

Health Surveillance of People With Intellectual Disabilities *Results of a Working Meeting* April 2010

Across their lifespan, nearly 4 million Americans currently are estimated to have intellectual disabilities (IDs).¹ There are significant challenges to accurately identifying and reaching this population for purposes of health surveillance. These challenges include lack of an agreed upon operational definition, difficulties of definition, communication, stigmatization, confidentiality, and proxy reporting. In spite of these difficulties, numerous studies have documented the unmet health needs of people with an ID.

As a group, adults with an ID experience poorer health outcomes than people without an ID. Compared with peers of a similar age, they are more likely to:

- Live with complex health conditions.
- Have poorly managed chronic conditions, such as epilepsy, hypertension, and obesity.
- Have limited access to appropriate health care and health promotion programs.
- Receive breast cancer and other health screenings at lower rates than those among the general population.
- Have undetected vision and hearing problems.
- Have mental health problems and potential overuse of psychotropic medications.

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 conducting population-based surveillance of the health status of adults with an ID. Results of the meeting are summarized in a white paper available online at http://www.cdc.gov/ncbddd/dh/publications/209537-A_IDmeeting%20short%20version12-14-09.pdf. From that meeting,

domains for a minimum dataset of health indicators were identified. These domains could be the foundation for an expanded population-based surveillance strategy. They were:

- ***Health and participation:*** Comprising health status, chronic conditions, health behaviors, participation in meaningful activities and socialization, quality of life, and premature death.
- ***Health care and health promotion:*** Comprising access to health care, quality and appropriateness of health care, effectiveness of health promotion, access to advocacy resources, communication supports and health systems.
- ***Associated and secondary conditions:*** Comprising indicators of particular importance for people with an ID, such as undermedication or overmedication (e.g., with psychotropic drugs), emergency room visits and hospitalizations, screening for vision and hearing, and conditions associated with disabilities or syndromes.
- ***Demographic variables:*** Comprising race and ethnicity, age, sex, etiology of the ID when known, and the type of residential setting.

An action plan comprising the following five steps also emerged from that meeting:

1. ***Define ID*** operationally using shared experiences and expertise from key stakeholders; define ID 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 an 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 an 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 second working meeting of representatives from government and research and advocacy communities, each involved in ID issues, was held in February 2010 to identify approaches to implementing the action plan. It was attended by 70 representatives of federal agencies, researchers, and advocates. Attendees summarized key issues related to surveillance for people with an ID:

- Operationalize the definition of ID for health surveillance in ways that take into account existing forms of measurement: categorical, programmatic, functional, environmental, and medical.
- Expand surveillance using mixed methods for different segments of the population and units of measurement, e.g., at the individual, organization, community, county, state, and national levels.
- Break down administrative and research silos and encourage systematic data sharing among organizations.
- Use a life-course approach that includes age groups from children to elders to measure and understand the health of people with an ID.
- Understand the influence of multiple social determinants of health and quality of life.
- Use improved surveillance data to report on evidence-based outcomes.
- Coordinate efforts to maintain visibility and build sustainability for health surveillance for ID by pooling resources.

“The landmarks of political, economic and social history are the moments when some condition passed from the category of the given into the category of the intolerable.”² Vickers, 1958.

There is growing recognition that the poor health of people with IDs is intolerable. Health is the last frontier for promoting the rights of people with disabilities. Documenting the problem through improved surveillance and subsequent analyses are the first steps toward change. Federal agencies, advocates, and researchers are ready to work together to document and ameliorate the poor health of people with IDs.

¹ The Tenth Revision of the *International Classification of Diseases* (ICD-10) defines intellectual disability (ID) as “...a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, contributing to the overall level of intelligence, i.e., cognitive, language, motor and social abilities.” Some neurogenetic conditions in which IDs might be present include Down or fragile X syndrome. Others, such as fetal alcohol syndrome, are environmentally induced.

² Vickers G. What sets the goals of public health? *Lancet*. 1958;1:599–604.

Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.