U.S. Surveillance of Health of People with Intellectual Disabilities

A White Paper

from the

Centers for Disease Control and Prevention (CDC) / National Center on Birth Defects and Developmental Disabilities (NCBDDD) Health Surveillance Work Group

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Introduction

Adults with intellectual disabilities (ID) experience poorer health outcomes than people without ID.[1] These disparities mean that people with ID are more likely to[2]:

- Live with complex health conditions.
- Have limited access to quality health care and health promotion programs.
- Miss cancer screenings.
- Have poorly managed chronic conditions, such as epilepsy.
- Be obese.
- Have undetected poor vision.
- Have mental health problems and use psychotropic medications.

However, the data supporting these conclusions are based on studies of populations who receive public services or on other convenience samples. The U.S. Public Health Service is unable to report on the health status of one of its most vulnerable populations — adults with ID — on a truly representational basis. The health of the general population is routinely monitored through national surveys, but the health of adults with ID is not. Because of recent calls for improved health surveillance of U.S. populations with disabilities,[3] our understanding of the health of people with general disabilities is improving. However, people with ID remain largely undetected in population health surveillance. What accounts for their absence?

Administrative data sets offer an explanation — and suggest an answer. The percentage of the population identified with ID drops dramatically among post-school-age young adults. After these individuals leave school, most of them disappear from national data sets. They “age out” of the education system and its records and may be missing from or unidentifiable on social services rolls. For example, analysis of linked interagency data in Alabama in 1994 indicated that, between childhood and adulthood, the prevalence of ID in populations tracked by administrative systems dropped from 3.2 outpatients to less than 0.5 outpatients per hundred.[4] Without knowing the number, health status, or needs of this group, we cannot plan for services that could maximize their health and productivity.

Efforts to improve surveillance for persons with ID parallel trends in de-institutionalization among populations with disabilities in which tracking service use becomes more difficult. The movement toward community living by people with disabilities has only strengthened the need to assess the health status and needs of people with ID to better plan appropriate service delivery and monitor its effectiveness. Health care costs for the 4.9% of the Medicaid population with ID account for 15.7% of total Medicaid expenditures.[5] Given the challenges facing this population and their caregivers, reliable data are essential to shape effective public policy and management of health services that respond to identified health needs.

Driven by similar factors, other countries are taking steps to better assess the health of their residents with ID, including a consortium of 13 European Union countries engaged in the Pomona Project.[6] These efforts have laid the groundwork for extending surveillance in ways that will help us meet the unique challenges of improving the health of people with ID in the United States and elsewhere.

Developing a plan

CDC/NCBDDD, with assistance from the Association of University Centers on Disabilities, convened a meeting in September 2009 to consider the feasibility of conducting population surveillance of the health status of adults with ID. From this meeting, key questions for pursuing an action plan emerged:

- What is the relative health status of adults with ID?
- What are their major health risks, and how do the risks vary for different subgroups of this population?
- How do access to and quality of health care relate to health outcomes for this population?

Identifying key health and health care variables

Answering key questions about health status, risks, and access requires the identification of appropriate health indicators — key variables of health and quality of health care.[7] Building on health indicators that are important for the general population enables us to make comparisons with subgroups. These generic health indicators can then be supplemented with others developed specifically for ID populations, such as the National Core Indicators or the indicators employed in the Pomona Project.[8]

We propose the following health indicators for the ID population in the United States:

- Health and participation: health status, chronic conditions, health behaviors, participation in meaningful activities and socialization, and quality of life.
- Health care and health promotion: access to health care, quality of health care, quality of health promotion, and health systems.

- Associated and secondary conditions: indicators uniquely important for people with ID, such as undermedication or overmedication (e.g., with psychotropic drugs), access to advocacy, communication supports, emergency room visits and hospitalizations, screening for vision and hearing, and conditions associated with disabilities or syndromes.
- Demographic variables: race/ethnicity, age, sex, etiology of ID when known, and type of residential setting.

Identifying the population

Another result of the meeting was a consensus to find better ways to identify the population with ID in the United States. Because existing data sets are based on different eligibility criteria, multiple operational definitions of ID may be required to capitalize on existing data.

In the formal developmental disabilities service system, people with ID are fairly easy to find. They either have more significant ID or additional disabilities that qualify them for public services. People with mild ID may receive services through other systems (e.g., Temporary Assistance for Needy Families, unemployment benefits, the judicial system, or mental health care) but not be identified as having ID.

Ascertaining the severity of ID could be valuable in investigating health disparities, but severity is difficult to measure without access to school, medical, or other administrative records. Distinctions about degree of disability can sometimes be made on the basis of difficulty with activities of daily living and instrumental activities of daily living. Ideally the data should allow for cross-referencing with other data systems, such as education and state Medicaid.

Collecting the data

After health indicators are identified and an operational definition of ID is agreed upon, the next step is to collect data. Administrative data tend to capture only populations that receive public services, thus missing many adults with milder ID or those who reside with their families and are not enrolled for services. Quality-of-life data are limited, and systems based on medical coding do not necessarily identify ID. Most data on the health of people with ID are from convenience rather than representative samples, and even very large samples, such as Special Olympics data, typically miss whole segments of this population.

Several administrative data sets provide valuable surveillance data that identify some segment of the population with ID, including:

- State data sets for Medicaid, which contain diagnostic and functional characteristics that can be merged with payment files, although these programs are operated at the state level and eligibility varies widely.
- State developmental disabilities agency data sets and waiting lists for people with ID who are eligible for services, although these also vary by state.
- Data sets from intermediate care facilities with programs for residents with intellectual disabilities.

- National Core Indicators project.

Obtaining data about and from people with mild ID is challenging because they typically vanish from ID service rolls after leaving the educational system. Possible data sets include the Special Olympics International Healthy Athletes and the Wisconsin Longitudinal Study.

Data collection presents diverse but surmountable difficulties. Standard survey questions may be too difficult for people with ID to answer. These questions require an understanding of the vocabulary and concepts, the capacity to make an assessment based on a relative norm, and the ability of the respondent to report his or her own health status. Moreover, many people are reluctant to identify themselves as having ID because of stigma, and personality factors can affect responses. For these reasons, surveys sometimes rely on proxy respondents, a process that presents its own challenges in terms of accuracy and the necessary permissions.

Possible approaches

Conducting more comprehensive health surveillance of people with ID presents unique methodological complexities. These include the validity of sampling strategies, case identification, access to data sources, measurement of health indicators, and resources. A comprehensive approach to these challenges could be undertaken in five overlapping stages that build on existing data and layer on different methodologies and approaches:

1. Using shared experiences and expertise from key stakeholders, define ID in ways that are clinically, functionally, and operationally valid. Determine the feasibility of and approaches to including people across the full range of ID.
2. After operationally identifying the population, 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, participation, and public health practice.
3. Extend past analyses of current data sources that capture health information for people with ID in ways that provide a richer background 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 nationally that may include conducting a national survey or linking new surveillance tools to existing surveys.

A call to action

Meeting participants developed the following call to action:

- There is broad recognition of the tremendous health need in this vulnerable population, which has been largely ignored. We need to begin a concentrated, resourced, collaborative, and continuous effort to meet this need.
- Getting valid and reliable health information for this population is the first step in planning and designing appropriate services and building the capacity to track service effectiveness.
- Surveillance should be an ongoing process rather than a single project, employing a multipronged approach that uses the best scientific methods and builds on existing information.
- People with ID should provide input for each step of the process.
- Methodological challenges must be overcome to improve health surveillance for this population. We outlined a multistage, methodological approach for developing these surveillance data.
- The United States can learn a great deal from similar efforts in the United Kingdom, Australia, and Canada.

The next step is to gauge interest, increase awareness, and organize the efforts of federal agencies, disability organizations, foundations, and others to collaborate for better surveillance of this population. Relationships with advocacy groups and stakeholders can yield data and support. For now, we must concentrate on documenting the need for and value of the information, the possibilities for its use, and cost of collecting it. Without useful and timely surveillance data, the health needs of people with ID in the United States can neither be understood nor met.

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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.*

Endnotes

[1] Horwitz, S., Kerker, B., Owens, P., and Zigler, E. (2000), "The health status and needs of individuals with mental retardation," New Haven: Yale University; and USDHHS, "The Surgeon General's call to action to improve the health and wellness of persons with disabilities" (2005), Washington, D.C.: U.S. Department of Health and Human Services, Office of the Surgeon General; and Krahn, G.L., Hammond, L., and Turner, A., "A cascade of disparities: Health and health care access for people with intellectual disabilities," *Mental Retardation and Developmental Disabilities Research Reviews* (2006), 12: 22-27.

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[3] See USDHHS, "Closing the gap: A national blue-print for improving the health of individuals with mental retardation," Report of the Surgeon General's Conference on Health Disparities and Mental Retardation (2002), Washington, D.C.: U.S. Department of Health and Human Services, Office of the Surgeon General; and USDHHS, "The Surgeon General's call to action to improve the health and wellness of persons with disabilities," (2005), Washington, D.C.: U.S. Department of Health and Human Services, Office of the Surgeon General.

[4] See Campbell, V.A., Hovinga, M.E., and Brezausek, 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.

[5] USDHHS, "Closing the gap: A national blue-print for improving the health of individuals with mental retardation," Report of the Surgeon General's Conference on Health Disparities and Mental Retardation (2002), Washington, D.C.: U.S. Department of Health and Human Services, Office of the Surgeon General.

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[7] Walsh, P.N., "Health indicators and intellectual disability," *Current Opinion in Psychiatry* (2008), 21: 474-478.

[8] The Pomona Project, funded by the EU Health Monitoring Unit, developed 18 health indicators for people with ID. Interim and final reports documenting this project between 2002 and 2004 are available at www.pomonaproject.org/index.php; Bradley, V.J. and Moseley, C. (2007), "Perspectives: National Core Indicators: Ten Years of Collaborative Performance Measurement," *Intellectual and Developmental Disabilities*, 45, 5: 354-358.