

Expanding Surveillance of Adults with Intellectual Disability in the US

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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.

Additional project materials can be accessed by contacting the Principal Investigator at Alexandra.Bonardi@umassmed.edu.

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1 Identifying the population with Intellectual Disability

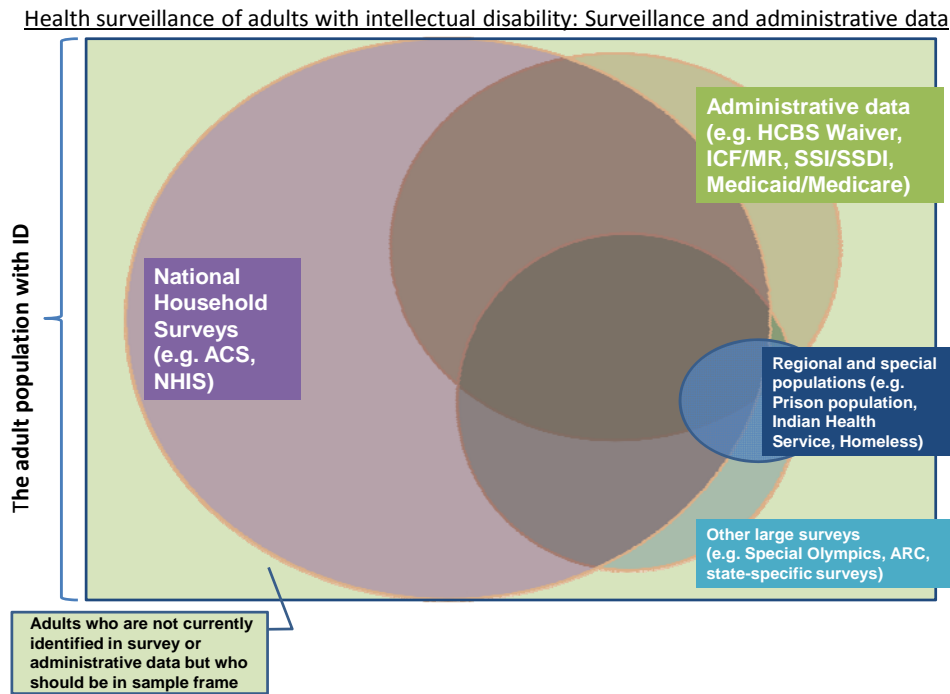
The United States Health service does not routinely report on the health of the population with intellectual disability (ID) largely because representative samples of health data from people identified with ID are not available in current national surveys (Krahn et al, 2010). This is recognized as an issue that demands action as this population continues to experience significant health disparities when compared to the general population. The U.S. Centers for Disease Control and Prevention's National Center for Birth Defects and Developmental Disabilities (NCBDDD) in collaboration with the Association of University Centers of Disability (AUCD) convened workshops in 2009 and 2010 to consider the methodological feasibility of conducting a systematic surveillance of the health of people with ID. *The Call To Action* developed by meeting participants included the need to gather valid and reliable health information about this population and the recognition that surveillance should be a sustainable, ongoing process that utilizes a multipronged, multistage methodological approach. The recommendations outlined in this section were developed by the CDDER/HSRI team in response to this Call To Action.

Two companion reports were also developed by the CDDER/HSRI team in response to the Call To Action, (1) *Recommendations for an Operational Definition of Intellectual Disability*, containing an expanded review of the challenges in case identification and recommendations for operationalizing the definition, and (2) *Compendium of Health Data Sources for Adults with Intellectual Disabilities*, a review of national, state, and regional data sources that capture health information pertaining to adults with ID.

Framing the Population

Framing the population with intellectual disability is an essential first step to advancing the surveillance initiative. No single source of census information exists for adults with ID. As discussed in the *Recommendations for an Operational Definition* report and detailed in the *Compendium of Health Data Sources for Adults with Intellectual Disabilities*, different segments of the population are covered by a range of general and specific population surveillance efforts. In addition the surveillance methods included in existing data sources contain built in biases that work against the inclusion and full participation of all people with ID. In most cases, those individuals with ID who *are* included in surveillance cannot be identified as a person with ID due to lack of survey items that flag functional or clinical conditions that could be used to circumscribe the population. The following figure provides a depiction of surveillance systems that may cover the population, including data collected in the administration of publicly financed programs. Note that a portion of the sample frame is thought to remain external to all formal systems currently in use.

Figure 1 : Framing the population with ID



The population with ID presents particular challenges in survey applications because it is defined by many precise conditions, which are variably applied in existing surveys. In order to effectively address the multiple challenges related to surveillance in this population, Hendershot, Harris, and Stapleton (2009) suggest that periodic special surveys or supplements may be required. As no one data source has been shown to effectively capture both a representative sample of the population and health data for this population, multiple data sources need to be utilized, including administrative data and national and state survey data. Data linkages hold promise as a powerful tool to maximize the coverage of any health surveillance system designed for this population. Ultimately, in order to fully understand the health of adults with ID, it is important that the combination of surveillance methods results in inclusion of adults across the lifespan, with varying levels of disability and across all types of living arrangements (including persons living with their families, independently, in community-based settings, and those living in nursing or facility-based settings). The surveillance system should also provide a benchmark for assessing overall shifts in the number, demographics and indicators of health of people with ID. Finally, and perhaps the greatest challenge to surmount: “surveillance demands uniformity, simplicity, and brevity” (Wharton et al, 1990). This population’s heterogeneity of conditions, experience of disability, and the influence that public policies such as public service eligibility criteria have on how it is defined for surveillance are constant confounding factors for researchers trying to gain a clear picture of its health.

Laying the foundation: An Operational Definition of Intellectual Disability

Based on input from a national consensus panel, and a review of multiple current applications of the definition of intellectual disability, the project team developed recommendations for an operational definition of intellectual disability that can be applied for 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.*

Details of the definition, including further steps to operationalize the definition are included in the accompanying project report "Developing an Operational Definition of Intellectual Disability for the Purpose of National Health Surveillance".

Compendium of Health Data Sources for Adults with Intellectual Disability

The accompanying *Compendium of Health Data Sources for Adults with Intellectual Disabilities* reviews existing data sources that capture health information pertaining to adults with intellectual disability, grouping them into those that hold high, moderate, and low potential to inform national health surveillance in the population. An assignment of high potential was an indication that, with some modification of the instrument or methodology, the data captured and sampling method were most likely to be useful for health surveillance in this population. None of the data sources were found to be sufficient

as a stand-alone data source in their current state. The compendium's assignment of a data set to 'high' potential was the result of the project team's assessment of several factors: 1) the variables captured in the survey are highly useful for health surveillance (e.g. the BRFSS), 2) the data source had potential of identifying adults with ID with modified or supplemental questions (e.g. the American Community Survey) is high, 3) the sample and questions are targeted to the population with ID and would inform health surveillance, even if the population is not representative (e.g. Longitudinal Health and Intellectual Disability Study). The purpose of the compendium is to serve as a baseline inventory, from which data sources may be gathered and reviewed.

2 Expanding methods to identify the population

While some existing health data sources may identify subsets of people with intellectual disability, many of these surveillance systems use methods that either have a sampling bias against the inclusion of a representative population with intellectual disability (such as the BRFSS) or do not clearly identify this population (such as the NHIS). Further, administrative data sets that identify the adult population based on eligibility for state support services due to a defined intellectual disability typically do not capture the portion of the population that does not currently receive formal supports. This group may be "unserved" either by choice (i.e., no support needed or receiving support from an informal source) or on waiting lists for formal services. Lakin et al (2010) estimated that nationally 122,870 persons with ID/D were waiting for residential services in 2009.

Outreach to Community Members and People with Intellectual Disability

As a complement to the compilation and critical review of data sources, the RTOI project team embarked on an exploratory effort to guide best practices for including a more representative population in surveillance through direct contact with community members. The purpose of this project component was to inform future outreach activity, generate themes and frameworks for further research efforts to increase the representativeness of surveillance efforts, and finally to inform the recommendations included in the last section of this report. The project team hypothesized that adults with ID who did not receive services from state I/DD service systems may be supported by other generic service systems or community networks, and that these community leaders may be able to therefore inform how surveillance efforts may work to include people with ID that do not receive state supports.

The RTOI project team identified 5 target communities that certainly include adults with intellectual disability, and in many cases may provide supports to adults with intellectual disability as part of the role of the support networks that exist within these communities. The team also explored available resources within these communities that could further inform case identification strategies and health surveillance efforts.

The populations targeted for the preliminary investigation were:

1. Faith-Based Communities
2. Homeless Population
3. Prison and Jail Population
4. Ethnic Groups
5. The population with primary mental health diagnoses

This effort included a review of the literature and several interviews with community leaders to generate ideas about strategies for ‘finding’ people with intellectual disability who are not served by the traditional service system. Community leaders were identified both through literature and through professional networks. Building from the interviews, the project team developed an outreach framework and questions to use in additional interviews with adults with intellectual disability and family members.

Individuals with intellectual disability and families were recruited to participate in interviews using several methods. An announcement was distributed through the Massachusetts Network of Information for People with Disability (which consists of approximately 135 provider agency executives and other local advocacy group leaders), and calls were made to the Massachusetts Developmental Disabilities Council and the Threshold Program at Lesley University. Project staff made an effort to identify people who were not currently being served by the public ID/DD service system as a means to gain insight into the population that may be ‘invisible’ to surveillance. A semi-structured interview format was used in all cases, and project team members reviewed summaries of the responses. Participants gave informed consent and were compensated for their time with a gift card.

The key informants for this portion of the report are listed in Appendix A (page31) and findings are summarized below.

Faith-Based Communities

Faith-based communities provide a range of services and supports that include both general and specific services for people with intellectual disability. Within communities, there is a growing awareness of issues relating to people with disability and in particular those with intellectual disability. There is no data describing the number of people with intellectual disability who receive support from faith-based communities. Delivery of supports is a grass-roots local endeavour, and thus identifying individuals with intellectual disability would be a local endeavour. The people with ID that are most likely to be supported by faith communities are those that are currently living with their family or have lived with family in the recent past. (Bill Gaventa, personal communication)

Homeless Population

Nationally, there is limited information on the prevalence of intellectual disability in the homeless population. While the population with disability among the homeless population is estimated to be as high as 37%¹, population estimates do not provide level of detail to identify the people with intellectual disability as a subgroup. In a study of the homeless population with intellectual disability, Mercier and Picard (2011) identified characteristics of the homeless population with ID that differ from the study location's general homeless population, suggesting particular focus on this population is essential. Though the association between intellectual disability and poverty has been demonstrated (Emerson, 2007), people with intellectual disability remain relatively invisible in the homeless population. The 2010 Annual Homeless Assessment Report to Congress (HUD, 2010) reported that 3.3% of all adults in permanent supportive housing, a support offered as a means to end homelessness, were identified as having a developmental disability, which would largely include those with an intellectual disability. The addition of an ID supplement to annual surveys of the homeless population would improve both efforts to target homelessness prevention and to develop a method for surveillance that can provide an accurate estimate of the presence of intellectual disability within this population.

¹ The Housing and Urban Development definition of disability includes substance abuse disorder, a diagnosis that is not included in the census definition of disability, and a likely contributor to the higher overall disability rates reported in the homeless population.

Prison and Jail Population

The prevalence of intellectual disability in the jail and prison population is not fully known due to variable screening practices and variations in how the population is counted (Scheyett et al, 2009). Fazel et al. (2009) suggested that typically 0.5-1.5% of this population were diagnosed with intellectual disability, noting that this is the lower limit of the actual prevalence and that particular attention should be paid to this population as it is one of the most vulnerable groups in the prison population. Studies that have investigated learning disabilities have identified much higher rates (over 25% of the population) (Smith, 2005), suggesting that screening, diagnosis, and perhaps questions used in surveys may not reveal the true extent of intellectual disability.

The National Inmate Survey, conducted by the Bureau of Justice Statistics, is the main source for health information. While one section (section Q) addresses disabilities, intellectual disability is not targeted in this survey (personal communication R. Trestman). Expanded surveillance in this population, perhaps as an extension of the National Inmate Survey, would greatly improve efforts to characterize the population with intellectual disability who lives in the prison system.

Diverse Ethnic Communities

Ethnic and cultural communities provide important social supports in the United States. Since disability is a social or cultural construct that is tied to the individual's experience and interaction with his or her community, it is likely that a person will be identified with an intellectual disability can vary among ethnic communities, as will the approach to providing needed supports. This poses challenges to health surveillance because individuals with a disability may be subject to underreporting bias due to both their racial or ethnic identity and their experience of disability.

National surveillance agencies have undertaken efforts to ensure that populations under surveillance include a diversity of racial and ethnic groups. Five race/ethnic advisory committees guide the development of the US decennial census (African American, American Indian and Alaska Native, Asian, Hispanic, and Native Hawaiian and Other Pacific Islander) to reduce undercount and improve data collection and enumeration strategies.

Data collection in areas related to health and disability are particularly sensitive among minority groups and while this can also vary by community, trusted members of each community are key players in promoting and implementing public health efforts that would include health surveillance (personal communication, Sheryl White-Scott). National surveillance efforts should be sensitive to cultural perceptions and terminology relating to disability when designing survey questions.

As part of the the VERB Youth Media Campaign, the Centers for Disease Control (CDC) has produced a ‘Multicultural Outreach Fact Sheet’ (CDC, Undated), highlighting a variety of health behaviors and values by cultural or ethnic groups. A similar effort that highlights attitudes about both health and intellectual disability could be a valuable product to help guide outreach and dissemination.

Population with a primary mental health diagnosis

Best practices in surveillance methods in the population with mental health issues can inform health surveillance among people with intellectual disability because of similar concerns regarding stigmatizing (application of a label in case identification), issues with self-identification, and the need for support by some respondents.

Highlighted best practices include:

- Employing a community sampling frame, such as in the National Health Interview Survey, allowing for households to be identified, and within the household, questions such as ‘Is there anyone in the family who has ---?’ can be asked. (personal communication, R. Manderscheid)
- The US Center for Mental Health Services report, *Mental Health, United States, 2004*, (CMHS, 2004) provides detailed and specific population assessment methodologies (Chapters 15 and 16), including methods used to access and link administrative Medicare and Medicaid data to assess prevalence and outcomes in the population with serious mental illness.
- Survey method designs that allow for extensive follow up to access subgroups of survey participants and collect data, as well as methods that allow for and make accommodations to allow the person to respond as fully as they can (Henry et al., 2007).

People with intellectual disability who have co-occurring mental health issues, particularly those with milder intellectual disability, may receive services and supports through the mental health system. Sampling schemes that include those with mental health diagnoses will very likely overlap with the population with intellectual disability, and specific methods to identify those with an intellectual disability should be tested in the surveillance of mental health.

Enhancing Outreach and Case Finding

1. Balancing ethical concerns regarding labelling with the need to gain good information is a theme that underlies all surveillance in this population. While key informants felt it was important for people to ‘be counted’ as members of society and to raise awareness of health support needs, efforts to identify those who may not self-identify as intellectually disabled must be approached with great caution. Questions about health and disability are perceived as sensitive questions by people with disability and their families.
2. ‘Grass roots’ outreach through trusted organizations is a recommended means to reach people. Surveillance and other public health efforts would be best applied in local settings such as exercise facilities/gyms, faith-based organizations, cultural groups and self-advocacy organizations. Repeated contact, through a ‘media campaign’ of notices given several weeks apart was identified by a self-appointed advocate as a successful strategy to gain participation in surveillance efforts. Several respondents noted that while they see the value in the activity of gathering health information from people who are not easily reached through routine surveillance or are not in services already, it may be a resource intensive process. Accessing existing social and support networks could serve as an important means for outreach.
3. Self-identification as ‘intellectually disabled’ or ‘mentally retarded’ is just one means of case identification; other means may include clinical records, or proxy identification in a household survey. Respondents suggested an approach that uses multiple means to identify the population.

4. Building awareness in local communities about the need for population health surveillance is a first step towards enhanced case identification for surveillance. Disability-specific resources that are targeted to each community should be tested as a means to enhance participation in surveillance efforts.

Recommendations for the Health Surveillance of People with Intellectual Disabilities in the United States

The following section identifies strategies to expand health surveillance for adults with intellectual disabilities (ID). Information gathered from the critical review of existing health data sources (see *Compendium of Health Data Sources for Adults with Intellectual Disabilities*), and an assessment of surveillance and sampling methods in the US and other countries were utilized to generate feasible methodologies and strategies to monitor the health of a representative samples of adults with ID in the United States.

Three general avenues for expanding surveillance were investigated by the CDDER/HSRI team. They include:

- I. Combining or mining **existing administrative or survey data sources** in new ways.
- II. **Modifying current data sources**, including expanding existing surveys through addition of questions to better identify people with ID, through modification of methods to include a more representative sample of people with ID or through creation of a disability module to be completed by a subset of the population.
- III. **Developing new data collection systems to address specific surveillance or population mapping needs.**

Establishing the population model:

An overarching consideration that each of these strategies requires is the development of a sampling scheme of the population of adults with ID in the US. Through the development of an operational definition of intellectual disability and the comprehensive review of data sources, the RTOI project has laid the ground work, but capturing a representative sample requires further efforts to identify and characterize the demographics of the population. Understanding the demographics of this population is essential to furthering its health surveillance; however, little information currently exists to inform valid population estimates. Without this basic knowledge, it is impossible to design a sampling scheme that would capture a representative sample. Building from the proposed operational definition of intellectual disability (see accompanying report), best practices in population identification must still be developed. This in turn will inform the development of reliable sampling schemes.

Below are detailed recommendations within each avenue with a discussion of recommended next steps.

I. New Analyses of Currently Collected Data

The CDDER/HSRI project team makes two recommendations for further exploration of existing data sources with the most potential to inform comprehensive health surveillance of this population. They include (1) Identification of the population with ID through International Classification of Disease (ICD) and other codes in medical service claims, and (2) Linking multiple existing data sources for enhanced health surveillance. Both recommendations are detailed below.

Recommendation #1: Identify adults with ID using ICD and other codes in medical service claims.

A wealth of information about health service utilization exists in medical service and pharmaceutical payment claims data and these data are routinely mined to assess population and service delivery outcomes. Claims data can be especially useful in locating hard-to-study populations (Quam et al. 1993). The CDDER/HSRI project team recommends utilizing health service claims data to determine mechanisms to identify people with ID and their health indicators. Examination of clinical codes for intellectual disability and related conditions (see Table 3 in *Recommendations for an Operational Definition of Intellectual Disability*) has been used by several researchers to identify the population with ID in administrative or clinical databases. ICD codes hold some potential for identification of people with ID, especially when claims are examined over a period of time to increase reliability of identification.

The use of ICD codes to aid in the identification of people with ID could expand utility of datasets such as Medicaid and Medicare, but also private health insurance claims, Medicaid Statistical Information System (MSIS), Medicare Current Beneficiary Survey, Medicare Health Outcomes Survey, and the Minimum Data Set Repository.

The project team does recognize the significant complexities to identifying disability using ICD-9 or other diagnostic codes. They include the lack of information on the severity of the diagnosis, incomplete coding, and lack of information on the functional status of the individual (Iezzoni, 2002). A diagnosis of ID may not be used as a reason for every service received by an adult with ID. However, the likelihood of including an ID-related service code is expected to increase when looking across a broad timeframe of data, covering multiple clinical encounters and possibly coded by multiple health care providers. While the sensitivity and specificity of this method is untested, preliminary work in this area suggest sensitivity may be quite high. One researcher suggests that the capture rates are more promising than originally

thought (Suzanne McDermott, personal communication 11-15-11) and that verification methods can be used to ensure high specificity.

Next steps: Identification of people with ID should begin with Medicaid and Medicare claims data and be tested against a known data set of people with ID to establish estimates of sensitivity. The CDDER/HSRI team recommends funding pilot studies to develop identification methods. At least one such project through the CDC is already underway. The objective of the project is to validate the ICD diagnosis codes for selected developmental disabilities in Medicaid claims among 8-year olds residing in Metro Atlanta area. (Vijaya Kancherla personal communication 11-22-11)

Recommendation #2: Link Multiple Existing Data Sources for Health Surveillance

Mining data for secondary analyses is a field that is gaining acceptance in medical and outcomes research. No single source of disability data has the quality or scope to fully characterize the health disparities and status of people with intellectual disabilities. However, through careful combination, data from multiple sources could yield answers to some of the major questions about this population. The benefit of these linked datasets may be in identifying people with ID, in directly informing health indicators, or both. For health surveillance of people with ID, data linkage offers the advantage of the ability to use existing data, without requiring significant additional resources for data collection, a major consideration in a time of fiscal constraint. As the field continues to evolve in both public and private sector applications, the efforts proposed will establish a foundation of best practice in linkages for population identification that will inform future efforts to monitor health, costs, and outcomes in this population.

Linking several administrative data sets

Use of combinations of state administrative data sets from multiple public agencies may have potential to inform health surveillance for people with intellectual disabilities at the state level. Data collected in the administration of publicly financed programs for people with intellectual disability (such as Medicaid HCBS Waiver programs) hold potential to inform health surveillance when matched through a unique identifier to Medicaid or Medicare payment claims.

Linking administrative and surveillance data

Bringing together administrative and survey data from multiple sources has several benefits including a better understanding of factors that influence the quality of life and health of people with intellectual

disabilities and the evaluation of the quality of public and community services (Glasson and Hussain 2008). Recent efforts by the Census Bureau, the Social Security Administration (SSA) and the National Center for Health Statistics to match national survey data to administrative data have demonstrated the power and importance of gathering useful information about people with disabilities and other populations. Of note are collaborations with the National Center for Health Statistics (NCHS) to match SSA data to NHIS and other NCHS surveys (Stapleton and Thornton, 2009), as well as to match Medicaid Statistical Information System (MSIS) records with linked with respondents in the American Community Survey Content Test (US Census 2010). Another example of successful linkage of such data is the examination of the effects of disability on the outcomes and treatments of women with disabilities who have breast cancer through the analysis of linked Medicare and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program data (Iezzoni et al., 2008).

The South Carolina Integrated Data System (SCIDS) is an additional example of robust dataset linkages. The SCIDS is a data warehouse of all health and social service data in South Carolina which maintains links across multiple agencies and organizations and has led to the development of a Disability Cube which focuses on the linkage of data about people with disabilities. The Disability Cube includes information about users of many state systems as well as Medicaid services and allows for cross-sectional and longitudinal analysis.

There are challenges in accessing, matching and interpreting data from multiple sources, including legal, political, confidentiality and methodological. The way in which people are identified in the different data sources can vary, as in the case of variable eligibility criteria for state ID/D services (Zaharia and Moseley, 2008). Special attention must be paid to ensure that individuals are uniquely identified. Other barriers include legal, political, privacy and confidentiality issues in obtaining approval to access data across systems. However, this strategy has great potential given that these data sets are already established for other purposes and the relatively low costs. Efforts to address these challenges are essential, and require clear methodology in study development.

Next steps: Data linkage useful for health surveillance can be accomplished through a stepwise approach that utilizes best practices in population identification and linkage. State-level administrative data in which the population with intellectual disability is already identified in a data source that can serve as the foundation to creating subsequent links.

To further examine the feasibility of linking administrative data across multiple sources, we recommend conducting demonstration projects in at least three states. The select states should be geographically and administratively different, with at least one state where the ID service system is funded centrally, another where program administration is carried out through local management (quasi-governmental) entities and a third state with a county-based system of public services. The feasibility of applying the proposed operational definition of intellectual disability to the data linkage project should be studied; this application will also advance efforts to apply a consistent population definition. The goal of these demonstration projects should be to develop best practices for a national model that is flexible enough to be applied on a state by state basis.

II. Modification of Current Surveillance Efforts

At present, people with ID remain largely invisible in current national health surveys. Some data sets likely contain people with ID and collect useful health information on this population, but do not identify ID. Others may identify people with ID, but their sampling or data collection methods minimize the likelihood that adults with ID are included in the efforts. The three primary issues with current data collection efforts are:

- (1) their failure to include a representative sample of the population of adults with ID,
- (2) their lack of appropriate validated measures to identify people with ID and
- (3) a survey methodology that prevents people with ID from fully participating in the survey.

In order to increase the utility of the existing surveillance efforts, the CDDER/HSRI team makes three recommendations: (1) include valid, unbiased and reliable screening questions in existing health surveys to identify people with ID, (2) expand sampling methodology using promising practices in order to capture a more representative and unbiased sample of adults with ID, and (3) for surveys, include communication methods and response options that maximize the potential for adults with ID and/or their proxies to participate.

Recommendation #3: Include valid and reliable questions in existing surveys to identify people with ID.

Building on the recommendations for an operational definition of ID, a set of valid and reliable screening questions that would identify people with ID can be developed and included in existing national and state

population-based surveys, such as the National Health Interview Survey (NHIS) and the Behavioral Risk Factor Surveillance System (BRFSS). An example of a similar process was the effort of the Christopher and Dana Reeve Paralysis Foundation Resource Center's (PRC) to develop survey questions identifying people with paralysis (Fox, et al. 2008). Their work was essential to the development of survey identifiers for people with paralysis.

Modifying existing surveillance is often proposed as a cost-effective and efficient approach to gain comprehensive data on people with disability at a national level (WHO, 2011). The foundational work of assessing current data collection methods and definitions and the development of case definitions have already been undertaken by the CDDER/HSRI project team and are detailed in the accompanying *Compendium of Health Data Sources for People with Intellectual Disability*.

Next Steps: To expand the utility of current surveillance systems to identify persons with ID, the CDDER/HSRI team proposes the development of reliable and valid survey questions that identify adults with ID. The 'pathways to identifying the population with intellectual disability' presented as a part of the operational definition of ID is an example of a framework that may be used to develop questions that will effectively describe the population with ID from national surveillance. Furthermore, the team recommends funding pilot projects that would field these questions either as part of an existing survey or as a follow-up module of an existing survey. For example, as suggested by Hendershot, Harris, and Stapleton (2009), a limited number of additional questions could improve the utility of the NHIS for understanding the health of people with intellectual disability. As another example, ID survey identifiers could be fielded as part of a follow-up module to the NHIS or the BRFSS. Those who respond affirmatively to the general disability questions in the main NHIS or BRFSS survey could be included in the follow-up survey.

Recommendation #4: Incorporate promising methods to include representative sample of adults with ID.

The current sampling framework and survey methods utilized in national and state-level health surveys tend to minimize the likelihood of including people with disabilities and, in particular, people with ID. For example, the BRFSS systematically under-samples the population with intellectual disability due to its exclusion of people who live in group homes or other alternative settings. The National Core Indicators (NCI) project currently only captures adults with ID who are receiving services. In order to utilize the existing surveillance systems to advance the health surveillance of people with ID, current

sampling methodologies need to be modified. Methods need to be developed to fully support the inclusion and participation of representative, unbiased samples of adults with ID.

Next Steps: In order to more effectively capture adults with ID who are currently not represented in existing surveys, additional sampling strategies need to be considered. Methods used in other studies hold promise for potential use, including group home sampling methods used in American Community Survey (ACS) and Survey of Income and Program Participation (SIPP) for group home inclusion methods. We recommend funding pilot studies that will draw upon promising sampling methodologies that are currently being used for other populations and test the feasibility of applying them to the population of adults with ID. In addition, targeted outreach to community groups and organizations that support people and families with intellectual disability and their families should include encouragement and support for participation in health surveillance efforts.

Recommendation #5: Incorporate question and response options in existing surveys to facilitate participation of adults with ID and their proxies.

The standard phrasing of questions and optional responses in most of the existing surveys may create a barrier for people with ID to respond accurately. All possible accommodations to enable people with ID to self-respond should be investigated (Chang et al., 2009). Mixed-mode approaches may be useful for increasing response rates for people with disabilities while controlling costs. Additionally, people with disabilities may require accommodations in order to fully participate in surveys. Examples include interviews split into multiple, short sessions, alternative wording or communication strategies and additional time to respond to questions.

While self-response is always desirable and should be used as much possible (Kaye, 2007; Stancliffe, 1999), the use of assisted or proxy responses can facilitate the inclusion of a more representative sample of people with ID by including people that are not able to respond for themselves. Such alternative methods need to be incorporated in current survey methods (Kaye, 2007). For example, the National Core Indicators (NCI) project allows proxy responses for a portion of its questionnaires. Self-appointed advocates, in discussions with project team members, indicated their preference to complete survey questionnaires with support to ensure that they understand the questions.

Surveys can incorporate certain strategies to improve the quality of information received from participants with disabilities by creating a survey environment that encourages and facilitates participation. Interviewer training can be an important part of this strategy, including training on cultural competency in disability and strategies to overcome common barriers to participation in interviews for people with disabilities such as communication strategies for speech and hearing impairments, stamina accommodations, and methods to accommodate varying individual needs such as processing difficulties (Mitchell, et al. 2006; Jackle et al. 2010).

Next Steps: We recommend funding pilot studies that will 1) incorporate existing promising practices in facilitating participation of adults with ID into surveys, 2) develop and validate new practices to support full participation, 3) investigate the effect of using assisted and proxy respondents.

III. Developing new data collection systems to address specific surveillance or population mapping needs

Recommendation # 6: Develop a longitudinal survey designed for health surveillance of people with ID.

While the recommendations proposed in the previous sections all would greatly improve health surveillance, several key questions about this population may remain unanswered, including the trends of health outcomes in the population as the population transitions to adulthood and then ages into later life, and the pathways for people who do not self-identify as intellectually disabled after leaving the education system. For this reason, the project team considered and arrived at a final recommendation: the design of a longitudinal study of the ID population, using the proper sampling methods to identify a representative sample.

Most existing surveys that include people with ID are cross-sectional, thereby limiting the ability to analyze the progression of the disability, disability-related consequences, the health and health care delivery needs of a population-based sample of people with ID. Creating a new, specialized survey would, among other benefits, allow the incorporation of features that would track individuals with ID through periods of transition from youth to adulthood and into mature adulthood. A longitudinal survey provides essential information on these transitions and the identification of those who ‘fall out’ of the service system at adulthood. Existing surveys such as the SIPP have a limited follow-up period of two

and a half years and include a small number of people with disabilities. Other longitudinal surveys such as Health and Retirement Survey sample and the National Longitudinal Survey of Youth survey specific subpopulations of older and younger cohorts. A longitudinal survey can have the capacity to combine data on the respondents' social, economic, psychological and physical well-being with contextual data on the family, caregiver, neighbor, community, social groups and health care providers. It could also afford an opportunity for the collection of biological data as in the Add Health survey (National Longitudinal Survey of Adolescent Health) to understand the social, behavioral, and biological linkages in the health trajectories of people with ID as they age.

This is the most involved and expensive avenue of health surveillance. Significant financial resources are required to effectively sample and follow-up with respondents. However, the benefits of a new system of health surveillance are also significant and provide many advantages over the other two avenues described. As such, it is included as the final recommendation.

Next Steps: The CDDER/HSRI project team recommends conducting a feasibility study of the design, implementation and sustainability of a national, longitudinal study on the health and health care needs of adults with ID. The study should include a scan of existing national and international longitudinal studies of people with ID and other conditions that make them hard-to-reach. The feasibility study should aim to include (1) the appropriate research designs, (2) costs of implementing each research design, (3) whether existing surveys such as the National Longitudinal Transition Study-2 or the National Core Indicators would be an appropriate sampling strategy or could be modified for this purpose, (4) the sampling design and selection, (5) the sample size, (6) the survey panel design, and (7) panel recruitment and potential attrition.

SUMMARY OF RECOMMENDATIONS

The recommendations presented in this report and summarized below are presented as the synthesis of findings and guidance from multiple sources including literature review, expert opinion, critical analyses of current data sources, and individual and community leader input over the course of the RTOI project period. Action in response to these recommendations is not intended to be sequential however the ‘low hanging fruit’- those recommendations that are most likely to be successfully completed, and produce the greatest impact with lowest resource requirements - is identified first:

Using *currently collected* data, validate approaches to identifying the population and monitoring health measures in the adults with intellectual disability.

Recommendation #1: Demonstrate the effectiveness of using ICD and other codes in medical service claims to identify adults with ID and monitor health measures.

- Use insurance (Medicaid and Medicare) claims data and test against a known data set of people with ID to establish estimates of sensitivity.

Recommendation #2: Link multiple existing data sources for health surveillance.

- Capitalize and expand upon on linkages between national health surveillance systems such as the National Health Interview Survey and administrative data sources that can both identify the population with ID and inform ongoing health surveillance.
- State level demonstration: Conduct demonstration projects in at least three states that have significant geographic and administrative variation. The goal is to demonstrate methods at the state level to identify a representative population and produce surveillance data that informs national surveillance systems.
- The proposed ‘operational definition of intellectual disability’ to the data linkage project should be studied; this application will also advance efforts to apply a consistent population definition.

Modify current data sources:

Recommendation #3: Include valid and reliable questions in existing surveys to identify people with ID.

- Current national ‘disability’ survey questions may capture the population with within the ‘cognitive disability’ group, but there is no means to separate those who have the lifelong experience of intellectual disability from those who have developed a cognitive limitation later in life due to ageing or injury, and can have very different experiences of health access and quality.
- Building from an agreed upon case-definition, develop and test appropriate questions for use in identifying the population in primary and follow-up surveys.

Recommendation #4: Incorporate promising methods to include representative sample of adults with ID in all health surveillance efforts.

- Use surveillance methods that include group quarters sampling frames as in the American Community Survey and test the capture rate for identifying the population with intellectual disability.
- Support inclusion of populations that are typically underrepresented through targeted outreach to community groups and organizations that support people with intellectual disability and their families to encourage participation. This includes non-English speaking populations.

Recommendation #5: Incorporate question and response options in existing surveys to facilitate participation of adults with ID and their proxies.

- Prioritize self-report but allow for mixed-mode reporting that allows for proxy responses and gathering of data from multiple informants.
- Test methods to enhance participation and response rate from individual and proxy response.

Develop new data collection systems:

Recommendation # 6: Develop a longitudinal survey designed for health surveillance of people with ID.

- Life transitions and aging processes are both areas that can have significant impact on the health of this population, and a longitudinal study is necessary to fully understand these.
- Initiation should include feasibility study of adding ID specific methodology to current national longitudinal studies and exploration of sampling frames that can be built upon or expanded from existing study designs, such as the National Core Indicators sampling framework.

Current advances in data linkage, increasing adoption of electronic health records, and a national move to use administrative data to improve outcomes suggest that the time may be right to capitalize on data source availability and develop a robust picture of this population's demographics and factors contributing to health disparities. National health surveillance of adults with intellectual disability is in its nascence. The recommendations presented above give direction to those working towards the goal of enhancing national health surveillance and to achieve the nation's goals of healthy lives for all Americans.

References

- Bigby, C. (1995). Is there a hidden group of older people with intellectual disability and from whom are they hidden? Lessons from a recent case-finding study. *Journal of Intellectual & Developmental Disability* 20(1), 15-24.
- Campbell, V.A., Hovinga, M.E., Brezaussek, C. (1996, December 3), Alabama's mental retardation surveillance program: Interagency administrative ascertainment across the lifespan, 1996 Annual Maternal, Infant, and Child Health Epidemiology Workshop, Atlanta, GA.
- Centers for Disease Control and Prevention (CDC) / National Center on Birth Defects and Developmental Disabilities (NCBDDD) Health Surveillance Work Group (2009). *U.S. Surveillance of Health of People with Intellectual Disabilities* [A White Paper]. Kingston, Ontario, Canada.
- Centers for Disease Control and prevention (undated) VERB Youth Campaign, Multicultural Outreach Factsheet. Accessed 11-15-11at <http://www.cdc.gov/youthcampaign/pressroom/PDF/6.1.01-NatMultCulFactSheet.pdf>
- Center for Mental Health Services. Mental Health, United States, 2004. Manderscheid, R.W., and Berry, J.T., eds. DHHS Pub no. (SMA)-06-4195. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2006.
- Chang, L., Krosnick, J. (2009). National Surveys via RDD telephone interviewing vs. the internet: comparing sample representativeness and response quality. *Public Opinion Quarterly*. 73(4): 641-678.
- Emerson E. (2007) Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 13, 107-113.
- Fazel, S., Xenitidis, K., Powell, J. The prevalence of intellectual disabilities among 12 000 prisoners – A systematic review. *International Journal of Law and Psychiatry*.
- Federal Register June 8, 2011 Vol. 76 no. 110 42 CFR Part 401 Medicare Program: Availability of Medicare Data for Performance Measurement.
- Fox, M.H., Rowland, J., Froehlich-Grobe, K., Vernberg, D., White, G., Haskett, L. (2008). Determining paralysis prevalence in the United States. *Disability and Health Journal*. 1(3), 172-179.
- Freeman, L., Chassler, D. (2004). Physical and behavioral health of adults with mental retardation across residential settings. *Public Health Reports*. 119:401-408
- Henry, A.D., Gallagher, P., Stringfellow, V., Olin, L., Hooven, F., Himmelstein, J., (2007) Notes from the Field: Contemporary Strategies for Developing Surveys of People with Disabilities: The MassHealth Employment and Disability Survey. In *Towards Best Practices for Surveying People with Disabilities*. Volume 1. Thilo Kroll, David Keer, Paul Placedk, Juliana Cyril and Gerry Hendershot. Eds. Nova Science Publishers. pp. 127-146.

- Gilmer, T.P., Kronick, R.G. (2011) Differences in the volume of services and prices drive big variations in Medicaid spending among US States and regions. *Health Affairs*, 30(7):1316-1324.
- Glasson E.J., Hussain, R. (2008). Linked data: opportunities and challenges in disability research. *Journal of Intellectual and Developmental Disability*. 33:285-91.
- Hendershot, Gerry E., Benjamin H. Harris, David C. Stapleton. (2009). "Health and Functional Status." In Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement, Andrew J. Houtenville, David C. Stapleton, Robert R. Weathers II, Richard V. Burkhauser, eds. Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, pp. 227-263.
- Iezzoni, LI., Ngo, LH., Li D., Roetzheim, RG., Drews, RE., McCarthy, EP. (2008). Early stage breast cancer treatments for younger Medicare beneficiaries with different disabilities. *Health Services Research*. 43:5.
- Iezzoni, L. (2002). Using administrative data to study persons with disabilities. *The Milbank Quarterly* 80(2), 347-379.
- Jäckle, A., Roberts, C. and Lynn, P., (2010). Assessing the effect of data collection mode on measurement. *International Statistical Review*, 78(1); 3-20.
- Kaye H. S. (2007) Inclusion of People with Disabilities in the NHIS and NHIS-D: Non-response, proxy response, and assisted response. In Towards Best Practices for Surveying People with Disabilities. Volume 1. Thilo Kroll, David Keer, Paul Placedk, Juliana Cyril and Gerry Hendershot. Eds. Nova Science Publishers. pp. 105-125.
- Kinne, S. Topolski, T.D. (2005) Inclusion of People with Disabilities in Telephone Health Surveillance Surveys. *American Journal of Public Health*, 95(3).
- Krahn, G., Fox, M., Campbell, V., Ramon, I., & Jesien, G. (2010). Developing a health surveillance system for people with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities* 7(3), 155-166.
- Lakin, K. Laron, S. Salm, P., Webster, A (2010) Residential services for persons with developmental disabilities: Status and trends through 2009. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Livermore, G., She, P., (2007). *Limitations of the National Disability Data System*. Ithaca, NY: Cornell University, Rehabilitation Research and Training Center on Employment Policy for Persons with Disabilities. Document No. PP07-137, 48 Pages
- Markesich, J. (2008). *Surveying Persons with Disabilities: A Source Guide Version II*. Mathematica Policy Research, Inc., Submitted to Cornell University, Employment and Disability Institute.
- McDermott, S., Turk, M. A. (2011). The myth and reality of disability prevalence: measuring disability for research and service. *Disability and Health Journal*, 4(1), 1-5.
- Mitchell, S, et al. (2006). *Removing Barriers to Survey Participation for Persons with Disabilities*. Rehabilitation Research and Training Center on Disability Demographics and Statistics at Cornell University.

Noonan Walsh, P. (2008). Brief Report: Applying an indicator set to survey the health of people with Intellectual Disabilities in Europe. *Journal of Policy and Practice in Intellectual Disabilities*. 5(3), 211–213.

Noonan Walsh, P. Pomona Project. (2008) *Health Indicators for People with Intellectual Disability: Using an Indicator Set, Pomona II. Final Report*.

O'Hara, B (2010) Is there an undercount of Medicaid participants in the ACS Content Test? U.S. Census Bureau, Small Area Estimates Branch, Washington D.C. Accessed 11-21-11 @ www.census.gov/did/.../Medicaid-Participants-ACS-Content-Test.pdf

Quam, L., Ellis, L., Venus, P., Clouse, J., Taylor, C., Leatherman, S. (1993). Using claims data for epidemiologic research: The concordance of claims-based criteria with the medical record and patient survey for identifying a hypertensive population. *Medical Care*. 6,498-507.

Reid, P., & Hand, J. (1995). The process, problems and rewards of identifying older adults with an intellectual disability in New Zealand. *Journal of Intellectual and Developmental Disability* 20(1), 3-14.

Slayter, E. (2010). Medicaid-Covered alcohol and drug treatment use among people with intellectual disabilities: evidence of disparities. *Intellectual and Developmental Disabilities* 48(5), 361-374.

Slayter, 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.

Souza, T. et al. (2009). Worst case housing needs of people with disabilities. *Supplemental Findings of the Worst Case Housing Needs 2009: Report to Congress*. US Department of Housing and Urban Development.

Stancliffe, R.J. (1999) Proxy respondents and the QoL-Q. *Journal of Intellectual Disability Research* 43(3) 185-193

Stapleton, C., Livermore, G., She, P. 2009. "Options for Improving Disability Data Collection." In *Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement*, Andrew J. Houtenville, David C. Stapleton, Robert R. Weathers II, Richard V. Burkhauser, eds. Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, pp. 381-418.

Stapleton, D., Thornton, C. (2009). *Is It Time to Establish a National Disability Data System?* Washington D.C., Center for Studying Disability Policy, Mathematica Policy Research.

U.S. Department of Housing and Urban Development (HUD) 2010 Annual Homeless Assessment Report (AHAR) to Congress (2010). U.S. Department of Housing and Urban Development Office of Community Planning and Development.

Walkup, J., Sambamoorthi, M., Chrystal, S. (1999) Characteristics of persons with mental retardation and HIV/AIDS: Infection in a state Medicaid population. *American Journal of Mental Retardation*, 104, 356-363.

Wharton, M., Chorba, T., Vogt, R., Morse, D., Buhler, J., (1990). Centers for Disease Control and Prevention, Case Definitions for Public Health Surveillance. *Morbidity and Mortality Weekly Review*. Vol..39 No. RR13.

World Health Organization (2011) World Report on Disability,
http://www.who.int/disabilities/world_report/2011/en/index.html

Yeargin-Allsopp M. et al (2003) Prevalence of Autism in a US Metropolitan Area. *JAMA*
289(1) 49-55.

Zaharia, R., Moseley, C. (2008) *State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants*, NASDDDS, Rutgers Center for State Health Policy

Appendix A – Key informants

Outreach to Community Members and People with Intellectual Disability

People who were formally interviewed or offered guidance included:

Bill Gaventa - Director of Community and Congregational Supports at the Elizabeth M. Boggs Center on Developmental Disabilities

Alexis Henry - Director, Disability Health and Employment Policy Unit, Center for Health Policy and Research University of Massachusetts Medical School

Lilia Teninty – Senior Policy Specialist. Human Services Research Institute.

Evelyn Hausslein – Parent Leader

Sheryl White-Scott - Associate Director of Community Health Services for the medically frail at AHRC New York City and Medical Director for Brooklyn Developmental Disabilities Services

Ron Manderscheid - Executive Director, NACBHDD

Vijaya Kancharla – Research Scientist, Centers for Disease Control and Prevention

Suzanne McDermott – Principal Investigator SC Interagency Office of Disability and Health

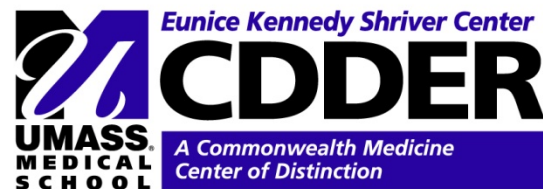
Theresa Souza - Social Science Analyst, Policy Development Division Office of Policy Development & Research, U.S. Department of Housing and Urban Development

Robert Trestman - Executive Director, Correctional Managed Health Care

Several additional people were interviewed but preferred to remain anonymous. The project team thanks all those who participated in these discussions and provided their valuable insights as well as the numerous colleagues who offered input and informal guidance throughout the course of this project.

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