

Proceedings of

The Use of Data in Achieving Health Equity for Individuals with Intellectual and Developmental Disabilities:

Developing the 2020-2030 Roadmap for Improving Data on Individuals with Intellectual and Developmental Disabilities

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Health and Human Services Administration

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Welcome and overview

Jennifer Johnson, Administration on Disabilities, Administration for Community Living

“We’re invisible in the data, we can’t make people believe we need more services if we don’t have data to back us up.”

- Surgeon General’s report in 2002 on health disparities in the ID/DD population.

Jennifer Johnson (*Administration on Disabilities, Administration for Community Living, HHS*) provided the background to today’s meeting. ACL engaged in discussions more than 3 years ago on the need for updated prevalence rates for the ID/DD population, which evolved to improving data to assess health equity. Better data on health of the ID/DD population can help in targeting resources and development of policies and programs.

Previous work traces back to 2009, when a similar group outlined steps to get better data on ID/DD population. The five steps of the 2009-2019 plan are nearly achieved: (1) defining ID/DD for health surveillance (2) synthesize what has been done, (3) extend analyses of existing data, (4) conduct state or regional demonstrations and (5) expand national surveillance. CDC is currently supporting projects for multi-state demonstrations and ACL is partnering with several other agencies to expand national surveillance.

A summit of multiple stakeholders in 2017 recommended next steps on further improving health surveillance data: (1) collaborate with NCHS to develop questions for national surveys that identify ID/DD respondents, and (2) examine opportunities in state and administrative data for a deeper understanding of health data. Two workgroups developed the following reports, each of which suggests potential next steps for improved data:

- **National surveys—agency collaborations and identification questions**

https://aclprdep01.azureedge.net/cdn/ff/1iflcHhToo9FRTlfo47Yw-wct5dWX-Sf_RHQqY0XJhl/1569854188/public/Aging%20and%20Disability%20in%20America/National_Data_Paper_AIDD-ACL_09.25.2019%20508%20compliant.pdf

- **State level—administrative data and promising practices**

https://aclprdep01.azureedge.net/cdn/ff/OATVJImFLs5gbVqdM6iUN0xHELxw4o-ogEah3HlsULA/1569854246/public/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf

- **Easy Read Summary**

https://aclprdep01.azureedge.net/cdn/ff/iD18_yTvSrqXwljihVXNfKNANn5WjPXP9ySdpJZNQU M/1569854262/public/Aging%20and%20Disability%20in%20America/Easy_Read_Final_Version--How_to_improve_health_surveillance_of_people_with_IDD%209.25.2019%20508%20compliant.pdf

In addition, AAIDD published a special journal issue on health surveillance and improving data for ID/DD population (<https://www.aiddjournals.org/toc/mere/57/5>). Arising from these discussions, ACL is collaborating with NCHS to develop and pilot-test several questions to

identify the ID/DD population in NHIS. Today's meeting is to provide an update on developments and to initiate planning of a road map for 2019-2029.

Panel I - Availability of data now and on the horizon

Moderator: Barbara Kornblau

Participants: Eric Carbone, Julie Weeks, Amanda Reichard, Bill Marton, Meagan Khau, Lok Wong Samson

Barbara Kornblau introduced the panel members and posed the questions of what data do they have? How are they using it? How to get data more available and shared?

Eric Carbone (*National Center on Birth Defects and Developmental Disabilities, NCBDDD/CDC/HHS*) provided an overview of related work at CDC. This includes the network of 19 state disability and health programs that include (but are not limited to) a focus on adults with ID; two national centers - National Center for Health, Physical Activity and Disability (NCHPAD) and Special Olympics Healthy Athletes; and the multi-state Medicaid data project where 10 states are examining their states' Medicaid data. The Medicaid multi-state data project is intended to: 1) identify patterns of health care inequities and underutilization for people with ID/DD, and estimate costs of potentially avoidable emergency room use through better management of diabetes, epilepsy, cardiovascular disease and other conditions; 2) improve access to services and evidence-based interventions through informing Special Olympics and the network of CDC-funded state programs (e.g., health promotion videos about self-management of diabetes); and 3) provide evidence to support policies and leverage resources, e.g., possible designation of ID/DD as a medically underserved population (MUP).

Challenges have included getting multi-state approvals and clearances for data use and publications, concerns about data quality and validity for ID populations, (e.g., diagnostic miscoding, variations across state programs), and coordination across CDC centers and institutes and across federal HHS agencies. Future directions include looking at different states' Medicaid policies impacting people with disabilities, increased attention to co-occurring mental health conditions and chronic illnesses, developing tools and resources to train health care providers and caregivers, and leveraging CDC Notice of Funding Opportunities (NOFOs) across centers and institutes to address health and access disparities of the ID/DD population.

Julie Weeks (*National Center for Health Statistics, NCHS/CDC/HHS*) affirmed the lack of current, national population-based data on people with ID/DD. The last comprehensive data came from the 1994-5 NHIS Disability supplement, a massive effort that would now be cost-prohibitive to repeat. The issue is then: "what can we add to national surveys that will identify this population and provide information about them from other data in surveys?" Challenges include that people with ID/DD are a very small target population; NCHS has never cognitively tested questions for this population; there are varying definitions of ID/DD; and living arrangements make it difficult to find people with ID/DD. Cognitive testing is needed to determine how they or their proxies understand the questions, and what quality of data will result. A partnership between ACL and NCHS's Collaborating Center on Question Design and

Evaluation Research (CCQDER) has developed key questions that are being cognitively tested now, as well as work to better understand their responses to all other questions on the survey. The planners started with the legislative definitional elements of DD from the Developmental Disabilities Act, considered what elements are already included in the NHIS questions, and added questions like age of onset.

The project of developing and testing questions is itself a project that will be an additional product. The staff are considering a series of questions: *how do respondents understand the question? In what context of their daily life? Do they bring different understanding based on their living arrangements? Are there linguistic variations? What are the methods of recalling information and forming answers?* Recruitment of adults with ID/DD is one of the biggest challenges faced by CCQDER. ACL has funded inclusion of age-of-onset question in 2020 NHIS, so survey data will be available even as the question's cognitive validity is being tested.

Amanda Reichard (*National Institute on Disability, Independent Living and Rehabilitation Research, NIDILRR/ACL/HHS*) reported on findings based on collaborations across CMS and ACL to examine Medicare claims data for people with ID/DD. The goal was to provide demographics and health outcomes for ID/DD and compare them with the non-ID/DD population. They combined 3 CMS data sets - Chronic Conditions Data Warehouse, Master Beneficiaries summary file, and Geographic Variations data for 2016 for fee-for-service recipients. This included 30 million persons supported by Medicare fee-for-service with both Parts A and B, and 1.56% (almost 484,000 people) were designated ID/DD. The ID/DD population was identified through a CMS algorithm of ICD codes that included 5 diagnostic subgroups - autism spectrum disorder, cerebral palsy, intellectual disability, learning disabilities, and other developmental delays and compared them with adults who qualified for Medicare due to age (over 65). About 3/4 of ID/DD population was under age 65.

Findings indicated a high prevalence of chronic conditions and of multiple chronic conditions. Co-occurring mental health conditions were common, with 59% of the ID/DD population having at least one mental health condition and 17% had 3 or more. Most common were anxiety, major depressive disease, and schizophrenia and other psychotic disorders. For example, the general population shows about a 3% prevalence of schizophrenia, whereas for the ID/DD population it's 24% and we know so little about why that is. The study showed value of using Medicare claims data as a complement to other methods for health surveillance. Separate information for the ID/DD population shows prevalence and demographics along with health outcomes such as overuse of emergency rooms and hospitalizations for ambulatory care sensitive conditions. Next steps will drill down further into the CMS databases to examine questions like what mental health conditions are most prevalent among ASD population. CMS is refining ICD codes, and then we can re-run analyses for even more information, and inclusion of questions in the Medicare Current Beneficiary Survey to identify ID/DD populations.

Bill Marton (*Office of the Assistant Secretary for Planning and Evaluation, ASPE/HHS*) provided an update on work with Helen Lamont. They are interested in collecting disability data using internet panels. These data are crucial for policy-makers and would replace door-to-door household surveys which have strengths of representativeness but are very expensive and not as timely. Internet panels offer data collection in a new way; they can be a platform

for collecting information on any topic – voting, consumer preferences, program participation, and other topics. Survey administrators can send out surveys instantaneously to 15-20,000 respondents. The current work looked at quality of information – validity, reliability – compared to traditional panels as benchmarks. They specifically examined GFK and NORC AmeriSpeak panel surveys. GFK is address-based, constructed from large roster of addresses, respondents recruited and then responses weighted; NORC is recruited by mail, with follow-up in person for representation. GFK is around 50,000 respondents, including Hispanic panels for targeted surveys; NORC is around 25-30,000 respondents and growing.

They examined traditional survey measures against 2 internet panels and noted significant variations among different panel types, not just with internet panels. Some difference arise from mode of survey – telephone vs in-person data collection, and so much depends on types of questions fielded. A technical expert panel reviewed findings and suggested continuation of this technical work to address statistical questions and methodologies, e.g., sample recruitment, use of proxies, loss to follow-up, and recruitment procedures. They are now working with NCHS to develop a series of questions via both telephone and internet panel to look at mode effects, qualitative analysis of results, look for differences from NHIS, and for differences in subgroups.

Meagan Khau (*Office of Minority Health, Centers for Medicare and Medicaid Services, HHS*), provided an overview of the new Transformed Medicaid Statistical Information System (T-MSIS) that is being rolled out. It represents a collection of utilization and claims data to provide robust statistical information for monitoring and oversight of Medicaid and CHIP for 73 million Americans. Currently covering data from 2014-16, it includes beneficiary eligibility and enrollment (demographic data that includes disability), provider enrollment, service utilization, service claims and managed care data. CMS has just created a series of data sets for analytics for T-MSIS with beneficiary-level data available under data user agreement for external data users.

Of interest to this group, the disability-need supplemental file includes beneficiaries who require long-term services and support, became eligible in the conception-to-birth option, received other government program assistance, or had a home and community-based services (HCBS) chronic condition, lock-in provider, disabling condition, or third-party liability coverage. HCBS includes age, physical, intellectual, developmental or other disability, autism, mental illness, brain injury, HIV/AIDS, or technologically dependent/medically fragile. The 2016 data on race and ethnicity has 20.3% missing data nationally, an improvement from the previous year of 30% missing data. Data from 2017 and 2018 should be available in 2020. External researchers apply for access through CMS ResDAC (Research Data Assistance Center). CMS will release documentation to guide researchers to access data.

Lok Wung Samson (*Office of the Assistant Secretary for Planning and Evaluation, HHS*) described a project to update and expand existing claims algorithms to identify people with functional disabilities including ID/DD. Project goals are to build on existing Medicaid and Medicare claims algorithms to better identify patients' functional status and to expand to include information from electronic health records (EHR) that will allow better capture of clinical information. It builds on work done by CMS in establishing Chronic Conditions Warehouse administrative claims data sets. Persons with functional disabilities are at higher

risk for poorer health outcomes, but lack of data limits targeting of interventions, implementing proactive services, and evaluation of effectiveness. These data are especially needed as value-based purchasing trends will incentivize providers for measures of outcomes instead of services.

Persons with functional disabilities have great care needs and drive a lot of costs; we want to improve measures to adjust for functional status. ASPE is establishing a project advisory task force and looking for expert input. The current focus is a validation study looking at post-acute care assessment data linked to Medicare claims data, focusing on dually enrolled beneficiaries. Post-acute care data already includes much functional information, especially for people using skilled nursing facilities and home health care. We will validate with electronic health records (EHRs) including standardized assessments, screening tools, with the intent of making predictive analytics more usable for this population. Frailty, also known as geriatric syndrome, emerges through reductions in abilities such as walking speed, grip strength, and clinical markers for aging. Predictive algorithms have been developed for decline in function. The Chronic Conditions Warehouse includes ID/DD, and they are seeking input on other conditions not already included and other data sources that could increase data available. For example, mental health and behavioral disorders often co-occur but are not addressed by clinicians.

Responses—Perspectives from the territories, the federal government, and the states

Moderator: *Barbara Kornblau*

Participants: *Kimberly Mills, Jennifer Johnson, Arun Natarajan*

Kimberley Mills (Virgin Islands University Center for Excellence in Developmental Disabilities) reported that the Virgin Islands (VI) is one of five US territories with human populations. US VI were transferred to the US in 1917. “Territory” refers to land purchased by another country, with each territory having a different history of ownership and colonization after indigenous settlement. Territorials are usually US citizens (except for American Samoa), but non-voting in Presidential elections. Territories have local government with the operating agreement through the Organic Act. Medicaid in the territories is not funded in the same way as in the states, but territories saw increased funding under the Affordable Care Act.

Dr. Mills noted that the purpose of data collection is not just to conduct interesting analyses, but its purpose is to change people’s lives. Despite the VI not having massive data sets, they still use data to create programs and change lives. One example was using clinical data and working with parents of autistic children and a senator to get funding for autism treatment in VI. Another example used data from her own dissertation to sponsor a Crime Reduction Symposium showing that people with disabilities are disproportionately involved in the juvenile justice system. This led to legislation that reduces sentences in return for increasing education level. In terms of disability data sources, VI uses some T-MSIS data, 2010 and 2020 census, Cornell University’s Disability Status Report, Kids Count, and other data sets that they gather. With a total population of 100,000, everyone knows everyone, so all it takes is a few

people to get things done. She stated that people from VI want their data included with the rest of the states — they don't want to be an addendum.

Jennifer Johnson (*Administration on Disabilities, Administration for Community Living, HHS*) noted that this meeting was convened because people with ID/DD are invisible in data, and we want to use existing data or create new data to make people with ID/DD visible. From a federal perspective, ACL will focus on 3 areas. The first is federal leadership in ensuring equity in data. The ACL leadership role is ensuring equity for ID/DD population through all of the federal government. They are charged with oversight of programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act and improving quality of life. But work is done in the absence of good information on prevalence of the DD population and their health status. Knowing that health is vital to everyday life, it's remarkable that we don't invest more in understanding their health. We need to recommit to ensuring health equity in data sets that include people with ID/DD. We need to see this population as part of the broader population and their right to participate as part of the national population. ACL currently invests in longitudinal studies about where people live, their employment status, and their long-term services and supports; but don't invest in longitudinal data on health. ACL should be held accountable for lack of health data equity.

Our second focus is to engage with people with lived experiences. We do a disservice to the community by not engaging them in developing their own future. Third, is the importance of data to federal agencies — we need better data to make more informed decisions. Just consider: what could we as a federal government do? Agencies could spend money more wisely and effectively. With quality measurement in health care, we could use data on critical incidents and follow-up; it could inform our debate on home and community-based services; and determine the true cost of care in achieving better health outcomes. But we don't have the data. The federal government is making an effort but we need resources; various agencies support some of the work but we need an infrastructure that coordinates. And good data needs to change over time as our systems change.

Arun Natarajan (*Center for Innovation and Partnership, Administration for Community Living, HHS and Office of the National Coordinator Health IT*) provided insights from his former position in managing Washington DC's waiver program for services for people with ID/DD. Funding primarily comes via Medicaid and in home and community-based services, using 3 authorities: 1915 (c) waiver, 1915 (i) state plan amendment, or receiving state plan services under 1115 (c) demonstration.

Mr. Natarajan noted that there is lots of data in multiple systems around assessments to qualify for Medicaid, authorization for paid and unpaid services, critical incidents, information produced by state-level systems of adult and child protective services, schools, rehabilitation services. Records may be on paper or electronic and may be hard to access. Data is often stuck in data silos - like little "data lakes" that are not interoperable—and don't create a national picture. On the other hand, almost every waiver program in the US has "point of intake" data in electronic format; this includes assessment, service planning, eligibility determination, access and outreach, individual selection of providers for paid and unpaid services. Additional data are collected on providers and provider processes, and a survey of beneficiary experience of care. The Health IT Stack graphic shows elements

required for a functioning health IT ecosystem from the federal government's view. A challenge is that state Medicaid agencies often develop systems in isolation from ID/DD programs. Use cases provide a view into longitudinal care for health care outcomes — longitudinal care management, episodic care management, improved service coordination among providers, outreach and preventative services, and quality measurements for basis of payment. Screening processes can provide new data.

Discussion on availability of data

One focus was on what's needed to have better interfaces across the isolated data sets and the importance of including human services in these frameworks. A concern is that many current measures document process and not outcomes, reflecting the purpose of data collection to document compliance with federal requirements. Participants noted a shift in thinking at national and state level to measuring individual outcomes, and infrastructure shifts to building a culture of data collection. Another issue is state data capacity—findings of a focus group study showed states don't have staff for proper data collection and may not understand what they are actually measuring. States lost over 200,000 positions in the recent recession and have still not recovered. Further, at the state level, the DD division is often in a different department from Medicaid, and the complexity of state systems is hard to navigate when people aren't working together. While National Core Indicators has 46 states' participation, there is high staff turnover so impact of staff training could be limited. At the national health data level - are we still invisible there?

Potential strategies included attending to the measurement tools, ability to aggregate data across states, and explaining data to federal agencies. Can we be more proactive and change what the federal agencies ask states to collect? Should we be looking at international data and develop more consensus on which outcome data to collect? Are there best practice models? The need was raised for a national center for health data about people with ID/DD that would assist states in using data. We need creativity on infrastructure, because states don't have resources. T-MSIS may be useful for comparative analytics of claims eligibility as potential areas for national benchmarking.

Summary of issues from the sessions on data availability:

Gloria Krahn (*Oregon State University*) summarized key themes from the morning that can inform next steps on roadmap for better data.

The first relates to excitement about the availability of new data sources, especially through Medicare and Medicaid, and including those with dual eligibility. There is a need to understand how the populations included in these programs overlap and where they differ (like Venn diagrams), as we try to build a data mosaic that paints the picture on health of people with ID/DD.

A second issue is the variability of data across states, quality of data at state and national levels, comparability in quality of data, and currency of data. Comparability of samples across data sets emerged as an issue in the November 2017 summit and came forward again now. These data are described as "data lakes" and our task will be to portage across these lakes.

A third issue related to interoperability of data and how that may change in the future.

A fourth issue as subtext for today's discussion relates to health. Once we shift to a focus on health of the ID/DD population, we get engaged with a new set of systems (health records, health services administration research) and matching up with new data elements. As we investigate health of people with ID/DD we encounter issues of co-occurring health conditions, including emerging findings on mental health data. These are powerful data that, in some states, are only now being considered together. Human services that address social determinants of health need to be included in these considerations.

A fifth issue is definitional around ID and DD—when are they the same, and when do they differ? Following the DD Act definition of DD, a substantial group of people with ID do not qualify as DD because they don't meet the criterion of substantial difficulties in at least three areas.

The sixth area relates to “what can we learn from other countries? The special issue of ID/DD on health surveillance includes a paper from Western Australia and Manitoba (Canada) that demonstrates linking administrative data on health and other services for people with intellectual disabilities. The UK and reports from its Learning Observatory have additional approaches to offer, noting that this work is all based on some type of national health system.

Finally, collaboration across agencies is essential. ACL is currently coordinating efforts in HHS to pursue equity in health in data by leveraging relationships across agencies, finding common ground and common outcomes to pursue. A decade ago when a group similar to today's met in Kingston Ontario Canada, they felt similarly challenged for developing a roadmap for improved data. Those efforts were highly successful in developing and then achieving the steps of the roadmap; we can do the same and advance a roadmap for the next decade.

Panel II - Reaching beyond the research community: Enhancing the utilization, dissemination and knowledge translation of data

Moderator: Tawara Goode

Participants: Samantha Crane, Donna Meltzer, Tawara Goode

Samantha Crane (*Autistic Self Advocacy Network--ASAN*) described ASAN's expertise in creating resources to make complex topics accessible to people with diverse disabilities. Making data accessible increases community engagement, makes it more useful for advocates, complies with 504/508 requirements, and helps data become more accessible to others with literacy challenges, limited advocacy experience, and limited English proficiency. The meaning of data should be clearly explained and be relevant to our lives - not just prevalence of disability, but quality of life items like access to housing, employment, autonomy. A good example of relevant data is National Core Indicators that includes information on people with ID/DD disaggregated by race, employment, residence and type of care. How variables are operationalized is important - e.g., employment isn't just 'yes' or 'no' but ideally provides for distinction of work below minimum wage and distinguishes non-competitive employment. Keep narrative in 'plain language;' use simple words like the top 1000 words of English. Avoid undefined terms, passive voice, and complex sentence structure. Each element should have its own sentence and its own line; illustrations could be included for each line.

Example

"The percentage of state respondents for whom a dual diagnosis was reported ranged from 34% to 64%."

Replace with:

"In one state 34% of people with developmental disability are dually diagnosed. That's 34 out of every 100 or one third. In another state it was 64% of people. That's 64 out of every 100, almost two thirds. In every other state, the number was between 34 and 64 out of every 100 people."

Using online tools, try to keep reading level at Grade 3. ASAN publishes resources in Easy-Read format - plain language, separated into individual lines, illustrations on each line that orient the reader to where they are in the document and what each line is about. Use graphs like people graphs for demographics; graphs using color blocks don't work for color-blind people. Include text-only description for people who have visual disability or learning disability for visual data. Provide information in a variety of formats to communicate to people with different needs, e.g., text-only, Easy-Read, visual-heavy, narrated videos with captions. "Easy Read" relates to this specific format, while "plain language" refers to 8th-12th grade reading level. Their website AutisticAdvocacy.org has tool kits and examples.

Donna Meltzer (*National Association of Councils on Developmental Disabilities -- NACDD*) NACDD is a non-profit, non-partisan national organization that supports 56 Councils on DD in the U.S. Their vision is that people with DD are full participants in their communities, enjoy

opportunities to achieve their potential, make their own decisions and exercise their civil rights. NACDD's three functions are federal advocacy, technical assistance for member Councils, and addressing trends and developing projects/workgroups so that Councils can serve as incubators for innovative solutions. Sixty percent of Council members must be persons with ID/DD or family members; members are appointed by governors. Data are crucial in reporting to governors, state legislatures, federal funders, and to evaluate Council's own progress.

Much of the data Councils use come from the three longitudinal data sets funded by ACL, National Core Indicators (NCI), and Case for Inclusion reports. Councils also conduct their own surveys. e.g., the Ohio Council is conducting needs surveys of medical professionals, business, and people with lived experiences. Trends in data sharing include more data tied to outcomes, less about outputs; more visual support in data presentations with less narrative and more icons. Prevalence data are crucial—consistent numbers will drive services and funding. If we don't have accurate prevalence, we're not getting appropriate funding and not reaching our target population. Presently we have conflicting numbers for how many persons there are with DD in the U.S. based on statistics from the disability supplement to the National Health Interview Survey (NHIS-D 1994/95), as well as more current data from CDC and Special Olympics. Each have their own numbers. Finally, we support efforts to ensure data from territories are included in national data sets, and that people with ID/DD are considered in every type of data collection

Tawara Goode (*Georgetown University Center for Excellence in Developmental Disabilities*) presented 2018 ACS data on culturally and linguistically diverse populations in the US, noting that 5% self-identify as 'some other race', and 3.4% self-identify as 'two or more races.' Another factor is languages spoken in US. In particular, she emphasized 'limited English-speaking households' in census data (households in which no one over age 14 speaks only English or speaks it very well). Usually associated with Hispanic households, the highest rates of limited English-speaking households are actually among Asian/Pacific Islanders. Other cultural factors beyond racial, ethnic and linguistic diversity affect design and dissemination of information. She recommended looking at the audience's understanding of 'data', their health literacy and numeracy literacy. Be prepared to address distrust of government sources, including questions of "how will the data be used? Will it be accurate? Will it portray my group negatively? Who's collecting and analyzing data?" Understand the characteristics of your intended audiences—a one-size-fits-all template does not work in presenting information. How does it fit with the inherent communal knowledge as you work to achieve knowledge translation. One strategy is to identify voices in the community that can bridge the gap between communal and formal knowledge to assist it in becoming part of 'big picture.'

Consider community expectations on the timeline for gathering and disseminating information, and note what issues are of interest to them. Share the consequences of refusing to participate in data collection—they need to know what's on the line by not participating. Know how information is disseminated in a community to enable the data project and engage community members and other stakeholders to facilitate it. Consider various methods of dissemination delivery - plain language document, video, and a variety of formats and graphics, knowing that the most effective methods may not be documents or websites. Budget for these dissemination methods. Challenges to engaging communities in acquiring and disseminating data include fiscal and personnel resources, adequate time, and the willingness

of academics, researchers and policy makers to value community expertise and engage reciprocally with awareness of the power differentials.

Discussion on utilization, dissemination and knowledge translation

Groups who need to be considered are self-advocates or those with lived experience with ID/DD from culturally, linguistically or racially diverse communities for whom health disparities and mental health are significant; people who are deaf or hard-of-hearing; and people who are blind. In this, we need to consider the influence of different service systems.

One dissemination goal needs to be making people with ID/DD more visible in data. Creating visibility means explaining why it's important to include everyone, including people with ID/DD. This means bringing forward the issues of those whose views are often not included—people with limited communication and cognition. Speak in plain language so that everyone can see the value of participating.

DD Councils can be intermediaries for identifying the questions for analyses and use of stories. There was general discussion on the importance of collaborating with DD Councils around data collation and analyses for longer term trends, including examining and reporting on data to reflect systems changes.

An issue of particular concern among communities of color is distrust—of disability disclosure, data gathering and its dissemination. In preparation for the 2020 census, there were discussions with the ADA coordinator on why measured prevalence of disability has reduced over the last decade. One factor may be non-responding or not identifying as having a disability. The possibility of launching an awareness campaign has been considered to explain the importance of answering questions accurately. Work on health disparities might offer strategies such as partnerships with communities, engendering trust via federally funded projects, and engaging communities to find out their interests, needs, and fears. Explain to persons with lived experiences that “because you filled out that survey, real changes happened” - we collect stories from you and bring stories back to you. NCHS recognized their need of communities to help tell the story of the data that they collect. Others suggested the need to build bridges to distill findings from surveys for use by end users with ID/DD. Ideas include creating and sharing tools for engaging participants. NCI is concerned about getting a representative group of participants. Strategies tried in some states are to prepare user-friendly version of results with indicators of interest for specific communities while still making the documents broadly appropriate. There is a need to explain purposes of data collection to representative groups so the products reflect lived experience. All data briefs should have a plain-language introduction and summary. The discussion concluded with the suggestion of adapting a truth and reconciliation model for communities that have been discriminated against. This includes offering an apology offered, naming the hurt, and acknowledging it was wrong.

Panel III - Mapping out the future of data analysis in achieving health equity

Moderator: Maggie Nygren, AAIDD

Participants: Alixe Bonardi, Susan Havercamp, Julie Hocker, Gloria Krahn

Maggie Nygren (*Executive Director of AAIDD*) noted that the journal IDD published a special issue featuring papers for this meeting's topic, with papers available online at [aaidd.org](https://www.aaidjournals.org/toc/mere/57/). <https://www.aaidjournals.org/toc/mere/57/>. This panel was structured with moderator questions and panelists responding with interactive discussion

I. What would health equity look like for the ID/DD population?

Julie Hocker (*Administration on Disabilities, Administration for Community Living, HHS*) stated that health equity is an important issue for AOD/ACL who has established their first-ever health equity team. One focus is on education of health care providers, so that people with ID/DD are afforded the respect and attention that others expect via quality of care assessments. In the long term, ACL wants to close the life expectancy gap between the ID/DD and general population, and will look for short-term outputs to drive long-term change.

Alixe Bonardi (*Human Services Research Institute*) stated that health equity would mean that we would know about health and health needs of people with ID; that we would see that conditions that are preventable (and not related to the underlying disability) are equivalent and well-managed. She agreed on equitable life expectancy as a goal post, and also looking toward excellent medical care and quality support systems to help achieve that. Further, people with ID/DD and their key supports would be informed and empowered to engage in healthy behaviors.

Gloria Krahn (*College of Public Health and Human Sciences, Oregon State University*) added that with health equity, people with ID/DD are a desirable patient group that providers feel competent to treat; and for whom they are incentivized to provide excellent care. She noted that quality care should be incentivized so that providers and systems would provide quality care for persons with ID/DD - not just because it's the *right* thing or the *required* thing to do, but because it's the *rewarded* thing to do—that good care aligns with the incentives of the health system, like monitoring and reimbursement rates.

Susan Havercamp (*Nisonger Center University Center for Excellence in Developmental Disabilities, The Ohio State University*) noted the need for benchmark data: “how many people have a specific concern?” and then “how can we develop better projections on how to achieve equity?” She stated the need to look at high-level benchmarks such as life expectancy but also at upstream issues that may affect access to supports and services that affect people's health outcomes. When we look at social determinants of health, there are significant disparities in access to home and community-based services, with variations based on racial, ethnic, linguistic differences or differences in functional support needs. Finally, health equity means that people with ID/DD and their key supports are informed and empowered to engage in healthy behaviors.

Panelists noted that engaging participants in their own care should be part of shaping health care design and system, and this will require specific additional targeted support. Health care providers may lack holistic knowledge about what it's like for persons with disabilities to live in their community. There was agreement that medical care is only a very small part of living with ID/DD. Focusing on health data equity, there is a need for disability and ID/DD identifiers in all data sets. *“Disability inclusion in data sets is a civil rights issue.”* When disability identifiers are available, data should routinely be examined for disability disparities.

II. What are the metrics/indicators for measuring health equity for the ID/DD population, including social determinants of health?

Panelists noted that data are a tool to help us see that there are health problems at a population level (not individual level), where the problems are, and how big of a problem they are. Analyses can inform us if programs or policies are making a difference at a population level. In these ways, quality data are vital to good program planning, policy development, and fiscal projections.

We need to start by considering who's responsible for gathering information and how data might be available. While we need data with ID/DD indicators, we need to be mindful that administrative data are often collected for purposes other than health surveillance. We need to respect states' right to organize their data collection and make sure metrics aren't increasing burden to states.

There will be new metrics available from TMSIS data and states' data that will allow us to look for benchmarks relative to the general population on standard health equity measure (e.g., diabetes control). It's heartening to see the progress that has been made, but there is still a long way to go. We may need new data collection initiatives, like longitudinal or extended surveys. In considering healthcare assets and core outcomes, we should consider not only life expectancy but also incidence of big-ticket chronic diseases like diabetes, asthma, cardiovascular. These all really compromise life expectancy. And we need to look at social determinants of health like employment, neighborhood, sense of safety, access to internet. We need to know what the community's own issues are (e.g., sexually transmitted infections). For example, findings from the deaf community indicate lower rates of mammograms related to their being less exposed to general information about the importance of mammograms.

We should consider adopting a standard public health framework to organize factors, including environmental exposures; and create models showing the relationship between individual decisions and long-term life expectancy. Access to dental care is another preventable issue that ties into social determinants and life expectancy. Highlight these barriers and others, such as transportation. Special Olympics takes a holistic approach by including physical fitness, dental, podiatric, vision, and other areas. Our approach also needs to address health promotion education, measuring how we can help people live longer healthier lives. Inclusion of health promotion and social determinants extends where we have to look for data. Data for pure outcomes are still valuable but they need to be put in context of multiple viewpoints on health equity.

III. Extending the recommendations of the workgroups, what are the current issues, gaps and best practices and how can they be addressed to inform practice and policy to help achieve health equity?

Alix identified the need for credible prevalence rates for people with ID/DD that starts with agreeing on definitions of ID and DD so that we can speak with one voice to make the case for better programs and policies. Definitions based on diagnostic categories vs functional limitations, and varying degrees of severity all contribute to inconsistency.

Susan added concerns about the very real limitations on interoperability of state-level data. There are mountains of data collected but often only usable at state or even county or provider levels. We have some records for health indicators but we won't be able to look at access and social determinants from state-level data. There are limitations in capacity at state level to use data. Virginia State University is an example of linking state-collected Medicaid data with outcome records from NCI and Supports Intensity Scale. She noted that proxy reporting is a very significant for this population. How can we handle proxy reporting vs. self-reported health status? We need to emphasize meaningful participant engagement - people with lived experiences participating in a meaningful way.

Gloria added that we have many "pockets of data" but we need a trained workforce to harness data, the idea of 'super-users' at multiple levels who know how to link and analyze data. The capacity to compare findings across different data sets, depends on similar definitions, sample populations and statistical controls. We need strategies and resources to compare or harmonize findings across large data sets such as NCI, Special Olympics, and administrative data, and for how to handle proxy-vs self-reporting. The CDC-sponsored Medicaid Multi-State process provided a nice example of comparing across states. Do we need a national center to support strategies and training? Further, accessible communications need to become more routine and standardized. We may need workforce training to standardize proxy vs. self- reporting and development of accessible materials.

Susan affirmed the importance of communicating clearly with constituents; to not get caught up in our ideas but hear what constituents want to know. Providing information is not about our own vanity in our work, but in what the recipients need or want to hear. We can learn from proxies on how to interpret information.

Julie noted that we need to address gaps simultaneously with getting better data; we can't wait for perfect data before taking action to achieve change. We need to get to the change we want to see, but also need to keep sight of data while making changes as we go. One strategy is to remove silos among our workers for greater access and understanding of data, reduce delays in changing course, and inform best practices. As AOD connects more with the medical community, it informs our decisions on what data to collect and what's still missing. Data and knowledge should inform policy and programs, where money goes, and connect us with other arms of HHS.

Discussion on future of data analysis

Themes in the discussion included the lack of a consistent definition of ID/DD that contributes to inconsistent numbers. Numbers from school data indicate around 15-19% of all children and youth are identified with disability but drops down substantially to 3-5% as adults. The workgroup used the DD Act definition of disability that focuses on functional limitations and is pretty conservative. In many other countries, universal health identifiers make tracking easier. The six question identifiers are now being asked on community surveys to uncover missing populations, but many interviewees with ID/DD remain completely invisible—uncounted, unserved, and unrecognized by states. We hope that the added functional questions to the NHIS and other surveys will pick up some hidden ID/DD community members. A participant suggested that data consistency might be partially addressed by asking three questions of adults— “Do you have ID? DD? or ASD?” From NHIS data, we know that about 85% of ID/DD adults live with family members their whole lives, and household surveys can access this group. Another participant noted that some parts of DD Act legislative definition may never be operationalized in data collection, but we have to resolve on a measurement definition that everyone can agree with.

Another theme was the need for a definition of health equity. The definition of Paula Braveman (2017) was recommended: “**health equity means** reducing and ultimately eliminating **disparities in health** and its determinants that adversely affect excluded or marginalized groups”

<https://www.healthaffairs.org/doi/10.1377/hblog20170622.060710/full/>). The range of disparities include availability, accessibility, acceptability, utilization, and quality. Disparities in health care system are not just due to ignorance or lack of experience, but can express implicit biases that must be addressed.

Third, there was considerable discussion on “where can people with ID/DD show up in data?” One participant observed that as the parent of six children with disabilities, she now realized that they won’t be counted anywhere - not in Medicaid or Medicare, because they are all working to some extent. It was suggested that they would be included in All-Payer Claims databases and could be identifiable if the medical notes include condition in the chart (e.g., CP, XYY chromosome). Another participant noted that some data are a catalyst for very fast change – we should look for data sets that might have powerful local effects and larger ripple effects, e.g., if everyone who is incarcerated gets a psychological review, it will be shocking to discover how many have hidden psychological illness in prison. Further, the move to managed care means that more of the ID/DD population will leave no footprint in governmental data. We will need to access All Payers Claims database to find them. The largest provider organizations have recently published powerful papers on autism spectrum disorder. Private databases are important into the future.

There was a call for getting disability and ID/DD identifiers included in other data collection systems. There was advocacy for ID/DD being included as a demographic variable in the decennial census because those data are highly influential for policy and funding. The ID/DD population is at much higher risk of poverty and other vulnerable characteristics - how can we get them counted in the census? Others questioned whether the census is the right place to identify ID/DD population because it is so small relative to national population. We only have 6 questions to address all disabilities, with nothing on psycho-social or some cognitive

disabilities. With questions on the National Health Interview Survey (NHIS), you don't have to do it every year and you can still get a lot of useful data. National data resources are as important as state data.

With respect to state data, one participant cautioned that that we assume that state agencies are keeping records. But some may not be, or records may be paper records retained in local offices and not readily accessed for aggregation. This was also noted in the workgroup report. When looking at outcomes for people who had left state-run institutions, they were provided handwritten data on papers taped together. States need to do a better job, especially for these populations. Vital statistics records belong to the states, and the federal government collates that data by buying it from states. The federal government train states on how to collect and record information and upgrade systems. That raises the question: “what partnership could we create for DD data to be collected and aggregated as analogous to this system?”

In looking for indicators, it was generally agreed that the first step needs to be asking what the community wants, and then work backward to achieve it, e.g., community's complaint may be that they can't get to work or find a place to live, or “I just want a friend.” Mental health was cited repeatedly as an important issue to include in health surveillance data. People with ID/DD are in mental health wards at hospitals and prisons. The staff are generally not trained to know how to provide care and services for them--data could help by showing them the range of issues they might anticipate.

The Division at CDC has materials that highlight health disparities among ID populations, including cardiovascular, obesity, and the relationship between mental and physical health. We see higher disparities in mental health. We need better research on why disparities arise, the role of stigma, and what can we do about them? Another participant noted that if you're disabled and looking for a job for many years but can't communicate, you're going to get depressed; “we must fight to get hospitals to ask questions of ID/DD patients.”

Finally, there was considerable discussion on need for health care provider education. Adults with ID/DD get trapped in pediatric practices because they can't find health care personnel in adult systems who understand that having a disability is part of who you are. It's important to educate medical professionals so that non-pediatric ID/DD populations can get their flu shot from their GP or discuss their healthcare in an informative and comforting way. This is an even bigger problem in rural communities. One study using an iterative survey with about 100 people with DD, parents, advocates, healthcare professionals found 95% agreement on six competencies for health care providers (provide link). Topics specifically mentioned included reproductive health and mental health.

Final thoughts from all participants

In presenting data, don't lump everyone into one category, disaggregate by racial, cultural, service systems.

Find ways to engage more directly with the ID/DD communities:

- Always speak from an inclusion perspective

- Say why supplying data is important— elicit stories and share stories of how the information had an impact
- Learn from what state DD Councils are doing
- Build bridges to use advocates and professionals with disabilities who can be consultants to this work
- Issues of trust come up in most contexts
- Consider use of truth and reconciliation model – “name the hurt”; apology offered, and acknowledging errors made and changes to make (people have been excluded from data collection previously)

Improve ways of presenting data to non-research audiences:

- Provide information back to the ID/DD communities that participate – create pamphlets or infographics on questions, or basic data, and mail back to them
- Present material that is largely stripped of methods; put technical material into an appendix
- Not all indicators are important to all the groups; customize your materials
- Let communities and participants see their contribution
- All data presentations need to have plain language introduction and summary

Summary: Where do we go next?

Jennifer Johnson noted that today’s meeting is the beginning for developing a roadmap for improved health equity data. What are thoughts for moving forward, starting with conversations from today’s conference to develop the roadmap through future discussions? who else should we consult? What “clusters” of work should we consider?

The discussion identified key issues that begin to define the roadmap:

A caution

One caution raised was the need to prioritize and collaborate. Given the many issues identified, this initiative will have to set priorities: What is most important and to whom? What are key issues? What are populations to include? What time frame to use? What are intended outcomes of the initiative? Participants have discussed concrete ideas for establishing prevalence. Some of the other topics are already being discussed elsewhere - what are the specific goals for this initiative and how to collaborate with related efforts?

Who needs to be part of this conversation now?

- People with DD and families, SABE: ACL is committed to start with the end and prioritize their needs and wants
- Diverse communities, understanding roles for better participation in data collection
- Disability groups arranged around particular communities
- Advocacy entities like Arc, Special Olympics or UCP with individual chapters that have connections with people in more rural environments
- State agencies and NASDDDS, Medicaid directors’ group
- Health care providers
- Health care industry, they are paying more attention to ID/D issues because of cost of care - e.g., All Claims Care data.
- Foundations
- Other HHS agencies; integration of disability into conversations with other agencies in HHS on investing in data and bringing it forward in HHS

What are the Emerging Areas to Work in?

1. Working toward a core measurement definition of ID/DD

- We have AAIDD but we need APA and some other organizations involved in diagnostic categorization at the table
- Has someone already done this work? If so, use their knowledge
- Look at 2017-8 NHIS and Washington Group questions on cognition - 2017 data showed 5% of those who reported difficulty in concentrating, remembering, making decisions, attributed it to ID/DD, but in 2018 this fell to 1% because ‘decision-making’ was removed from list - this is incremental progress

2. For Indicators:

- Ask persons with lived experience to get indicators – use information as you go to create impact
- In the advocacy communities, there are different ideas from data community about what the communities' issues are. Attend a CCD (Consortium of Citizens with Disabilities) meeting to hear their views and ask some targeted questions on what issues they see – useful set of inputs, how data might be used on the ground incrementally as it's developed
- Return to question of what we want the data for – end-user question, what do they need from us? Numbers and prevalence matter to us, not to person who needs services, can't get a job or education, or are facing health disparities
- Mental health has come up repeatedly today
- Sometimes we don't know what we don't know (e.g., it's hard to remember that we didn't know that ID/DD had much higher risk for diabetes). Examine what we have in available data sets
- We may need to clean up core data and get ID/DD identifiers into data sets, while also looking at critical questions to ask of the data

3. For Data:

- T-MSIS opens new vistas
Both qualitative and quantitative information from the community - e.g. recent pain survey got 8000 responses
- Prevalence data is important
- Also longitudinal work, think creatively and don't just add on to other surveys—do we need panel studies?
- The data puzzle is a metaphor, we need to find and lay out all the pieces on the table at the same time, find overlaps and gaps across available data sets. This is some of the real work in finding the big picture, e.g. measuring in Medicaid, Medicare, state services – where and what are we not measuring?
- As we move toward managed care, how will we get data? If it's not available via the states, access will be problematic.

4. For Utilization and Dissemination:

- Recognize that it is our role to give them information. We're listening to them, their stories are powerful
- Communicating for different audiences in different way, with plain language as standard

5. For Analytics:

- Use IT expertise that already exists for interoperability of data;
- Big Data scientists who look at data analytics in a different way could help us approach data management issues
- Analytic workforce capacity is a major issue at state and national levels; this includes interoperability, linking data sets, harmonizing findings

Meeting Adjourned — Thank you to participants and organizers