intellectual Abilities	■		■	○	■	■
2. Adaptive Behavior		■	■	○		■
3. Health			■	○	■	■
4. Participation		■	■	○		
5. Context						
Age of onset*	■	■	■	○		■
Support needs*	■	■		○		■
¹ State definitions of intellectual disability for eligibility for state-funded services vary and are based on the other definitions identified in this grid. States use some or all of the domains indicated.						

Consensus group members deliberated and proposed guidance for an operational definition, using the following assumptions.

1. Focus for surveillance is to be on **adults** with intellectual disability, recognizing that life-span considerations are important.
2. Focus on health surveillance (only), recognizing that health is one of many important areas of quality of life that include participation, employment, and meaningful social experiences.
3. Intellectual Disability = Mental Retardation. Changes in State and Federal statutes to replace ‘mental retardation’, with ‘intellectual disability’ have specified that the terms should be considered synonymous for the purposes of service eligibility and delivery.
4. Health surveillance demands the use of samples that are representative of the population. The group recognized that efforts to characterize the population to date have mostly been one-time studies or samples of convenience, and that a full understanding of the population is essential in order to gather meaningful information.
5. Ethical issues related to labeling must be considered. Intellectual disability (and mental retardation) may be perceived as negative labels by either a person who has an intellectual disability or people who care about them. The group was mindful that there must be sensitivity to this issue that carries throughout efforts to build surveillance.

6. The definition of intellectual disability under discussion was primarily for health surveillance and was not intended to modify or propose changes to eligibility for services or supports.
7. Definition recommendations need to accommodate ('fit over') current, ongoing, and any *de novo* data collection efforts.

At the conclusion of the summit, the project team compiled notes and a preliminary definition for review by the summit participants. Summit notes are attached as Appendix B (page33).

The project team incorporated feedback into a draft definition that was presented at the 'Health Frontier for Intellectual Disability' conference (May 2011, Bethesda MD)² which was attended by national and international policy makers and experts in health and health surveillance efforts in the population with ID.

A second round of feedback from the conference participants was incorporated and developed into final recommendations which are presented in the following section.

² Sponsored by NCBDDD, CDC (National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention), and Administration on Developmental Disabilities (ADD) under Contract to the Association of University Centers on Disabilities (AUCD)

The Operational Definition of Intellectual Disability for the Purpose of National Health Surveillance

Final Draft Recommendations

Public health surveillance demands uniformity, simplicity, and brevity. The operational definition of intellectual disability must stem from an agreed-upon conceptual definition that can be used to describe the population for general or lay audiences as well as public health officials (CDC, 1990).

The recommended ID definition for national health surveillance is therefore presented in three components:

1. A ***conceptual (population) definition***, describes narratively the population to be included in the health surveillance system. This definition includes those identified in the operational definition and is intended for use in policy documents in which a description of the population must be clear and understandable;
2. An ***operational definition*** that resulted from the consensus panel and subsequent revisions. The dimension of the disability to which each item corresponds is indicated by square brackets. This definition is intended for use by researchers/analysts and provides specific descriptions of populations that should be identified through surveys or secondary data analyses;
3. A series of ***'pathways'*** by which population groups or individuals would be identified and included in the 'national population with ID' for the purpose of health surveillance. The pathways are useful for operationalizing the definition, and for understanding how the use of certain methods may affect the inclusion or exclusion of portions of the population with ID.

Conceptual Description of the Population to be Included in National Health Surveillance.

The population of adults with intellectual disability includes people who:

1. Have intellectual limitations* that significantly limit the person's ability to successfully participate in normal day-to-day activities such as self care, communication, work, or going to school, **and**
2. Developed the intellectual limitation during the 'developmental period' (before approximately age 22), **and**
3. Have an intellectual limitation that is anticipated to result in long-term adaptive or functional support needs, **and/or**
4. Are eligible for State or Federal public support programs because they have been diagnosed as having an intellectual disability.

* The World Health Organization's International Classification of Diseases and Related Health Problems (ICD), defines four levels of intellectual limitations, based on IQ score: mild (IQ of 50-70), moderate (IQ of 35-49), severe (IQ of 20-34) and profound (IQ of under 20).

By definition, the population does not include:

- People who have a related condition such as Autism Spectrum Disorder (ASD) or severe and persistent mental illness but no evidence of significant intellectual limitations.
- People who develop a cognitive limitation due to injury, illness, or dementia after becoming adults.

Operational Definition of Intellectual Disability for the Purpose of Health Surveillance

****** If a person can be included in the first four categories (#1, #2, #3, and #4), OR this person is in the fifth (#5) category, then this person will be considered to be an 'Adult with Intellectual Disability' by researchers when collecting information about population health. ******

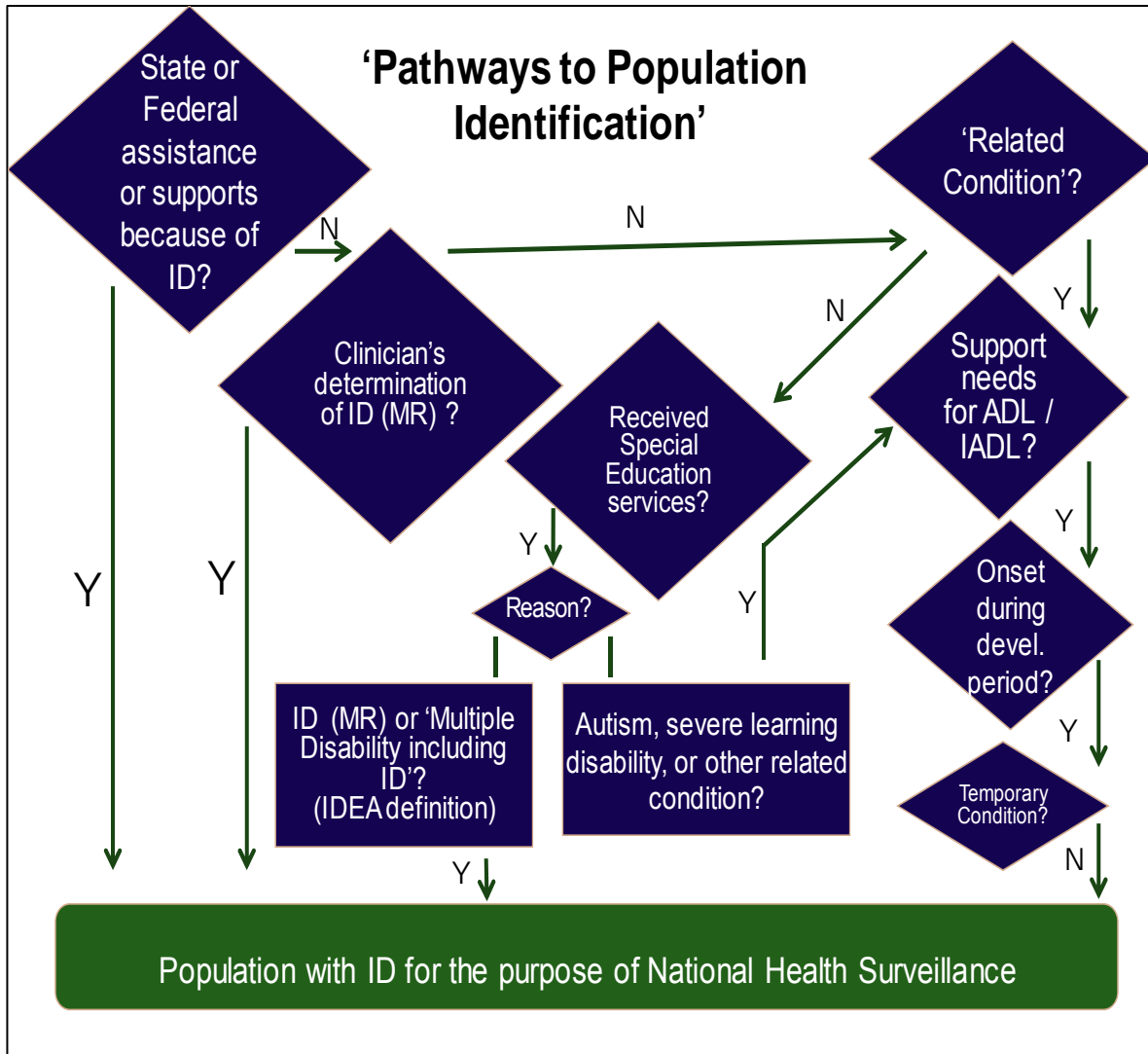
- [#1] Person has been tested and has an IQ score of approximately 70 or below, OR a clinician has told the person that they have an intellectual disability, OR the person has a "related condition" along with support needs because of difficulties in learning, concentrating, or problem solving. Related conditions are specific diagnoses that often cause an intellectual disability, such as Down Syndrome or Prader-Willi Syndrome. [Intellectual Abilities and Related conditions]
- AND [#2] person needs support with activities of daily living (ADL) or instrumental activities of daily living (IADL). These are things like dressing, bathing, shopping, cooking, transportation, communication, or money management. Support can be 'formal' (for example, staff, help with housing, Social Security if a person can't work), or 'informal' (family or friends helping). [Adaptive behavior]
- AND [#3] person was diagnosed with an intellectual disability or related condition in the 'developmental period'. The time in a person's life from childhood to becoming an adult is called the 'Developmental Period.' [Age of onset]
- AND [#4] person is expected to have the intellectual limitation their entire life. Depending on the person's life circumstances, they may need formal or informal supports for their entire life in order to participate and live in their community. [Life-long]
- OR [#5] person is eligible for State or Federal public support programs because they have an intellectual disability. Examples of public support programs are SSI, SSDI, other federal programs that specifically support people with a disability or services from a state disability agency. [Support needs]

Pathways to Identifying the Population with Intellectual Disability for National Health Surveillance

This section provides pathways to operationalize the definition previously presented to assist researchers in case identification (beyond state and federal eligibility). The questions are ordered with data availability in mind to guide researchers through an efficient case identification by starting with pathways with a high specificity, and moving toward more sensitive pathways. Figure 1 provides a visual organization of the following pathways.

1. Has the person been determined eligible for an ID-specific program (i.e. state ID-specific (not DD) service system, or SSI because of an intellectual disability)?
(If yes, include. A yes to this question is sufficient due to the criteria used in the eligibility process for ID-specific services and the accompanying support need for which they are seeking services.)
2. Does the person have an IQ score of approximately 70 or below (2 or more standard deviations below the mean) on an ‘individualized, standardized, culturally appropriate, psychometrically sound test’, or a determination by a clinician that the individual has an intellectual disability (i.e. using ICD-9+ or DSM-IV+)?
(If yes, include. A yes to this question is sufficient due to the criteria in ICD or DSM and it is assumed the person has support needs related to this disability.)
3. Has the person been diagnosed with a ‘related condition’ (neurodevelopmental disorders), including those named within state DD services eligibility, with evidence of ‘difficulties in learning, concentrating, or problem solving’. A list of ICD-10 (or ICD-9) ‘related conditions’ may be defined.
 - a. If yes, does the person require support needs for activities of daily living? *(Yes required for inclusion.)*
 - b. If yes, was the onset during a developmental period? *(Yes required for inclusion)*
 - c. If yes, is the condition temporary? *(No required for inclusion)**Criteria of all three steps of this question are necessary and sufficient together for inclusion.*
4. Does the person have a history of receiving special education? *(Yes required for inclusion)*
 - a. If known, through what special education category did the person receive services? *(If ‘Intellectual Disability’ or ‘Mental Retardation’, then sufficient for inclusion. If ‘Autism’ or other related condition, continue screening. If ‘Multiple Disabilities’, is ID part of the disability combination? If yes, continue screening. If no, exclude.)*
 - b. Does the person have support needs for activities of daily living due to their intellectual disability? *(Yes required for inclusion, unless sufficient evidence in 4a.)*
 - i. If yes, has the person always needed support with daily living activities? *(Yes required for inclusion.)*
 - ii. If yes, is the condition temporary? *(No required for inclusion.)*

Figure 3: Pathways to Population Identification



'Related conditions' as a means to identify the population

Step #3 of the 'Pathways' approach identifies the use of 'related conditions' (neurodevelopmental disorders) to enhance the ability of researchers to define and identify the population that may not otherwise be included in the sample. This step considers those who are not currently identified or receiving support due to an intellectual disability, but do have an intellectual disability due to a neurodevelopmental disorder, and therefore are of interest for public health surveillance. Conditions must be defined as clinical diagnoses and can be identified in various ways, depending on the methods used. Examples of these methods are review of medical records, queries in administrative data for ICD or DSM codes, or the implementation of a detailed survey questionnaire such as in the NHIS-D.

The analyses of the NHIS-D reported related conditions by Larson et al. (2000) provide a good foundation and methodological approach to defining the population by combining both functional responses and clinical diagnoses of both 'mental retardation' and those diagnoses identified as 'related conditions'. Additional work to validate the use of identified 'related conditions' is necessary to establish the feasibility of using this approach to identify the population with ID in existing or future data sets. This is discussed further in the accompanying 'Recommendations for Expanding Surveillance of Adults with Intellectual Disability' report.

Table 3 provides a review of the use of ICD-9 (and ICD-10) codes to assist with identifying the population in several studies. The fact that the use of clinical diagnoses varies across studies emphasizes the necessity of further work to establish utility of this approach to define and identify the population. DSM coding, when available in administrative datasets have proven useful as well (NZ Ministry of Health, 2011) and may be a feasible method to further screen for or identify the population, as detailed in the 'related conditions' step in the proposed 'Pathways' approach.

Table 3: Use of Diagnostic (ICD) codes in identifying the population with ID

Diagnoses that give definite indication of intellectual Disability	ICD-9 code ⁺	ICD-10 code ⁺	Allagar (2008) ¹	Slyater (2010) ²	Larson (2000) ^{3*}	Larson(2004) ⁴
Mild Mental Retardation	317	F 70	x	x	x	x
Moderate Mental Retardation	318.0	F 71	x	x	x	x
Severe Mental Retardation	318.1	F72	x	x	x	x
Profound Mental Retardation	318.2	F 73	x	x	x	x
Unspecified Mental Retardation	319	F 79	x	x	x	x
Fragile X Syndrome	759.83	Q 99.2	x			
Prader-Willi Syndrome	759.81	Q 87.1	x			x
Down Syndrome	758.0	Q90.9	x		x	x
Rett Syndrome	330.8	F84.2	x			
Screening statement of MR or Developmental disabilities						x
<hr/>						
Identified diagnoses that give possible indication of Intellectual Disability and need to be verified with additional records and/or evidence of functional limitation (ICD coding may require levels of sub-coding. Detail not included in this analysis)			Allagar (2008) ¹	Slyater (2010) ²	Larson (2000) ^{3*}	Larson(2004) ⁴
Aphasia						
Attention Deficit Disorder Disorders						
Autistic Disorders				x	x	x
Bardet-Biedl						x
Branched Chain Amino Acid Disturbance					x	
Cerebral Palsy, unspecified						*in combination with other diagnoses
Congenital Anomaly					x	
Congenital Hypothyroidism					x	x
Congenital Syphilis					x	
Copper metabolic syndrome					x	
Deformity of the skull					x	
Edward's Syndrome						x
Encephalopathy					x	
Epilepsy						*in combination with other diagnoses
Hyperkinesis with developmental delay						
Hyperkinetic conduct disorder (w/out developmental delay)						
Hydrocephalus						*in combination with other diagnoses

[Continued from prev page] Identified diagnoses that give possible indication of Intellectual Disability and need to be verified with additional records and/or evidence of functional limitation (ICD coding may require levels of sub-coding. Detail not included in this analysis)	Allagar (2008) ¹	Slayter (2010) ²	Larson (2000) ^{3*}	Larson(2004) ⁴
Infantile autism				x
Infantile cerebral palsy				*in combination with other diagnoses
Klinefelter's Syndrome	x		x	x
Leukodystrophy			x	
Lipidoses			x	
Noxious Substances affecting Newborn			x	
Marfan syndrome				
Mixed developmental disorder				
Other brain or CNS condition or deformities			x	
Other specific learning difficulties				
Other specified delay in development				
Patau's Syndrome				x
Reduction Deformity of the brain			x	
Sex chromosome anomaly			x	x
Spina bifida			x	
Thalasseмииs			x	
Tuberous Sclerosis			x	x
Unknown Congenital or birth injury			x	
Unspecified delay in development				
<p>⁺ ICD coding provides general codes. Specific sub-codes may be associated with each diagnosis. [*]This analysis of the NHIS defined the population using reported diagnostic categories (in interviews) but not ICD-9 codes. It is included because the 'related conditions' identified through this analysis are useful for future work to operationalize the population.</p> <p>¹Allgar, V, Mir, G. Evans, J., Marshall J, Cotrell, D., Heywood, P., Emerson, E. (2008) Estimating prevalence of people with learning disabilities: template for general practice. British Journal of General Practice June 2008, 423-431. ²Slayter, E. (2010). Demographic and clinical characteristics of people with Intellectual disabilities with and without substance abuse - Disorders in a Medicaid population. Intellectual and Developmental Disabilities 48(6), 417-431. ³Larson, S., Lakin, C. , Anderson, L . et al (2000) Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D MR/DD Data Brief April 2000, Vol. 2. No. 1 Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota ⁴Larson, S. (2004) Minimum Dataset Fact Sheet: gender and ethnicity of nursing home residents with and without intellectual or developmental disabilities in 2000. Research and Training Center on Community Living, University of Minnesota. Accessed November 15, 2011 www.rtc.umn.edu/misc/pubcount.asp?publicationid=82</p>				

Discussion

The operational definition presented in this paper was developed to guide case definition in both existing and new data collection. With a broad range of potential applications, designed to address a complex social phenomenon such as intellectual disability, the definition offers overarching recommendations that can be applied to emerging methodologies to improve health surveillance in the ID population. The multidimensional approach to identifying the population through both functional elements related to support needs and structured medical diagnoses (as in ICD-9 or ICD-10 codes from medical or administrative records) is considered essential in disability research (McDermott & Turk, 2011).

The three components of the recommendation: conceptual (population) definition; operational definition; and ‘pathways to identifying the population’ provide a broad description of the population to be included, as well as to guide researchers to clarify who belongs in the sample frame. The ‘Pathways to Identifying the Population with ID’ is a stepwise approach to efficiently identify early the largest possible population with a relatively high specificity (for example, those receiving services). Further steps with higher sensitivity can be used as resources and data availability allow to work toward a sample more representative of the diversity of this population.

Currently there is no one perfect solution for health surveillance among adults with intellectual disability in the United States. Pragmatists will recognize that efforts to improve health surveillance in this population may need to use samples that are as close as possible to a representative population with intellectual disability amid constraints in data availability and definitions applied when the data were collected. Significant work remains to be done to fully understand the demographics of the population with intellectual disability. It is the intention and hope that the recommendations for an operational definition in this report, together with the conceptual description and pathways to application, will serve to help frame the population that ‘should’ be included in US national health surveillance, and how data collection efforts may be improved in the future.

Inclusiveness of the population definition

When considering health surveillance, the summit participants noted that there is value in broadly defining the population with intellectual disability, as it can result in a defined population size that supports greater attention and advocacy efforts. On the other hand, this population definition may result in including people who do not identify themselves with the label ‘intellectual disability’ (or possibly any disability), who may not have an intellectual disability, and who may have a different health experience than those with ID. Concerns about labeling and stigma in this population were expressed by several participants and must be considered in future efforts to identify this population.

Etiology as a component of the definition of Intellectual Disability

The cause of an intellectual disability can be identified in over 50- 60% of cases (AAIDD, 2011). From a clinical perspective, the etiology or cause of the intellectual disability may be as important as monitoring the population health outcomes. Intellectual limitations can result from a range of genetic, environmental, perinatal, and other causes, each of which may in turn be associated with increased risk of co-morbid conditions. Such heterogeneous etiology drives increasing effort on the part of clinicians to identify the cause of an intellectual disability so prevention and health promotion efforts can be targeted to the risks particular to a syndrome or condition that may be present (Sullivan et al., 2011). Diagnoses are also useful means of identifying people who have recognizable conditions that cause intellectual disability, such as Down Syndrome. The etiology of intellectual disability is essential to clinical treatment, as discussed by several participants in the operational definition summit. (Appendix C)

Since not all cases of intellectual disability can be ascribed to a genetic or clinical condition, a functional approach is essential as well. Intellectual disability is a complex association between etiology, the environment, and the roles an individual must play in society. In the ICF model of disability, a clinical diagnosis does not adequately describe or predict an individual's experience. The Washington Group on Disability Statistics cautioned against basing disability statistics (and population definitions) primarily around 'diagnosable conditions' because of challenges in reliability of reporting from individuals, as well as bias that can be introduced in data from proxy respondents, correlations with education, socio-economic status, and access to health services (Washington Group, 2009b).

Application in existing datasets

In the case of existing data, the definition of the population is pre-defined in the purpose and method of data collection. Few large surveys capture the level of detail that allows follow-up analyses to later identify the population with ID. In some cases, variables have been used to construct a detailed population definition (as in the NHIS-D), but often the population captured only includes those who meet eligibility requirements to participate in a service or support program, or those who are broadly included in a 'cognitive impairment' group, as in disability questions in the ACS [reference].

Administrative data may be used to capture the population that is identified with an intellectual disability for the purpose of receiving federal or state services. This is expected to include a significant portion of the population. The National Core Indicators (NCI) survey in participating states includes questions that collect information on whether the person in the sample has an intellectual disability. The application of the operational definition serves to highlight the populations (such as those who received special education) who may be considered to be part of the population with intellectual disability, and who would need to be included for an analysis to more fully represent the US population with intellectual disability.

For existing surveys, the operational definition can serve two purposes. First, it provides a means to identify a segment of the population that currently is not likely to be captured. For example, the application of this definition to a dataset based on responses to the two BRFSS questions or the six ACS disability questions demonstrates that the population cannot be distinguished from those with other cognitive or mental impairments due to the manner in which the data were collected. Second, the recommendations may be used to suggest modifications to survey questions that would better define the population. For example, a broad question about history in special education may be used in conjunction with questions about current functional status and any diagnostic information.

What does the term ‘intellectual disability’ mean to most people?

Intellectual disability, a term used for many years in other parts of the world, is still a relatively new term in the United States. Despite significant advocacy that resulted in legislative changes and a major media campaign to remove ‘mental retardation’ (‘The R Word’) from use, the term remains in clinical and diagnostic terminology and may be more familiar to individuals and families who have not followed the issues in this field. Similarly, ‘learning disability’ may be more familiar but describes a broad range of learning challenges in the United States but is used in the United Kingdom to mean ‘intellectual disability’. While ‘intellectual disability’ is supposed to be a synonym for ‘mental retardation’ (Schalock et. al., 2007), there is little research into the understanding of this shift among the general population, or how deep this term had penetrated into the American lexicon. A quick review of the term ‘intellectual disability’ in the commonly used website Wikipedia reveals a definition that does not comply with any of the conceptual or diagnostic definitions here discussed, including a statement that the onset can occur at any point in life.³ For national surveillance, cognitive testing of questions and the use of the term ‘intellectual disability’ (or any terminology used in screening questions) is essential.

Developmental disability/Intellectual disability and Autism Spectrum Disorders

The concepts of intellectual and developmental disability are interrelated but are not the same, and are often grouped together for reporting and service provision. States vary in their eligibility requirements, with some including those only with intellectual disability, and others applying a broader ‘developmental disability’ framework to eligibility.

The operational definition recommended in this report is similar to the definition laid out in the US Developmental Disabilities Assistance and Bill of Rights Act (2000) except that the operational definition of intellectual disability specifies that an intellectual limitation must be present. Intellectual disability is

³ The author has inserted links to AAIDD definition page on Wikipedia. The author’s experiments with modifications the text of the definition on the Wikipedia page have been ‘reversed’ on several occasions by the cadre of editors monitoring revisions, with notes regarding the need to be inclusive or to focus beyond American definitions.

thus a sub-set of ‘developmental disability’, which is broader and encompasses both physical and mental impairments that became evident during the developmental period. Larson et al (2000) reported from the NHIS-D analyses that approximately one-third of the population within ‘Intellectual and Developmental Disability’ had only a developmental disability. The distinction is an important one for health surveillance. Examining health disparities related to health care access, utilization, and health behaviors specific to the population with intellectual disability may suggest public health actions that could not otherwise be identified.

Autism Spectrum Disorders (ASD) are a developmental disability that continue to be increasingly identified in national surveys and administrative records (CDC, 2009). Up to 70% of children with ASD also experience intellectual disability (Yeargin-Allsopp et.al., 2003). A review of IDEA Special Education services eligibility criteria have demonstrated an increasing trend in ASD diagnoses (Newschaffer, Falb, and Gurney, 2005). Rates of the identification of autism vary by ethnic group and the presence of an intellectual disability has been demonstrated to influence the identification and diagnosis of autism (Mandell, 2009). The overlap and relative incidence of ASD and intellectual disability is an important consideration in future surveillance. As with the discussion related to developmental disabilities (of which autism is one), the presence of an intellectual disability is an important factor for health surveillance.

Cognitive Impairment and Intellectual Disability

The American Community Survey and CPS Questions contain one question which can be used to identify the group that self identifies as having to have a ‘cognitive disability’:

Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

As it is presented, the question does not allow for analysis to distinguish intellectual disability from age-related or other dementia, from an injury, from a short-term issue affecting cognition, or from significant long-term mental illness. The 2010 American Community survey identified 41.7% of the population who identified with any disability (4.2% of the total population) as having a cognitive disability. Studies of the health of this population have identified increased risk of mortality in those over 60, but it is unclear what portion may be those with an intellectual disability (Sachs et al., 2011). Braddock (2010) estimated the following distribution within the cognitive disability group.

Table 4: Estimated prevalence of cognitive disability in the US

	Prevalence
Intellectual Disability	4.9 M (21%)
Severe, Persistent Mental Illness	6.6 M (29%)

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Brain Injury	6.2 M (27%)
Stroke	.8 M (3%)
Alzheimer's	4.63 M (20%)
Total Cognitive Disability	23.13 Million persons

Source: D. Braddock (2010) *The State of the States in Developmental Disabilities* Boulder, CO University of Colorado, Coleman Institute for Cognitive Disabilities

Work to further characterize the typical distribution within the ‘cognitive impairment’ group would help to better develop a model of a representative population of adults with intellectual disability.

Conclusion

Disability rates are projected to continue to rise, with a major driver of disability being the aging of the US population (Institute of Medicine, 2007). In this context, it is particularly important to better understand how to interpret the health of the population of adults with intellectual disability. The lifetime experience of a person with an intellectual limitation that emerged in childhood will likely be quite different from a person who develops a cognitive limitation later in life, and a surveillance system that does not recognize the unique life experience of intellectual disability will not do any service to this population or achieve the public health goal of reducing disparities among identified populations.

The multiple and complicated factors that influence the ability of a person with an intellectual disability to participate fully in society and to live a healthy life are at the core of the challenges that exist in surveillance. Yet complexity is not an excuse. It does, however suggest the need for a thoughtful and stepwise approach to uncover the most important influences on health in this population. The recommendations for an operational definition of the adult population with intellectual disability are just an initial step in the path toward representative health surveillance, but one that moves towards building upon the best available knowledge and the desire to ensure that people with intellectual disability are fully represented in the nation’s public health and policy decisions.

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Appendix B – Notes from Summit and preliminary operational definition

APRIL 13, 2011 Summit:

Developing an Operational Definition of Intellectual Disability for the purpose of Health Surveillance

Final Meeting Notes

On April 13th, 2011, national experts, researchers, and stakeholders⁴ met for a one-day summit in Marlborough, Massachusetts at the Special Olympics Yawkey Sports Training Center.

The goal of the discussion was to describe an overarching definition of the population of adults with Intellectual Disability (ID), and to create an operational definition that may be used to identify the population in current and future health surveillance efforts. The meeting began with a recognition that...

“For every complex problem there is an answer that is clear, simple ... and wrong.”

~ H.L. Mencken

Summit participants brought their knowledge and expertise to the day’s discussion in the spirit of advancing the efforts operationalize a definition of intellectual disability for the purpose of national health surveillance, recognizing there are multiple challenges to overcome in ensuring that the population is appropriately identified and ‘counted’.

Overview

The agenda⁵ for the morning was primarily devoted to ***framing the operational definition*** through a facilitated group process to identify and prioritize the essential elements of the definition of intellectual disability for the purpose of national health surveillance. The discussion and draft definition that

⁴ Attachment A

⁵ Attachment B

resulted are included in this document “ Summit Notes -Part 1: Framing an operational definition for the purpose of health surveillance.

The afternoon’s discussion focused on **refining the operational definition** through discussion of how the definition might be applied in current practice, and what methods might be used to identify the population as defined. The result of this discussion is included in “Summit Notes – Part 2: Pathways to Identifying the Population with ID.” This document concludes with next steps, and questions to be considered by summit participants and others.

Appendices include meeting materials and are available as a separate document.

Following the summit, the RTOI project team contacted executive board members of the, Self Advocates Becoming Empowered (SABE) to elicit additional input from self-advocates. Comments on the draft definition received at the time of writing are included in this draft

Opening Discussion (9:10 – 10:10)

The discussion was facilitated by Steve Staugaitis and Alixe Bonardi⁶. In opening comments, Gloria Krahn provided context for the day’s summit and encouraged the group to use this opportunity to move past the hurdles that present themselves when trying to define intellectual disabilities for health surveillance. Dr. Krahn’s comments are summarized below

At this stage, we have a good indication that people with disabilities, in general, have poorer health than people without disabilities from existing data. The subset of people with intellectual disabilities is thought to be a group that is at risk of not getting the attention they need in relation to health surveillance and policy; we require data to change this.

Health surveillance data for the general population has been collected and reported in several ways, but there continue to be methodological challenges in identification and collection of health outcomes in the population with ID. Instead of issuing an RFR to have another group try to collect the data, the suggestion was to take a step back from the data collection in order to strategize about how to reach what is thought to be a representative population of people with ID and the key variables for health surveillance. For example, what do we mean when we talk about ‘people with ID’?

This summit is one component of a cumulative set of activities:

The Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities, in collaboration with the Association of University Centers on Disabilities (AUCD), convened a meeting in September 2009 to consider the feasibility of

⁶ Steven Staugaitis and Alixe Bonardi are RTOI project team members. Alixe Bonardi is the RTOI Principal Investigator.

conducting population-based surveillance of the health status of adults with an ID. From that meeting, domains for a minimum dataset of health indicators were identified, along with an action plan comprising the following five steps:

1. Define ID operationally using shared experiences and expertise from key stakeholders, in ways that are clinically, functionally, and operationally valid. Determine the feasibility and approaches to including people across the full range of IDs so that people with an ID can be identified at the population level.
2. Compile and synthesize a knowledge base of research, practices, policies, and procedures, including data sources and surveillance techniques that summarize our understanding of ID and the relationship of ID to health, community participation, and public health practice.
3. Extend past analyses of existing data sources that capture health information for people with ID in ways that provide a more complete delineation of needs and possible justification for enhanced surveillance.
4. Pilot state or regional demonstrations to explore the feasibility of comprehensive efforts to implement effective surveillance methodologies for people with ID using multiple approaches.
5. Develop sustainable approaches to expand surveillance that might include conducting a national survey or linking new surveillance tools to existing surveys.

A panel convened in February 2010 found there was a need/interest in this data from federal agencies, and also a sense of urgency. Dr. Krahn urged the group not to get caught up with how difficult the task is – it's important that progress is made. Within CDC, the Affordable Care Act (ACA) Work Group is moving forward on efforts to identify the disability population, as required by the ACA.⁷

Preparation for Summit

Participants prepared for the Operational Definition Summit discussion through:

1. Participation in a pre-conference call (March 1, 2011) to review goals and assumptions prior to the meeting.

Assumptions that were reviewed and discussed in advance included:

⁷ Affordable Care Act Section 4302. Understanding Health Disparities: Data Collection and Analyses includes a requirement that a 'federally conducted or supported health care or public health program, activity, or survey ... collects and reports, to the extent practicable.... sufficient data to generate statistically reliable estimates by racial, ethnic, sex, primary language, and **disability status** subgroups'.

- i. The focus for this project is to develop a definition that applies to adults with intellectual disability.
- ii. Health surveillance is the primary purpose of the definition being discussed today, recognizing that health is one of many important areas of quality of life.
- iii. Intellectual Disability = Mental Retardation. The group agreed to use the term Intellectual Disability as a direct synonym for the term 'mental retardation' that is being replaced in legislation and regulation.
- iv. Health surveillance demands a representative population. This implies that there is a research imperative to establish means to understand the population that may not currently be identified in surveillance.
- v. Ethical issues of labeling must be considered. Intellectual disability as a label or a diagnosis can be associated with negative perceptions or stereotypes. It has the potential to influence case identification or have unintended effects on subjects of surveillance.

2. Review of materials developed by the RTOI project team and distributed prior to the summit ("Definitions of Intellectual Disability in National Data Systems").

Clarifying Purpose and Context

During the opening comments on April 13th, group members framed important contextual questions and comments, which are summarized below.

What is the audience for the health surveillance conducted with this definition?

The main audience is public policy makers. The lack of sound population surveillance that is available to the CDC and other federal agencies is the primary reason that this effort is underway. It is anticipated that the information gained through this effort will subsequently be used to inform education and practice of health care providers, as well as positively influence other areas.

Susan Havercamp described the vision for this process in this way: "Once we have a definition, and once we are able to collect good information about the population's health, then we can write policy briefs that really inform education and practice."

The definition proposed by this process is not intended to directly influence eligibility for state-funded supports and services specific to the population with intellectual disability.

"It's hard to consider an operational definition without the context of what we're doing with it."

Val Bradley offered the comment "Unless we assume that there will be sufficient money out there to do a *de novo* survey, which I doubt, this effort will have to be highly reliant on extracting information out of existing data. Whatever we come up with has to be a template that can fit over a number of different data collection efforts."

The intended use of this definition is two-pronged – both to provide a structure for defining the population and making use of data that is currently collected AND for use in work going forward.

For future surveillance, the goal is to clarify the population that should be identified by national health surveillance, thereby informing survey processes and methods used in any new surveillance efforts.

Guiding Principles:

Participants agreed that the definition should:

- Be useful in the future funding and political climates that may be markedly different from current conditions.
- Refrain from putting a negative value on people with intellectual disabilities, and instead emphasize that they have significant value as participants in society.
- Include a functional component to the inclusion criteria, and should not solely be based upon IQ scores.
- Be inclusive of people with Intellectual Disabilities who do not receive services from the state I/DD-specific service systems, and should therefore go beyond service eligibility definitions.

Specifically:

To create an inclusive definition for health surveillance, it's important to think beyond criteria used for service eligibility in various systems.

There are many people outside of these service systems that have an I/DD that affects their health. Service eligibility is politically- and financially-driven, and in the current financial and political climates, it's likely that the group of people outside of this traditional service system will increase. In the meeting held in September 2009, participants were sensitive to the fact that data may suggest a certain population prevalence of I/DD at the end of high school. For example, data presented at that meeting from Alabama suggested a prevalence of about 3% of the population when looking at school records, but when looking at adult service recipients as a proxy for prevalence, that percentage may drop as much as tenfold, to 0.3% of the population. There needs to be consideration of how to identify this population that is 'lost' to surveillance.

As much as possible, the definition should be applicable in future climates and systems of support.

There should be a functional component to the inclusion criteria for the population when considered for health surveillance.

One panelist commented on how the term— intellectual disability — is used and what it means to her. She noted that the definition of 'intellectual' is someone that is really smart or knowledgeable, but that the addition of "disability" automatically means someone with an IQ of 70 or below. She emphasized that not everyone with a disability has an IQ below 70, and that many people can have disability that affects their health. She also questioned how people with

autism might be included in the defined group as they can have very high IQs, but also have substantial support needs. As services are tied to the definition of an IQ of 70 or below, the definition leaves out a group of people with significant disabilities. She encouraged the group to move away from a definition based upon intelligence, and to make sure functional ability and support needs are also considered. She brought up the example that her state's Department of Developmental Services (DDS) eligibility criteria historically used a higher level of IQ than it does now, and that the policy change was thought to be related to budget cuts.

Ideally, health surveillance data should be tied to the specific cause of intellectual disability.

Matt Holder expressed that, as a medical doctor, he's frustrated with the term 'intellectual disabilities' as it is not helpful clinically. Instead, he would prefer to know the actual *cause* of a person's intellectual disability because that's the aspect that's clinically relevant. Because of the importance of the etiology of the disability to health, having a data set on the lesser-known conditions would help guide doctors on what they know and how to treat people with these conditions. Dr. Holder encouraged specificity in the health surveillance activities as this will help ensure these activities are ultimately useful in creating actionable data for physicians. The policy argument was offered by Gloria Krahn: broad-based advocacy may not be possible for the many smaller clinically defined groups, but a look at the health outcomes of the larger population with ID may be useful from a national surveillance and advocacy perspective.

Family members and consumers must be included in policy discussions about health.

The low rates of payment to medical providers was another concern highlighted by a panelist, noting that they particularly affect the group of people that take longer to see than other patients. This is an issue of inequity in access. The static reimbursement rate provides a disincentive to provide medical care to these people. She questioned how to define the group that requires extra time or effort to be seen by medical professionals, such as requiring more time in an office visit or requiring translation during an appointment, etc. Ms. Rico noted that often, families and consumers are not at the table for the discussion of decisions like reimbursement rates that affect them.

Recognize the influence of cultural and political factors on terminology, categorization and self-identification.

The example of autism was used to demonstrate the impact of categorization changes. As awareness of the autism spectrum grows, people with autism who might have been previously labeled with a diagnosis of I/DD may or may not identify as having an I/DD .

As in the 'Forgotten Generation' described by Charlie Lakin, people with mild or 'borderline' ID or severe learning disabilities often have the same functional support needs as those diagnosed with ID. Language, terminology and how people are found eligible for supports or self-identify is known to change over time, and we should be aware of populations that are included, and that they may be functionally similar but excluded when crafting a definition.

Developing an operational definition:

The definition of intellectual disability is multidimensional so an approach that allows for structured consideration of the major dimensions was necessary. The group facilitators identified the five domains of a multidimensional definition proposed by the American Association on Intellectual Disability (AAIDD) as a framework for review. The domains include 'Intellectual Abilities', 'Adaptive Behavior', 'Health', 'Participation', and 'Context'. [The project team added 'Age of onset' and 'Support needs' as components of the definition that needed to be considered].

This set of domains was proposed because:

1. The AAIDD domains can be used to relate the 6 major definitions of ID currently in use in the United States {AAIDD, ADA, SSI/SSDI Eligibility definition, definitions established by state DD systems (general discussion as these vary), ICD-10, DSM-V). A crosswalk of these definitions identifies the similarities by domain, and the need for inclusion of 'age of onset' and 'support needs'.
2. The relationship of the AAIDD 'domains' and the 'components' of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) are can also be demonstrated and allow for a construct that is conceptually in line with international approaches to classification of disability.

As the summit participants moved to 'Framing the Definition of ID for Health Surveillance,' each Domain was discussed in turn. Group members proposed the elements that were most important to include in the definition of the population for health surveillance:

Intellectual Abilities Domain

An IQ score of approximately 70 or below (2 or more standard deviations below the mean) on an 'individualized, standardized, culturally appropriate, psychometrically sound test.'⁸, or a determination by a clinician that the individual has an intellectual disability.

'Related conditions' (neurodevelopmental disorders) includes those named within state DD services eligibility, with evidence of 'difficulties in learning' and/or need for support in activities of daily living (ADL) or instrumental activities of daily living (IADL). A list of ICD-10 (or ICD-9) related diagnoses may be included.

Rationale: Group members agreed that it is generally accepted that there needs to be a discussion of intellectual ability in any definition. The validity of the test, its administration, and application is

⁸ As described in the DSM-V definition.

something that was questioned and discussed. Group members noted that for the purpose of this discussion, there must be an assumption that test administration is validated and culturally appropriate.

Input from self advocates during and following the meeting noted that classifying people on the basis of IQ can sound overly judgmental, so it is good to have alternatives to only IQ to identify people with ID.

The point was raised that some people with an intellectual disability may not have had an IQ test, and that a definition based solely upon an IQ score may be exclusionary of subgroups of people with ID. However, there may be other screening questions that can be used to help identify candidates for inclusion through broader questions about things other than an IQ score:

‘Related conditions’ are commonly used in the definition as well. For the purpose of identification of the population for health surveillance, the group suggested that specific related conditions may be appropriate to name, and that these may be used as ‘screeener questions’. For example, diagnosis of autism or cerebral palsy may not mean that a person has ID, but would be a reasonable means to identify a broader population that could be addressed with follow up analyses or queries in a survey.

Another screening approach that was discussed in this context was to ask (in a survey or through review of administrative records) if the person has ever received special education (SPED) services. The group recognized that this casts a broad net, but noted that this would identify the population who are considered to have an intellectual disability but who do not go on to receive services after the transition from school-based services upon reaching 18 or 22 years of age.

Adaptive Behavior Domain

Limitations in ability to perform (alternate language: demonstrated challenges in) ADL or IADL, with need for support in these areas.

Supports needed: Requires support (natural (informal), formal, or cash) to perform ADL, IADL.

Rationale: The ability (or inability) of a person to successfully perform basic functions of life, such as basic activities of daily living (ADLs), instrumental activities of daily living (IADLs), mobility, and communication was noted as an important area of consideration by group members. All participants agreed that this domain should be represented in a definition of this population for the purpose of health surveillance.

Discussion: As noted in the AAIDD and other definitions, measures of adaptive behavior can be assessed as a standardized measure.

Several group members noted their discomfort with the term ‘adaptive behavior’, preferring ‘skills’, ‘function’, or ‘ability to survive’, yet there was not any agreed upon way to routinely measure this presented during the discussion.

Gloria Krahn noted that this domain is not one that is included in other definitions that are in use in Europe, for example. This may be due to the variability in measurement ability and cultural context across Europe.

This concept could only be adequately described by the group in the context of ‘support needs’. There was a discussion about self-identification in this area. For example, it was discussed that other projects have found that people may not readily admit that they are ‘non-adaptive’, but may be more likely to express the need for help.

In follow up comments, Max Barrows from SABE pointed out that it is especially important to include people who need support to manage their own health needs, such as taking prescription medication on time, or scheduling appointments.

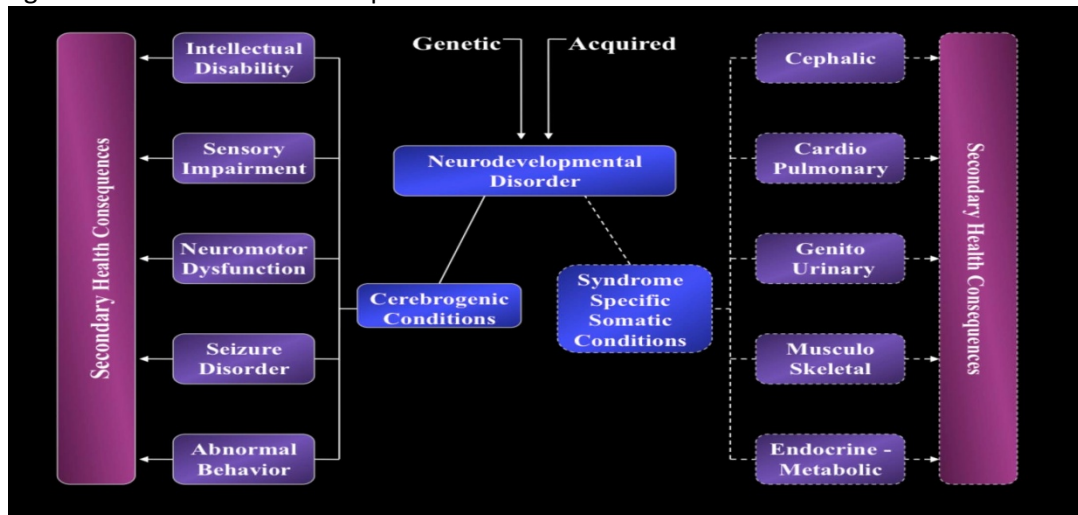
Health Domain

[This element is discussed under ‘Related conditions’]

Discussion:

The health domain, as defined, is a broad interpretation of health that includes diagnostic information (etiology), health promotion behaviors, and health outcomes. Matt Holder offered the AADMD framework for understanding the relationship of neurodevelopmental disorders, intellectual disability (and related conditions such as sensory impairments), and secondary health effects.

Figure 1: AADMD Neurodevelopmental Disorders Framework



Due to advances in genetic and diagnostic testing, it is becoming more and more possible to clinically determine the cause of ID (whether genetic or acquired) in a significant number of presenting cases of ID. Dr Holder suggested that in practice, only about 50% of people who are identified with ID have a known cause. In laboratory testing, only about 6% of people with ID cannot have the cause of their ID identified.

The presence of a known etiology or associated neurodevelopmental condition is seen as another means of 'screening' for this population. This information does not necessarily need to be included in the definition, except in the context of the 'related conditions'. It may also be useful in confirming the medical diagnosis of intellectual disability for those that self-identify as having an intellectual disability but may not have been tested for IQ. The group did not come to a decision on whether to include people based on specific diagnoses that are known to include intellectual disability.

Note: If a survey were being developed, that asked about the 'cause' of intellectual disability, there will always need to be an 'unknown' option.

Participation and Context Domains

While the group noted that context is an essential component of the qualitative understanding of an individual's circumstances, this is not specifically included in a definition to be used for the purpose of health surveillance because aggregate data cannot be used to describe this domain.

Discussion: The group discussed these two remaining 'domains' only briefly. Participation was seen as being covered under the 'Adaptive Behavior' domain for these purposes.

While 'context' is understood as an important consideration for how an individual is able to function (as in the 'convents or covens' comment), the group noted that no good source of aggregate data could be used to inform this definition.

Age of onset

'Developmental period', as defined by ... [not specified]

In addition, the length of the experience of intellectual disability should be for an 'Indefinite period', or 'Expected to be a lifelong condition'. While it is acknowledged that functional ability of a person may change over time, the person is expected to need a significant level of support indefinitely.

Rationale: This is consistent with current definitions in service delivery systems. The onset during the developmental period is significant in its impact on future development for the individual and their ability to function.

Discussion: Intellectual disability is typically characterized as having manifested during the developmental period, and the group agreed that it is important to include this parameter in the definition that is used for the purpose of national health surveillance, as it adds an important level of specificity to the definition.

The group recognizes that 'prior to age 22' is the cut-off that is typically used for the upper range of the developmental period, but that this is generally applied because of a shift to adult service system from school-based services. The group did not specify a particular age; rather there was an assertion that any operational definition of this population for the purpose of health surveillance must include a consideration of how the onset and developmental period are defined.

Support Need

Determined eligible for State or Federal public support programs as an adult or eligible for Special Education program of supports by virtue of a determination of intellectual disability.

Rationale:

The need for 'support' in order to function is a significant feature of intellectual disability in the context of health surveillance, as this suggests vulnerability that may negatively affect health access and health behaviors. As discussed by the group, 'support' is broadly defined to include formal (e.g. DD-specific), generic (e.g. section 8), natural supports (e.g. family, co-workers), or cash supports (e.g. SSI/SSDI).

Charlie Lakin noted that the group of people who get SSI/SSDI cash support is the broadest group of people identified with ID in administrative data. It would be useful to look at the actual numbers. [Meeting follow up by RTOI project team: Social Security Administration (SSA) data presented by Richard Balkus in a presentation to the February 2010 AUCD/CDC planning meeting: In 2008 the SSA paid benefits to 1.3 million adults with a diagnosis of intellectual disability, including those diagnosed with borderline intellectual functioning]

Proposal for an Operational Definition for use in Health Surveillance:

Based on the review by domain and preliminary efforts to establish wording during the summit, the project team synthesized the discussion to develop a 5 part 'Proposed Definition of Intellectual Disability for the purpose of Health Surveillance'. This is offered on the following page for reaction and response by summit participants and others.

SUMMARY of PROPOSED Definition of Intellectual Disability for the Purpose of Health Surveillance from April 13th meeting

****** If a person fits into the first four parts (#1, #2, #3, and #4), OR they are in the fifth (#5), then they will be considered to be part of the group ‘Adults with Intellectual Disability’ by researchers when collecting information about population health. ******

[#1] Person has been tested and has an IQ score of approximately 70 or below,

OR a clinician has told the person that they have an intellectual disability,

OR the person has a “related condition” along with support needs because of difficulties in learning, concentrating, or problem solving. Related conditions are specific diagnoses that often cause an intellectual disability, such as Down Syndrome or Prader-Willi Syndrome. [Intellectual Abilities and Related conditions]

AND [#2] person needs support with activities of daily living (ADL) or instrumental activities of daily living (IADL). These are things like dressing, bathing, shopping, cooking, transportation, communication, or money management. Support can be ‘formal’ (for example, staff, help with housing, Social Security if a person can’t work), or ‘informal’ (family or friends helping) [Adaptive behavior]

AND [#3] person was diagnosed with an intellectual disability or related condition in the ‘developmental period’. The time in a person’s life from childhood to becoming an adult is called the ‘Developmental Period.’ [Age of onset]

AND [#4] person is expected to have the intellectual disability their entire life. The person might learn new skills, get new jobs, and live independently, but the person is expected to need some help for their entire life. [Life-long]

OR [#5] person is eligible for State or Federal public support programs because they have an intellectual disability. Examples of state or federal public support programs are SSI, SSDI, Section 8, or services from a state disability agency. [Support needs]

Refining the Operational Definition

The definition proposed on page 12 describes the population that should be included, and was developed with availability of data in mind. Summit participants readily noted that there remains a gap between the population described at the conceptual level and that which can be readily identified through either existing or proposed data collection as this was designed to be broad enough to overlay a range of methods.

The work of the summit participants is important because of the necessity to have the population well-defined, which can then allow for the development of the questions that could identify the population. In order to advance the operationalization of the definition of ID, the RTOI project team have developed a series of proposed 'Pathways' to identification of the population with ID, based on discussion among summit participants. These are proposed in the accompanying document: 'Summit Notes PART 2: PATHWAYS to identifying the Adult Population with Intellectual Disability for Health Surveillance.'

These pathways are proposed to promote discussion to:

1. Clarify the questions that researchers will need to ask of the data, and the steps that might be followed.
2. Establish a base level of sufficiency for inclusion, with a description of the population that may be erroneously counted through 'false positives' or 'false negatives'.
3. Allow researchers to apply decision criteria to available or new data collection in a way that standardizes how the population with ID is identified and reported.

These pathways will be presented for review and discussion at the upcoming 'Health Frontier in ID' with the goal of eliciting input into the reliability, validity, utility, and feasibility of this structured method to identify the population with ID.

Conclusion and Additional Considerations

The RTOI Project team would like to thank all participants at the Operational Definition of ID Summit for their clear and compelling arguments, their engaged and respectful sharing of opinion and expertise, and for their dedication to this challenging but important topic. During the discussion several important issues were raised which, while significant, were beyond the scope of the group's goal to define the population.

These comments and recommendations are included in the following list of key considerations for future action.

- The validity of clinical assessments of intelligence remains something that is not fully addressed by this group. As well, the context of their use (for example, for eligibility for services) may have bearing on the validity.

- As autism gains greater prominence in clinical and school settings, the group expressed concern about how this diagnosis will be used. For example, there are an increasing number of children diagnosed with autism who may not then meet the eligibility criteria for adult services. Additionally, there is speculation that autism diagnoses may be increasing as a means for clinicians to support individual or family's access to supports and services.
- The group agreed that there should be a concerted effort to distinguish between people who primarily experience mental health issues and those with an intellectual disability.
- Access to special education services is highly variable by region, locality, or cultural group.
- The percent of the population with ID receiving supports varies by state (from less than 1% to 3%).
- Surveillance processes may likely require a screening step – identify people who could potentially be included and then filter with more detailed questions to get at definition.
- Regarding surveillance: comment that a lot of people don't receive [preventive screening] tests because they are not treated well at the medical visit, and are not told what is going to happen during the screening. This is an important outcome to monitor.
- Cultural issues related to identification of people with intellectual disability, and natural supports are an important consideration when attempting to identify the population. Cultural differences may affect whether (and in what way) people will acknowledge their own disability (or a family members). Literacy and English language competency must also be considered as potential reasons for the artificial exclusion of people with intellectual disabilities from surveillance activities.
- It is important to consider the language used in the screening questions and the source of the information. For example, the term 'intellectual disabilities' is not a familiar term to some people, who may understand or identify more with terms such as 'mental retardation', even though the term is being replaced in the majority of service settings. When considering 'filtering' questions, consider what terms people are going to be familiar with (e.g. 'formerly called MR'...)

Operational Definition of Intellectual Disability for the Purpose of National Health Surveillance

Summit Meeting – April 13, 2011

Special Olympics Yawkey Sports Training Center, Marlborough MA

SUMMIT GOAL: Establish recommendations for operational definition(s) of intellectual disability for the purpose of national health surveillance

9:00 Welcomes, introductions, goal of the day and process, self advocate and family perspective, national and international context of this activity.

(Reminder: Assumptions and preliminary discussion included in presentation and notes from 3/1/11 conference call.)

10:00 *Framing the operational definition.*

Facilitated group process to identify and prioritize the essential elements of the definition to define intellectual disability **for the purpose of national health surveillance.**

(Reference material prepared: “Definitions of Intellectual Disability in National Data Systems Review Material for the April 13th, 2011 Summit : Developing Recommendations for an Operational Definition of Intellectual Disability for National Health Surveillance”)

Questions for consideration:

- What elements of intellectual disability are essential to include in a definition to describe this population for the purpose of national health surveillance? (What is the rationale?)
- How sensitive should the definition be? (i.e. Is it more acceptable to ‘miss’ people but be very specific and reliable, or ‘over count’ and make sure to everyone with an ID?, What should be the target for sensitivity in the context national health surveillance of this population?)
- Inclusion and exclusion criteria: What is unique about this population that differentiates people with ID from the general population? From related conditions such as DD, mental illness, injury or age related cognitive impairment? What must be included in any definition of ID that will always separate this group of individuals from other groups?
- Can the ‘essential elements’ be prioritized?
- How does this definition crosswalk with the multidimensional framework provided by AAIDD (table attached). [This conceptual framework has a significant degree of compatibility with WHO’s ICF]

Facilitators will record discussion, guide the process towards consensus of the essential elements. (Expect a brief break around 11:00)

12:00 Lunch

1:00 *Refining the operational definition.*

Questions for consideration:

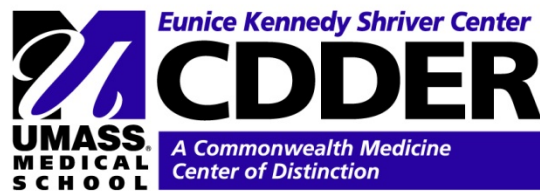
- What elements of the definition are essential for an operational definition of intellectual disability that uses survey or administrative data that is currently collected? (For example, if data sets were combined, what would be essential to define the population with intellectual disability?).
- Is there an expectation that the operational definition for health surveillance will change with anticipated technological, biomedical advances? (for example, increased role of EMR in providing health/diagnostic information, advances in genetics providing more basis to etiology) If yes, how?
 - Are the words used in the definition the least complicated possible?
 - For each element, and for the definition as a whole: Reliability, Validity, Utility (Usefulness), Practicality for the purpose of national health surveillance.
 - Implications of the application of this definition?

~ 3:00 Break

3:15 Summary and wrap up – Final comments and next steps: project staff will be compiling the definitions, recommendations, notes for review and response in preparation for presentation May 23rd at ‘Health Frontier in ID’ conference.

4:00 Meeting ends

4:15 Shuttle bus returns to Royal Plaza Best Western



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