From invisible to visible to valued: Improving population health of people with intellectual and developmental disabilities

Gloria L. Krahn, PhD, MPH
Barbara Emily Knudson Endowed Chair in Family Policy Studies, Director of External Relations
Oregon State University
Office: 541-737-3605
2631 SW Campus Way
Corvallis, OR 97331
Gloria.Krahn@oregonstate.edu

Susan M. Havercamp, PhD
The Ohio State University Nisonger Center
1581 Dodd Dr
Columbus, Ohio 43210
Susan.havercamp@osumc.edu

RUNNING Title: from invisible to visible to valued

KEY WORDS: health surveillance, intellectual disability, developmental disability

From invisible to visible to valued: Improving population health of people with intellectual and developmental disabilities

Gloria Krahn and Susan Havercamp

The concern that most people with intellectual and developmental disabilities (IDD) are 'invisible' in health surveillance has been the focus of attention for at least two decades since the publication of the Surgeon General's *Closing the Gap* report (Office of the Surgeon General, 2002). Surveillance refers to systematic and repeated collection, analysis and interpretation of health related data to inform planning, implantation and evaluation of public health practices. This concern of 'invisibility' has been exacerbated by recent changes in two U.S. surveillance systems, the National Health Interview Survey (NHIS) and the Survey of Income and Program Participation (SIPP) that no longer contain questions to allow monitoring of the health of this population. 'From invisible to visible to valued'— this special issue is intended to increase knowledge of researchers, policy-makers, program planners, and advocates on health surveillance of people with IDD, bringing forward directions to improve the health and wellbeing of this population.

The invited papers in this issue present ongoing efforts in the U.S. that are informed by work from other countries to improve U.S. health surveillance that, in turn, can inform policy and programs for this population. In addition to the authors, we greatly value the reviewers who generously shared their diverse expertise in strengthening the papers. The reviewers include: Colleen Boyle (National Center for Birth Defects and Developmental Disabilities (NCBDDD)), Michael H. Fox (formerly with NCBDDD), Adriane Griffen (Association of University Centers

on Disabilities), Jennifer Johnson (Administration for Community Living), Donald Lollar (University of Kentucky), Margaret Nygren (American Association on Intellectual and Developmental Disabilities), David O'Hara (Westchester Institute on Human Development), Karrie Shogren (University of Kansas), and Sue Swenson (Inclusion International). Their insightful reviews enhanced the knowledge communicated by each paper in this issue. As guest editors of this special issue, we discerned several important themes emphasized throughout the papers.

First, better and more targeted health surveillance of people with IDD is essential in order to cost effectively improve health, services and supports for people with IDD. Havercamp & Krahn (2019) summarize the current U.S. context, identifying three foundational issues for understanding the current data conundrum on health for this population. They note the dramatic increases in community living that came about through advocacy for greater autonomy, advances in knowledge, and changing societal views on disability. These changes were reflected and advanced through a sequence of legislation. There was no corresponding process, however, for monitoring the health of adults with IDD who increasingly were living in their communities. The authors review models of disability that have resulted in different approaches to measurement, notably those using identification by diagnoses vs ones based on functional limitations. Finally, they raise the 'denominator' issue, and the difficulties of understanding health of adults with IDD when data are based only on those receiving developmental disability services.

Krahn (2019) calls for better data to inform federal agencies' policies and programs to improve health of people with IDD. In an era of data-driven decision-making, better data are essential for fiscal projections, planning, and evaluation of programs and policies. Despite this need, the recent development of standards for disability identification in national surveillance (US DHHS, 2011) does not allow for the identification of people with IDD, making it impossible to ascertain data specific to the IDD population. Krahn introduces the sampling issue that plagues research in this field, differentiating the 'served' from the 'unserved' population, with estimates that only about one-fifth of adults with IDD are known to the developmental disabilities services system in their states. She concludes by calling for improved national health surveillance that utilizes different data types while continuously asking "who is missing from this sample?" and "what implications does that have?"

Second, continued collaboration across federal agencies and partnerships with the private sector are essential to make adults with IDD visible in health data. Efforts to improve IDD health data has benefited from ongoing collaborations. Earlier work to promote improved data was highly collaborative across the Centers for Disease Control and Prevention (CDC) and the Administration on Intellectual and Developmental Disabilities (AIDD) at the Department of Health and Human Services, and the then National Institute on Disability and Rehabilitation Research at the Department of Education (see Krahn, Fox, Campbell, Ramon & Jesien, 2010; Fox, Bonardi & Krahn, 2015). These collaborations have expanded recently to include other agencies within HHS, including the National Center for Health Statistics (NCHS) and the Centers for Medicare and Medicaid (CMS). Havercamp and colleagues (2019) summarize the work of a national collaborative work group hosted by the Administration for Community Living

that included members across a number of HHS agencies, university researchers, and national advocates. Based on an established clinical definition for intellectual disability (ID), and the definition for developmental disabilities (DD) from the Developmental Disabilities Assistance and Bill of Rights Act of 2000, the paper identifies priority constructs that need to be added to the National Health Interview Survey (NHIS) question set – specifically learning, independent living, and age at onset – to identify respondents with ID and DD. This core question set is intended to be a standard for use in other surveys.

Third, greater awareness of different operational definitions for IDD is needed; and efforts to adopt standardized methods to identify persons with IDD to allow greater linkage and harmonization across data sets. Havercamp and Krahn (2019) note the changing ways of looking at disability over time and the different definitions of 'developmental disabilities' that are currently used. These differences are largely responsible for the variance in IDD prevalence rates reported in the literature (see Anderson, Larson, MapleLentz & Hall-Lande, 2019). Definitions differ along a number of important dimensions. First, whether the definition is based on diagnostic categories (e.g., cerebral palsy, ID, autism) or on functional limitation (e.g., limitations in mobility, thinking or remembering). A second distinction is severity level — whether the limitations are significant, or whether no mention is made of severity. Finally, the population and sampling frame determines who will have opportunity to be included in the sample and, correspondingly, to which populations the findings apply. Several papers recognize the differences between people 'served' by the DD systems compared with those 'unserved.' Additional distinctions are beginning to be explored between who is included and excluded from the Medicare system, the Medicaid systems, and private health insurer systems for interpreting

findings. These definitional and sampling differences all contribute to different findings on prevalence and health status of adults with IDD.

Operational definitions of ID and DD are an important consideration across the subsequent papers. Many of the authors wrestled with the differing definitions used by the programs or datasets they were drawing upon. This issue brings attention to these differences in operational definition without trying to bring them into a single, unifying definition. In 2003, Fujiura and Taylor (2003) noted this predicament of different operational definitions of ID and cautioned against striving for completely accurate measurement. The AAIDD definition of ID (Schalock, Borthwick-Duffy, Bradley, Buntinx, Coulter, Craig, Gomez … Yeager, 2010) is a commonly accepted clinical definition that requires deficits in intellectual functioning plus two areas of adaptive behavior. The DD Act defines DD as substantial functional limitations in at least three of seven major life activities. This results in a significant portion of people with ID not meeting criteria for DD as defined by the DD Act. Diagnostic approaches to define IDD, on the other hand, are categorical (e.g., cerebral palsy, Down syndrome, ID) and typically do not take severity of the condition into account. The state databases for DD services, Medicaid, and ID/DD registries use their own unique operational definitions to identify individuals with IDD.

Havercamp and colleagues (2019) summarize the issues considered in recommending content domains for a standard set of survey items to identify adults with IDD in national surveys. They note that a significant challenge in measuring IDD is distinguishing the *ability* to learn or exhibit a skill from the *opportunity* to learn and exhibit that skill. This confounding of concepts is nowhere as present as in the inter-related concepts of “self-direction” and “self-determination.”

Bonardi and colleagues (2019) recognize the differences in definitions within and between states. They recommend greater consistency in how people with IDD are identified calling on policy-makers to promote greater consistency in definition that are informed by statutes applicable to all states (such as the DD Act). They further call on researchers to develop standardized methods for identifying people with IDD in large datasets, citing several recent examples of such methods.

Balogh, Leonard and colleagues (2019) describe examples from Canada and Australia in developing data linkage capacity across multiple administrative data sources as an ongoing resource in data rich environments. These methods allow researchers to extract data across databases while ensuring individuals' privacy. By establishing IDD identifiers, they are able to address a broad range of research questions about health of people with IDD through such data linkage systems. This approach has contributed to a better understanding of the prevalence of IDD, sociodemographic correlates of IDD, higher rates of chronic health conditions, much higher rates of hospitalizations for ambulatory care sensitive conditions, disparities in cancer screenings, and much higher rates of mental health conditions in both children and adults with IDD. Findings that emerge across the two countries include the higher prevalence rates from Australia when a birth registry is used rather than data based on the served populations as occurs within the Manitoba and Ontario data linkage systems. Importantly, in both Canada and Australia, these findings are highly influential in policy and program planning. Both examples illustrate the importance of visionary leaders in establishing the data-linkage capability, observed growth and expansion over time, the need for ongoing support and funding, and the value of including persons with IDD in helping to realize the potential of data linkage.

Fourth, capacity for enhanced and more sophisticated data analyses is needed. While health data for persons with IDD may be sparse, greater utilization is needed of data that are currently available. The relative dearth of information on health of persons with IDD will only be improved if health data are improved, and if there is expanded capacity among researchers to analyze data in ways that inform policy-makers to support data-informed decision-making. Current analytic expertise is concentrated among a relatively small group of researchers and centers. As interest and understanding of health determinants for people with IDD grows among policy-makers, more extensive and more distributed analysis expertise is needed. For example, "super users" are analysts at the state or national level who can combine data sets across agencies and use sophisticated modeling techniques to determine how best to interpret the data. Additionally, tutorials or learning collaboratives on IDD data analyses, could support analysts to increase their own skills in a peer-learning format. Such a method, if implemented across the network of University Centers for Excellence in Developmental Disabilities (DD Act; P.L. 106-402; see https://www.aucd.org/template/index.cfm) for example, could build inter-connected capacity across the country.

Health services research methods are beginning to be applied to administrative data for persons with IDD. Through a CDC-sponsored initiative, researchers are analyzing Medicaid data to gain insights into health of enrolled adults with IDD (e.g., McDermott, Royer, Cope, Lindgren, Momany, Lee…Armour, 2018; McDermott, Royer, Mann & Armour, 2017). In this issue, Haile, Reichard and Morris (2019) use Medicare data from enrollees who are dually eligible for Medicare and Medicaid. They document health conditions and health care utilization of

Medicare Fee-for-Service beneficiaries with IDD identified through ICD 9/10 codes and compare them with beneficiaries without IDD for calendar year 2016. We believe this analysis of almost 31 million beneficiaries, with 1.56% having IDD, to be the first publication on this population through this data source. These data document substantially higher rates of having one (73%) or multiple (30.5% with 3 or more) chronic physical conditions for persons with IDD, aligning with previous survey research findings on greatly increased risk for select chronic conditions (Reichard & Stolzle, 2011; Dixon-Ibarra & Horner-Johnson, 2014). Current Medicare analyses indicate dramatically high rates of mental health conditions such as psychotic disorders (20.4%), major depressive affective disorder (28.9%), and anxiety disorder (31.5%). In concordance with analyses of Medicaid data (McDermott, et al, 2018), the authors note substantial variability across states in IDD diagnoses, likely reflecting differences in eligibility requirements for services and variability in recording of IDD codes across states and systems, raising questions of comparability and generalizability of findings across states. These issues will undoubtedly be explored in the near future as we anticipate that Medicaid and Medicare data sets will be used increasingly to understand health of the IDD population.

Fifth, data collection and analyses need to routinely examine race, ethnicity and other characteristics that are known to contribute to marginalization and health disparities in U.S. society. Havercamp and colleagues (2019) and Krahn (2019) call for more attention to race/ethnicity and to data collection in the U.S. territories for a better estimate of national prevalence and more information on opportunities to promote health equity. Efforts to understand how the health care barriers faced by people with disabilities are compounded by race or ethnicity have been slow to emerge. A scoping review in 2014 found only 1 among 73

published studies where the researchers specifically framed the study design to examine barriers to health care access for people with disabilities who are also members of underserved racial or ethnic groups disability (Petersen-Besse, Walsh, Horner-Johnson, Goode & Wheeler, 2014). Nine additional studies had other stated purposes, but included data on health care access barriers at the intersection of race/ethnicity. Recently, the National Academies of Sciences, Engineering and Medicine commissioned a paper to identify key issues in the compounding effects on health disparities at the intersection of disability and race and ethnicity (Yee, Breslin, Goode, Havercamp, Horner-Johnson, Iezzoni & Krahn, 2017).

In their systematic review of 13 prevalence studies, Anderson and colleagues (2019) note that studies on children with IDD have disaggregated data by race, ethnicity, or other social factors; but no studies on prevalence of IDD in adults reported race and ethnicity data. Similarly, Bonardi and colleagues (2019) identified few administrative datasets that allowed disaggregation by race or ethnicity. Race and ethnicity are critically important in understanding health of persons with IDD as illustrated by Haile and colleagues (2019) who found striking disparities across racial and ethnic groups. Tassé and colleagues remind us that innovative health promoting technologies are not equally available to groups marginalized by race, ethnicity or poverty.

Finally, closer relationships among researchers, advocates and policy-makers can identify the most urgent research questions for analysis, capitalize on emerging technologies, and determine directions for policy and programs. Collaborations across policy-makers, advocates, and researchers have produced many of the advances in health surveillance of people

with IDD — from the Surgeon General's report of 2002, to the initial CDC-led initiative (from 2009 to the present), to the current ACL-led summit and workgroups (from 2016-present).

The two workgroup papers illustrate the value of close relationships for identifying the most pressing current problems and the possible directions for solutions. Havercamp and colleagues (2019) describe the thoughtful process for determining the core domains to assess in order to identify people with IDD in national surveys. Bonardi and colleagues (2019) highlight efforts to identify people with IDD in administrative databases across single states, territories, and multiple states, capturing rich information on health care and service utilization. They describe new developments in accessing Medicare data, and efforts to harmonize data sources available through the All Payer Claims Databases. Survey data such as the National Core Indicators and other state systems provide opportunities to build a richer picture of the health of people with IDD in each state or region.

In glimpsing the future for IDD and health surveillance, Tassé and colleagues (2019) summarize some of the as-yet unrealized promises and the all-too-realized perils of electronic health records (EHR) in providing data aggregation across populations. Technology advances in other segments, like precision medicine, may promote greater inter-operability across EHR systems for persons with IDD. Their overview of wearable technologies and use of 'smart home' technologies indicates the possibility of technology monitoring to simultaneously increase personal autonomy while also promoting the health and safety of adults with IDD. These are especially promising directions given the current and predicted shortage of direct support staff.

The papers in this special issue highlight the importance of improved health surveillance of people with IDD. In the two decades since the Surgeon General's call for better data (Office of the Surgeon General, 2002), we have learned a great deal about how to measure and what to measure to understand and improve the health of people with IDD. This slow but persistent progress is a testament to the leadership and collaboration across federal agencies, purposeful advocacy, and the ongoing support for targeted research undertaken by an expanding corps of committed and talented social scientists trained in the latest statistical and epidemiological methods and policy analysis. As guest editors of this special issue, we are grateful to the authors and reviewers who generously contributed their time and expertise. With them, we look forward to progress in the coming decades that will result in people with IDD becoming fully visible and valued, their place in health data, programs and policies universally recognized and secure.

References

Anderson, Larson, MapleLentz, Hall-Lande. (2019). A systematic review of US studies on the prevalence of intellectual or developmental disabilities since 2000. Intellectual and Developmental Disabilities, (this issue)

Balogh, R., Leonard, H., Bourke, J., Brameld, K., Downs, J., Hansen, M., Glasson, E., Lin, E., Lloyd, M., Lunsky, Y., O'Donnell, M., Shooshtari S., Wong, K., & Krahn, G. (2019). Data linkage: Canadian and Australian perspectives on a valuable methodology for intellectual and developmental disability research. Intellectual and Developmental Disabilities, (this issue)

Bonardi, A., Krahn, G.L., Fay, M.L., & Lulinski, A. (2019). Unlocking the potential of state level data: Using state level data for monitoring outcomes in people with intellectual/developmental disabilities. Intellectual and Developmental Disabilities, (this issue).

Dixon-Ibarra, A., & Horner-Johnson, W. (2014). Disability status as an antecedent to chronic conditions: National Health Interview Survey, 2006-2012. Preventing chronic disease, 11, 130251. doi:10.5888/pcd11.130251

Fox, M. H., Bonardi, A., & Krahn, G. L. (2015). Expanding Public Health Surveillance for People with Intellectual and Developmental Disabilities in the United States.

Fujiura, G. T., & Taylor, S. J. (2003). Continuum of intellectual disability: Demographic evidence for the "Forgotten Generation". Mental Retardation, 41, 420–429.

International review of research in developmental disabilities, *48*(4), 73.

Havercamp S.M. & Krahn G. (2019). What matters in population health and how we count it among people with intellectual and developmental disabilities? Intellectual and Developmental Disabilities, (this issue)

Havercamp, S.M., Krahn, G.L., Larson, S., Fujiura, G., Good, T., & Kornblau, B. (2019). Identifying people with intellectual and developmental disabilities in national population surveys. Intellectual and Developmental Disabilities, (this issue)

Haile, E., Reichard, A., & Morris, A. (2019). Characteristics of Medicare beneficiaries with intellectual or developmental disabilities. Intellectual and Developmental Disabilities, (this issue)

Krahn, G.L. (2019). A call for better data on prevalence and health surveillance of people with intellectual and developmental disabilities. Intellectual and Developmental Disabilities, (this issue)

Krahn, G., Fox, M. H., Campbell, V. A., 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.

McDermott S, Royer J, Cope T, Lindgren S, Momany E, Lee JC, McDuffie MJ, Lauer E, Kurtz S, & Armour BS. (2018). Using Medicaid data to characterize persons with intellectual and developmental disabilities in five U.S. states. American Journal on Intellectual and Developmental Disabilities,123(4), 371-381.

McDermott S, Royer J, Mann JR, & Armour BS. Factors associated with ambulatory care sensitive emergency department visits for South Carolina Medicaid members with intellectual disability. (2017). Journal of Intellectual Disability Research, 62(3), 165-178.

Office of the Surgeon General (US); National Institute of Child Health and Human Development (US); Centers for Disease Control and Prevention (US). Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. Washington (DC): US Department of Health and Human Services; 2002. Available from: https://www.ncbi.nlm.nih.gov/books/NBK44346/

Peterson-Besse JJ, Walsh ES, Horner-Johnson W, Goode TD, Wheeler B. (2014). Barriers to health care among people with disabilities who are members of underserved racial/ethnic groups: a scoping review of the literature. Med Care. 52(10 Suppl 3):S51-63. doi:10.1097/MLR.0000000000000195.

Reichard A, Stolzle H. (2011). Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. Intellect Dev Disabil. 49(3):141--154.

Tasse, M.J., Wagner, J., & Kim, M. (2019) National surveillance of intellectual disability: Technology tools that can increase national reach. Intellectual and Developmental Disabilities, (this issue)

Schalock, R. L., Borthwick-Duffy, S.A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., Gomez, S.C… Yeager, M.H. (2010). *Intellectual disability: Definition, classification, and systems of supports*. Washington DC: American Association on Intellectual and Developmental Disabilities.

United States. Congress. Senate. Committee on Labor and Human Resources. (1990). The Developmental Disabilities Assistance and Bill of Rights Act of 1990 : report (to accompany S. 2753). [Washington, D.C.?] :[U.S. G.P.O.],

US Department of Health and Human Services. (2011) Final data collection standards for race, ethnicity, primary language, sex, and disability status required by section 4302 of the Affordable Care Act, October 31, 2011.

https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=53. Accessed February 21, 2019.

Yee, S., Breslin, M.L., Goode, T. D., Havercamp, S. M., Horner-Johnson, W., Iezzoni, L.I., & Krahn, G. (2017). Compounded disparities: Health equity at the intersection of disability, race and ethnicity. Paper commissioned by the National Academies of Sciences, Engineering and Medicine. Available at: http://nationalacademies.org/hmd/Activities/SelectPops/HealthDisparities/Commissioned-Papers/Compounded-Disparities.aspx.