

Intellectual and Developmental Disabilities

Recruiting the Voices of Persons with ID/DD in Policy Development Priorities for Health Equity Data

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Abstract:	Through focus groups, adults with ID/DD provided their priorities for health equity data, surveys, and information dissemination by US federal agencies. Participants reported privacy concerns about sharing information, need for better data to promote access to quality health care and services, and need for information on social contexts that influence quality of life. Data should include functional limitations, health risks, and priorities for health care, and should support choice and self-determination. Adults with ID/DD believe parents or support persons do not always share their views, raising concerns about proxy-reporting. Surveys and information need to use clear language, visual aids, and provide neutral supports. Information should be shared broadly, including to persons with ID/DD and families, health care professionals, and policy-makers.

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Recruiting the Voices of Persons with ID/DD in Policy Development: Priorities for Health Equity Data

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Key words: intellectual and developmental disabilities, health, equity, focus groups, policy

Recruiting the Voices of Persons with ID/DD in Policy Development:

Priorities for Health Equity Data

Through focus groups, adults with ID/DD provided their priorities for health equity data, surveys, and information dissemination by US federal agencies. Participants reported privacy concerns about sharing information, need for better data to promote access to quality health care and services, and need for information on social contexts that influence quality of life. Data should include functional limitations, health risks, and priorities for health care, and should support choice and self-determination. Adults with ID/DD believe parents or support persons do not always share their views, raising concerns about proxy-reporting. Surveys and information need to use clear language, visual aids, and provide neutral supports. Information should be shared broadly, including to persons with ID/DD and families, health care professionals, and policy-makers.

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Recruiting the Voices of Persons with ID/DD in Policy Development:**Priorities for Health Equity Data**

The dearth of health data for persons with ID/DD in the U.S. has been lamented for more than two decades, dating back to the Surgeon General's report of 2001 (US PHS, 2001). Recent renewals in the call for better prevalence and health data for persons with ID/DD relate to suspected disparities in health (Hatton et al, 2015; Krahn, 2019; Majner et al, 2021) and documented disparities in COVID-related morbidity and mortality (e.g., Landes et al, 2021; Turk et al, 2020). The *IDD Counts!* initiative represents a federal inter-agency effort within the US Department of Health and Human Services (DHHS) led by the Administration on Community Living (ACL) to develop a roadmap for achieving better health equity data for persons with ID/DD. The roadmap is intended to guide and document data achievements over the 2020-2030 decade.

A formative part of this effort is to ascertain the views of multiple stakeholder groups on what health data are needed for persons with ID/DD. Consumer engagement in developing health policies and practices has increased in the past decades. Health care entities have begun to include community representatives on their advisory councils, interventionists may engage with potential participants to determine acceptability of programs, and federal and state agencies post their proposed actions through mechanisms like the Federal Register to seek public input. Health care insurers, both private and public, need data to develop projections based on factors such as risk for additional conditions (e.g., diabetes, coronary heart disease, Alzheimer's syndrome) and annual cost of care per enrollee for such conditions. Health care providers may need data for

their practices on the likelihood of comorbid conditions or uptake of clinical preventive services (e.g., vaccines, mammograms). Families may value better data on health risks, behavioral health, and effectiveness of health promotion programs for their family member with ID/DD.

But what are the health priorities for adults with ID/DD? What variables are needed in data sets to track their priorities? Soliciting the voices of persons with intellectual and developmental disabilities (ID/DD) for policy development is practiced very infrequently if at all. Much more frequently, reports by parents or other support providers are used as proxy-reporters whose reports may or may not agree with those of the person with ID/DD (e.g., Simoes & Santos, 2016; Tournier et al, 2020). The increased adoption of a social model and the International Classification of Functioning, Disability and Health (ICF) view of disability is now pressing for routine engagement of persons with disabilities in research, policy-making and practice. Further, calls for greater use of self-report by persons with ID/DD (Shogren et al) are pushing researchers and policy-makers to understand the views of persons with ID/DD on their health and how their environments can be altered to increase their participation, health, and well-being.

Engagement of stakeholders with ID/DD in program planning is relatively new, but related literatures have informed this endeavor. Research with persons with ID/DD typically relies on interviews (e.g., Black & Kammes, 2019; Gibbons, Owen & Heller, 2016; Griffith et al, 2019; LeRoy, 2004;) and focus groups (Brown & Gill, 2009; Parish, 2008). These methods allow flexibility in wording of questions and explanation of terms. This contrasts with more structured processes such as surveys that require skills in reading, comprehension, and calibrated decision-making. Photovoice is a newer qualitative approach that has been used with persons with ID

whereby participants photograph scenes or objects that reflect their views and feelings about a topic (e.g., Ausderau et al, 2019).

Recently, Bains & Turnbull (2021) recommended processes for engaging persons with ID to recruit their input on intervention development. These include using an advisory group of persons with ID, a staged process for providing information about the project, “easy read” materials, pilot testing the questions and process in advance of implementation, identifying accommodation needs, explaining the purpose of their input, and inviting participants to take breaks as needed (Bains & Turnbull, 2021).

Previous research has solicited the voices of persons with ID/DD to define good health. Health has been characterized by adults with ID/DD as absence of pain, disease and symptoms; adherence to or not requiring medical treatment; physical self-care; mental or spiritual self-care; and the ability to perform the activities one wants to do (Gibbons et al, 2016). Photovoice methods documented the meaning of health to include personal identity with being healthy, nutrition, and meaningful participation or occupations for health (Ausderau et al, 2019). Other qualitative research has demonstrated that for an intervention to be effective, participants with ID/DD need to understand it and be motivated (Griffith et al, 2019).

The purpose of the current study was to employ methods previously found to be effective to determine the perspectives of adults with ID/DD about: a) their priorities for health and health data, b) how information should be collected and disseminated, c) whom they think should receive such information on health of people with ID/DD, and d) how adults with ID/DD regard the priorities of other support persons relative to their own. The findings are intended to inform other researchers and organizations as well as federal agencies about the health data priorities of adults with ID/DD.

Methods

Data Source

For this study, deidentified data were drawn from the *ID/DD Counts!* stakeholder engagement dataset. To assist in program planning, data had been collected through separate focus groups with adults with ID/DD, health care providers and researchers, health insurance industry representatives, family members, and direct support professionals. Implementation was conducted through the auspices of the ACL and monitored by a Steering Committee of federal agency and national organization representatives and academic researchers. Like all federal requests for constituent input, it was not subject to an Institutional Review Board (IRB) review process. The current project represents secondary analysis of the deidentified information collected from the focus groups with adults with ID/DD.

Sample

Three national advocacy groups representing people with ID/DD assisted in recruiting participants for the focus groups. Requirements for participation were that they be English speaking and, with support, could engage in a videoconference call. Each group was asked to recruit 5-7 participants that varied in age, gender, race/ethnicity, and geographic region of the country. These groups were Self-Advocates Becoming Empowered (SABE), the Council on Leadership and Advocacy (COLA) of the Association of University Centers on Disabilities, and the Autistic Self-Advocacy Network (ASAN). This resulted in focus group sizes of 5, 5 and 6 respectively. Focus groups were conducted in the fall of 2020.

Because the purpose of this project was to solicit input for future federal agencies' planning, participants were not asked to provide demographic information. Based on their self-introductions and comments, we understood that the 16 participants came from 11 states dispersed across the US, 10 were presumed to be females and 6 males, with at least two indicating LGBTQ identity and at least three from racially or linguistically diverse communities. Some were married or partnered, some were parents of children that ranged in age from 3 to 37 years; one described having a college education, and several mentioned their employment. One used an augmentative communication device to share his views.

Procedures

The project was conducted in ways to maximize participation of persons with ID/DD in every phase of the process. A Steering Committee provided overall oversight for the project, including identifying the core areas for input. Its members include federal agency representatives, national disability organization representatives, and researchers. The staff member directing the current project lives with a developmental disability and is a strong spokesperson for persons with ID/DD. An advisory group of adults with ID/DD from Ohio State University, a major ID/DD research center in the US, provided input to the focus group process and to initial wording of questions. A moderator who self-identifies with ID/DD provided additional refinement to the questions and process for conducting the focus group. She also moderated each of the three focus groups. A coder for the data is a former special education teacher with close ties to the ID/DD community. Both the staff member directing the project and the moderator reviewed the coding for accuracy of coding, interpretation of findings, and are co-authors of this paper. Participants were compensated financially for their participation.

The composition of each focus group was based on organizational affiliation (i.e., a group for each of SABE, COLA, ASAN). Each session was scheduled for 1.5 hours and was conducted using an online platform (Zoom). One week in advance of the session, all participants were sent brief background materials in an Easy Read format. This comprised brief background on the *ID/DD Counts!* initiative as a power point presentation, a copy of the questions for discussion, and a question about any needed accommodations. This allowed participants time to consider the questions and plan their responses in advance.

The following language was used to explain the purpose of the focus groups: “Thank you for participating in this focus group. You are here to represent yourself and other people with intellectual disabilities and developmental disabilities, or ID/DD. The Administration for Community Living (ACL) wants to learn about the health of all people with ID/DD all across the country. We want your help to know what questions to ask other people with ID/DD to find out about the health of all the people with ID/DD. It is important for the government to know what questions to ask to learn about the health of people with ID/DD.”

The sessions began with a brief overview of the agenda for the session, self-introductions by all participants and staff members who were online (modeled by the moderator), a brief overview of the project using the power point presentation, and time for questions about the project. This was followed by presenting the key questions for discussion used to elicit their input. Near verbatim notes were taken of comments made and were verified by viewing the recorded discussion and transcripts. These notes served as the basis for summarizing focus group input.

Questions for Discussion—Key Questions and Probes.

The questions presented in Table 1 were distributed in advance and presented as slides during the session. Additional questions used by the facilitator were recorded as probe questions.

Insert Table 1 About Here

Analyses

Following grounded theory procedures as used by others (e.g., Gibbons et al, 2016), the research team used the following process: (1) data were deidentified, (2) raw data files were configured into a single document; (3) the raw data were unitized to create separate units of different ideas and then compiled in a spreadsheet; (4) two coders read the raw data in detail in the narrative format several times and began to develop the range of thematic ideas in the data; (5) the coders met to compare their codes and collaboratively developed a draft system of codes; (6) the coders independently coded the data, adding new codes as needed, and allowing for primary and secondary codes if more than one thought was reflected in a statement; (7) initial inter-rater reliability was calculated (overall agreement = 73%) and the two coders met to confirm agreements and discuss disagreements, generating new codes as needed or reducing codes to avoid overlap; (8) the coders recoded the data and inter-rater reliability was recalculated (overall agreement = 88%); and (9) all final disagreements were discussed to reach consensus on the coding. Because our intention was to capture all ideas offered, not just the most common, we retained all ideas presented by participants. Using a framework proposed by others (Evans & Randle-Philips, 2018), the quotations of participants represent first order constructs, the thematic

codes are second order constructs, and synthesis across meaningfully related codes represent third order constructs.

Coding was conducted by an experienced qualitative researcher (member of the Steering Committee) and a disability advocate (special educator and administrator). Findings were summarized in a written report. To address potential bias in how the data were described, validity of this written summary was determined in the following ways: (1) the written report was reviewed by the second coder for agreement that the findings were summarized accurately and comprehensively; (2) the director of the project (adult with ID/DD and a member of the Steering Committee) reviewed the transcribed notes and the written report to confirm the findings and suggest additional edits; (3) the moderator provided additional edits, and (4) edits were discussed to reach consensus on the report.

Findings

Findings are summarized first to determine participants' understanding of the need for data—did participants' comments reflect they understood the questions? Then findings are presented for the three primary purposes of the study —What are the priorities of adults with ID/DD on which data need to be collected? How does this compare with priorities of their parents or others who support the individual? How should information be collected and disseminated? Finally, who are the target audiences for the resulting information on health of people with ID/DD? Broader themes were used to group coded themes. Brackets within the quotations indicate researcher-added words to provide context to the statement. Each section includes one or two sample quotations. Table 2 provides additional sample quotations (first order

constructs) grouped by questions asked to illustrate the codes (second order constructs) that are grouped as themes (third order constructs).

Insert Table 2 About Here

Why Is It Important to Know More About the Health of People With ID/DD?

Participants demonstrated that they understood the request for their input by talking directly to the issues of how improved data could be useful. In addition, participants voiced privacy concerns regarding sharing information about their health and disability status with people they might or might not trust.

Need for Better Data

Responses indicate that participants clearly understood the request for their input by identifying the need for better information. This included information about any unmet needs and the value of longitudinal data across the lifespan of the individual.

“It’s important to know about everyone, and in the past we haven’t been very vocal, but now we need to be.”

Need for data to improve access to quality health care services. Participants acknowledged the lack of data and the need for more information so that it can inform action for improved health.

“If there are areas of concerns, how are we addressing those needs?”

Need for longitudinal data. Participants across the groups were interested in the need for longitudinal data to monitor changes over the lifespan. Such data would help them anticipate

what health changes might come with increasing age and do what they could to promote their health.

“It’s good to know what things to be prepared for as people age—your health changes as you age, and helping people be prepared for those changes.”

Information to help others. Participants wanted information about health conditions affecting friends so they can help them and others. Much of this assistance was described within the immediate context of helping a friend at the time of need.

“If they have seizures, and what they want me to do if they have a seizure, so I don’t panic and they’ll be safe.”

Access to quality health services. Many responses addressed the need for access to quality health services to improve health. Participants noted that in addition to health concerns shared with people without disabilities, they may have unique or complex health conditions and quality health care needs to address that complexity.

“A lot of us encounter health problems because we don’t have access to the help we need.”

Barriers to accessing care. A number of barriers to accessing care were mentioned. These included limitations by the type of insurance coverage, and concerns about accessing care when no longer covered by a parent’s plan. Participants were also concerned that providers are not adequately trained to address needs of persons with ID/DD, and whether care addresses all their needs.

“Certain doctors won’t take Medicaid and that’s a big problem all over America.”

Need for Better Services

Participants were very attuned to the need for better and more available services that extend beyond physical health care. In particular, they called out the need for developmental disability services for all people with ID/DD.

“Some friends with hidden disabilities...are on the waiting list and don’t have a staff person or support--they didn’t have the ability to talk to people—I gave them help and support for where to go.”

Need for better general (developmental disability) services. All groups noted the importance of services and supports. One group of respondents was vocal about the need to eliminate waiting lists for services.

“I wish we didn’t have waiting lists.”

Mental health needs. Mental health concerns were specifically noted and emphasized across all groups. These included mental health issues and anxiety related to past traumas and to current concerns around COVID. Some participants raised concerns around coercive care and ineffective medications.

“We’re traumatized by experiences and are less likely to go to see docs; more likely to talk with whoever is with us.”

Concerns About Sharing Information

A major concern voiced by many participants and across questions was about sharing personal information. This included information about their health conditions, whether to disclose disability status, and their harmful experiences of discrimination and negative stereotyping. Participants indicated they might withhold information from program staff and physicians if they didn’t feel they could be trusted

“Staff—they come and they go, so I don’t want to tell them.”

Trust and privacy. Several participants raised concerns about sharing their information, while others stated their belief that it is important to share information to allow for the best care.

“You never know what the person has on the inside—we are all human beings and need to know each other; if they know you, they trust you more.”

Disclosing or identifying with disability. Members from all groups expressed thoughts about the important issue of disclosing or not disclosing disability status when asked—some described reasons for nondisclosure of disability while others wished they were asked about their disability in surveys.

“A lot of people hide their disabilities, or they have them but they don’t know.”

“I have CP and do not have questions asked about DD—I would like them to ask if you have a DD.”

Attitudes/misconceptions/stereotypes. Across all groups and many questions, participants discussed the attitudes, misinformation, and stereotypes that others, especially health care professionals, hold about people with ID/DD. These views held by others about people with ID/DD were almost always negative, incomplete and harmful. Participants reiterated that persons with ID/DD should be understood for who they are, and for others not to prejudge or make assumptions about them. Some participants discussed the harm done by researchers and practitioners who adopt a mental age theory about ID/DD.

“A lot of people in medicine have ideas about us that don’t match our truth.”

“Most researchers don’t have IDD and aren’t able to be respectful of us, especially if [we’re] black or queer/LGBT.”

What are the Priorities of Adults with ID/DD on Which Data Need to be Collected?

Participants addressed a range of areas on which they believed data should be collected. These included information on their limitations, health risks, and health care.

Functional Limitations and Health Risks

Information is needed about the person with ID/DD so that care can accommodate their needs, health risks, health behaviors, and the larger contexts of their lives.

“Sometimes it’s our social or mental health context that’s the problem but it is only treated from a medical basis.”

Functional abilities. Participants indicated the importance of knowing what a person can and cannot do. This is important for friends and health care providers to know in order to determine how to help. Participants with autism called out their unique challenges with communication.

“[we have] communication challenges”; “[it’s] hard to talk with doctors.”

Information on health risks. Respondents described wanting to know more about potential risks to their health and what to do to help manage or prevent them. Participants wanted to be part of the process of addressing risks and promoting their own health.

“Ask ways on how [a condition] can affect you and the risks and figure out how to make it better and easier—the process.”

Healthy lifestyle behaviors. Participants talked about healthy lifestyle behaviors, but often because these behaviors (diet, physical activity) were advised by others.

“They [parents/carers] just tell you to go on a diet and lose weight. Focus on weight, weight, weight and use bad words about it. Either weight, or behavior.”

The social context of our lives. Several respondents noted the need to ask questions about the social context of their lives. This includes where they live (e.g., in an institution), and the larger social context of their lives that contributes to their health.

“[it’s important to ask] ‘do you live in an institution?’”

Health Care

Many issues raised about health care focused on medications and the need for durable medical equipment, and whether these interventions worked for them.

“Like medication for depression doesn’t help all the time and may make things worse.”

Medications. Participants were very vocal about medications— the importance of knowing what medications a person is using, and whether the medications are effective or not.

“Overuse of psychotropic medications--we are among the most vulnerable people, but docs rush to psychotropics that have side-effects... Medication is a crutch for society.”

Medical and assistive devices. Some participants talked about their medical devices, specifically hearing aids and glasses, and whether or not they work well for them.

“I have hearing aids and they fall out; so I wish they were designed to go right into my ear.”

What Others Should Know About the Health of People With ID/DD

Participants described very holistic approaches to considering health, the importance of choice and self-determination, and clear communication for making health care decisions.

“You can’t just isolate IDD from everything else in our lives, our families, our lives, poverty.

Statistical researchers look at only one thing and that makes it harder.”

Holistic health. Across the groups, there was a strong emphasis on taking a holistic approach to health. This included considering how physical and mental health are related and are connected

to their disability, and the problem of multiple concerns all being attributed to the disability (i.e., diagnostic overshadowing).

“I would like to know more about dental health and reproductive health—we miss the person’s whole being because we focus on the main diagnosis.”

Control/Self-determination. The importance of control and self-determination was emphasized across all groups. This related to full participation in the process of improving their own health and other aspects of their lives. Participants described a priority as determining the extent to which people with ID/DD have control over their own care.

“People with IDD should always be part of decision-making in research. Often people think people with disabilities can only be recipients, but they should be part of the full process in coming up with the questions, data—people in the community will know it’s more legitimate and know the information has been vetted.”

Communication. Adults with ID/DD emphasized the importance of communication—communicators need to talk to the person with ID/DD, be respectful and patient in communicating, use clear language that is easy to understand, and truly listen to what the person with ID/DD is saying.

“An agency person should give the person a chance to talk; don’t like it when people push you to saying things you don’t want to say.”

What Would Your Parents or Direct Support Person Say Is Most Important About Your Health?

In describing what parents and other support people would prioritize, participants primarily talked about health behaviors and trust/privacy. There was a marked difference in

responses to this question between respondents who identified with intellectual disability (ID) and those who identified with developmental disabilities (DD) but not ID, specifically within the autism focus group. Generally, though not always, participants with ID agreed with their parents or support people. Among persons with DD but not ID, many stated that the opinions of others are not important because of self-determination or because they are estranged from their families. Participant comments addressed health behaviors framed within concerns of trust of family members and support persons.

“I do not have a speaking relationship with my parents, because I came out as queer, and they are fundamentalist, and they are not very involved in my life.”

Health behaviors—Many participants reported that their parents or support persons would emphasize health behaviors for reasons that could be considered social acceptability, particularly weight management through diet and exercise. For other participants the health behaviors related to slowing down or managing their diabetes.

“I do agree that I need to exercise and diet--what’s tricky is figuring out meal-planning and where to start.”

Trust/privacy. These questions triggered discussion in all three groups about disclosure, privacy, trust, and estrangement from family members. When participants talked about staff members, they generally stated they would not share information with staff.

“Whoever gives the survey they need to be a friend and explain why it’s important for them to know.”

How Should Information be Collected and Disseminated?

Participants offered ways in which people with ID/DD could be helped to participate in surveys. The most common ways address the need for plain or clear language, neutral supports, and other accommodations like visual supports (pictures), definitions, and potentially musical tunes for attention and retention.

“[Give] definitions, pictures and the words, and that it’s about them.”

Accommodations

Clear language and visual supports. Participants repeatedly recommended using language that is easy to understand. This also included providing definitions, using short questions, and giving examples.

“Sometimes people understand better with pictures and give them a tracking to the question better sometimes. Like cartoons, and you’re staying attentive and don’t get burned out.”

Neutral support. Several ideas related to providing a source of neutral support, someone who could assist in understanding and completing the survey without influencing responses. These include a resource center and hotline, like a 211 response center, or other persons who know not to influence responses. Participants also suggested physical supports, such as technology or use of multiple formats for answering.

“Offering some neutral support, a lot of health information is private and might not want parent or DSP[direct service professional] to know; maybe someone from the research team

Communication and challenges. Across all groups and many questions, participants identified communication with health care providers as challenging. They offered suggestions such as providing summaries, and emphasized talking directly with the person with ID/DD.

“One thing that would help us—explain it to us about what’s going on to you—instead of PCAs [personal care attendants] and family members—they need to break it down for us; that will clear up a whole lot of stuff, even if they have to be in the room.”

Survey Methodology

Adults with ID/DD gave numerous suggestions for improving how survey data might be collected. Participants made concrete suggestions for data collection, noting the need to address the diversity among people with ID/DD.

“Survey needs to be in simple language.”

Survey methodology. Several participants suggested survey methodologies to use, including going through agencies to have surveys completed, and the importance of reaching out to the communities of persons with ID/DD. They also recommended that surveys ask about how people decided on their response, and whether or not they understood the question.

“I think surveys should ask how you decided on your response; some people think it fits into a category, but did they understand the question?”

Diversity among people with ID/DD. Several participants indicated differences among people with disability that related to race, ethnicity or language, reflecting awareness of diversity in responding.

“As a black person with DD but not ID, people think you’re smart because I have a degree, and think I’m fine; or they’ll see me as disabled and black and they’ll treat me as a child and ignore me.”

“if they have limited English?”

Who Needs to Get the Information?

Participants identified a number of target audiences for the resulting information on health of people with ID/DD. Responses to this question suggested that, across participants, some were thinking about disseminating general health information about all people with ID/DD to different audiences, while others were thinking about their individual health information and who should receive that individual information.

“Policy-makers because without these data, we can’t influence policy-makers or assess potential cost.”

The numerous groups suggested could be grouped into several categories that might need the information in different ways.

Recipients for direct use of the information. These include persons with ID/DD and their families who might use the information to modify their own behavior or become more aware of potential health risks.

Recipients for use of the information in advocacy efforts. These named recipients include self-advocacy groups such as People First, SABE, ASAN, and Independent Living Centers. Other recipients mentioned included disability organizations and advocacy groups, such as University Centers for Excellence in Developmental Disabilities, The Arc, the National Association of State Directors of Developmental Disabilities Services, American Network of Community Options and Resources, and United Cerebral Palsy.

Program staff and care providers. This group includes those responsible for program planning such as formal support systems (case-managers, staff at day programs, direct service professionals, social workers, vocational rehabilitation, teachers); and those providing health care (doctors, therapists, neuropsychologists, dentists).

Policy-makers, policy implementers, and researchers. Other target audiences were those directing policy change such as governments and other authority groups (state and federal agencies, the criminal system, policymakers and funders). Also included are those building bases of knowledge, such as researchers and disability and health programs.

Ideas for Disseminating Information

Multiple ideas were offered for how to disseminate information to persons with ID/DD, professionals and policy-makers.

“I like short videos and music, because of the short attention span ---easier to remember tunes that are focused.”

Suggested formats included different media outlets (e.g., newsletters, internet, Facebook), individualized methods (e.g., putting information into your file, individualizing information to support people on what they need help with), training and checklist formats (e.g., seminars, short videos) that could include use of music, and traditional venues such as academic journals. Participants also provided specific ideas for how improved information could inform programs and policies. These included that people need to implement the changes in programs or policies to make change happen.

Discussion

This study demonstrates that with appropriate planning and effective supports, adults with ID/DD can provide meaningful input to program policy and planning. As advocated by others (McDonald et al, 2021; Shogren et al, 2021), when efforts are made to provide accommodations, adults with ID/DD can report their experiences and perspectives for research, clinical care, and program planning. What participants said in response to the question on need for data

demonstrated that they understood the purpose of the focus group. They articulated the clear need for data, including longitudinal data. They described data as necessary to improve health care, including access to mental health and support services. Areas for needed data collection broadly related to functional limitations and health risks and to health care (medications, medical devices).

Importantly, some of the current findings might not have been obtained if reporting had relied only on proxy-respondents. These findings indicate the need for caution in relying on proxy-reporting and emphasize the need to understand the perspective of persons with ID/DD directly from them. For example, the finding that trust is needed by the respondent with ID/DD to decide whether to disclose disability status and health needs is vitally important for generating accurate health and disability data. Expressed reluctance to share information with program staff indicates that these support providers may not be privy to personally held health information. Researchers' assumptions about use of proxy-reporting is further challenged by participants' reports of being estranged from their families while others report that they are unlikely to share their health concerns with program staff.

Adults with ID/DD want to know more about their health issues. Specifically, they expressed interest in understanding risks to their health, how disability affects health, and whether people with ID/DD are as healthy as others. Further, they want to understand health over the lifespan and what issues they might encounter in the future. Participants also wanted to send a message to health care providers and others to take a holistic approach to health. They want health care providers to communicate directly with them directly and not through proxies, and to respect their agency and capacity for self-determination. These concerns are substantiated by recent

findings that almost 75% of physicians do not generally talk to the adult patient with ID (Campbell et al, in press).

Important for data collection are the differences between what adults with ID/DD report as their priorities for health data and what they see as their support person's priorities. Many adults with ID/DD did not see their family members and support people as being aware of the array of their issues and concerns. For some, support people might not know about physical or mental health concerns of the person with ID/DD and were seen as primarily focusing on weight and challenging behaviors. One interpretation is that family members and support persons may place more emphasis on social acceptability than the person with ID/DD.

Participants offered several comments relating to differences due to race, ethnicity or language. These related to presumptions that are made if a person is black, or to inaccessibility of participation if one does not speak English. At least two participants also commented on family estrangement resulting from their LGBTQ+ status. However, their comments did not extend to impact on health care or health data. We note that the focus group questions did not ask about intersectionality issues of having a disability and being marginalized in other ways. More examination of the intersectionality of disability with other identities (race, ethnicity, language, LGBTQ+, poverty) is needed in recruiting and hearing the voices of persons with ID/DD.

While the stated purpose of the focus group was on how and what data to collect to improve health of people with ID/DD, participants shared many observations about their dissatisfaction with their current health care experiences. They shared freely about their experiences of discrimination and inadequate attention by health care providers to the multiple aspects of their health. They described communication styles of health care providers that did not

recognize the agency of the person with ID/DD nor support their participation in the health care experience and decision-making.

In terms of how information should be collected and disseminated, adults with ID/DD had numerous practical recommendations. What was recommended most consistently was use of clear language and visual supports in asking questions in surveys. They also recommended using multiple formats for sharing findings and preparing information for dissemination to multiple audiences.

The diversity among people with ID/DD suggests that a range of accommodations and competencies are needed. Addressing the communication challenges is essential for recruiting and incorporating the input of adults with ID/DD. Participants were clear that they want to provide input without being influenced by the biases of their support providers—sources of neutral support for participation are vitally important as a needed accommodation.

This study is limited in several ways. The number of participants is small, and they were likely recruited because they are articulate spokespersons for their respective organizations. If other participants had been recruited, the findings would likely have raised different or additional ideas. Another qualifier for this study is that qualitative findings can be presented in a range of ways, emphasizing different aspects of the data. The current study used processes intended to be comprehensive (coding and integrating all comments) and to reduce researcher bias (i.e., independent coding, using all data within the data set, validating findings with the facilitator), but some bias likely still remains. Finally, the study did not directly address the impact of social determinants or impact of other marginalized identities (e.g., race, ethnicity, language, sexual identity, poverty). Had we done so, we might have learned even more about the priorities for health equity data among the diversity of people with ID/DD.

Implications for Policy and Practice

“Here is the simple summary—the lives of people with ID/DD are important, our experiences matter, our quality of life matters”

--Focus Group Participant

Focus groups conducted with adults with ID/DD to recruit their input into plans for developing a roadmap to improve health equity data for persons with ID/DD. Their views have immediate implications for implementation. For policies and surveys, the findings should sensitize researchers and agencies on the need for trust by adults with ID/DD before they may disclose their disability status and personal health information. Without such trust, under-reporting of disability and health needs is likely. Data collection methods should address longitudinal as well as cross-sectional data to provide a life course perspective on health. Health trajectory information is desired that is specific to conditions. Planning for collection of health data for persons with ID/DD should ensure active engagement of persons with ID/DD in all aspects, from planning of content areas to interpretation of findings. Data collection and information dissemination should use clear language, with multiple formats (e.g., visual, graphics) and multiple response options. Methods should include queries to ensure that respondents understand the questions. Neutral sources of support may be needed to ensure that adults with ID/DD can express their own views without undue influence of support persons or systems.

Implications for practice and programs are that professionals communicate directly with the adult with ID/DD even in the presence of family members or support personnel. Communication needs to be based on clear and simple language, again using visual aids as appropriate.

Communications should ask persons with ID/DD about their priorities and questions. Finally, where appropriate, health professionals should provide anticipatory guidance for what to look for, and what to expect.

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Table 2. Themes, codes and sample quotes of adults with ID/DD providing input to health equity data planning.

Themes (Third order construct)	Codes (Second order construct)	Sample Quotes (First order construct)
<i>Why do we need to know more about health of people with ID/DD?</i>		
Need for Better Data	Need for data to improve access to quality health care services	<p>“That way we could address what the problems are and get good treatment.”</p> <p>“If there are areas of concerns, how are we addressing those needs?”</p>
	Need for longitudinal data	<p>“It’s good to know what things to be prepared for as people age—your health changes as you age, and helping people be prepared for those changes.”</p>
	Information to help others	<p>“I feel more comfortable with them telling me about their health, and how I can assist them, like opening medicine for them, how many to give them.”</p>
	Access to quality health services	<p>“It’s kind of contradictory, we’re like everyone else in some ways, and we are also unique with our own unique needs.”</p> <p>“There can be complicated care and the complexity needs to be addressed.”</p>

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	Barriers to accessing care	<p>“How many have dentists are there as part of healthy communities?”</p> <p>“A lot of doctors don’t try to learn how to work with people with IDD and their complex needs.”</p>
Need for Better Services	Need for better DD services	<p>“We need access to supportive people in our homes and our communities.”</p> <p>“I wish we didn’t have waiting lists.”</p>
	Mental health needs	<p>“For mental health, coercive care or forced care. It happens especially to non-speaking, or people considered ‘intelligent’ because they have a college degree or have a job.”</p> <p>“I feel I live in a state of unwellness. I worry about my long-term health.”</p>
Concerns about sharing information	Trust and privacy	<p>“You never know what the person has on the inside—we are all human beings and need to know each other; if they know you, they trust you more.”</p> <p>“I don’t trust docs and rely only on a specialist.”</p>
	Disclosing or identifying with disability	<p>“One reason is people have it and don’t want to admit they got it.”</p> <p>“Some people want you to know about their disability. The person comes first, and the disability second.”</p>

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	Attitudes/ misconceptions/ stereotypes	<p>“[Others’ attitude is:] If we have IDD, we’re not worthy of being listened to—it comes out in every area of health care (routine, emergency, etc.); docs assume what is best for us.”</p> <p>“Not to judge people by how they look.”</p> <p>“Ableism negatively impacts the health of people with IDD, and I’d like to know more about that—some of these issues aren’t really specialized care but about common decency in how to treat people—gap between knowing and doing. How health of people is affected by ableism?”</p>
<i>What questions do you think surveys should ask you about your health? What should others know?</i>		
Functional Limitations and Health Risks	Functional abilities	<p>“If people have trouble reading”; “can they read instructions to take pills.”</p> <p>“People need to learn to be patient with people with IDD; that person could have a speech impairment.”</p> <p>“How disability affects your health—like for speech, it’s hard to explain yourself.”</p>
	Information on health risks	<p>“There may be a new risk and did they explain it to you? Like going to a dentist or dermatologist—and you don’t know the risk and they haven’t told you about a new risk, and you’re affected.”</p>

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	Healthy lifestyle behaviors	<p>“Sedentary lifestyles.”</p> <p>“It’s important to wear a mask to stay safe –I saw that in a chat stream.”</p>
	The social context of our lives	<p>“Sometimes it’s our social or mental health context that’s the problem and is only treated from a medical basis.”</p>
Health Care	Medications	<p>“Ask if the person is on psychotropic meds, and what it is being used for –e.g., behavior; then it could be there is something else. Psychotropics are addictive, though we often don’t think this is an issue.”</p> <p>“Like medication for depression doesn’t help all the time and may make things worse.”</p>
	Medical and assistive devices	<p>“[There are] reports on hearing aids sometimes working, and sometimes not.”</p> <p>“I have glasses but they don’t always help, so I like larger print and up closer.”</p>
What Others Should Know	Holistic health	<p>“Diagnostic overshadowing—when you have a main diagnosis, people focus on that and miss other things.”</p> <p>“A lot of mental health is linked to physical health—how can you feel happy if you’re body doesn’t feel well?”</p>
	Control/Self-determination	<p>“Health and controls—do you get control in decisions about who you get to see at your doctors, and how</p>

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		<p>often—are you getting to choose?” “Do people with IDD have a choice about their meds?”</p> <p>“It’s my health so think it should be driven by me and my medical team.”</p>
	Communication	<p>“Ask questions that I can understand.”</p> <p>“To be kind, listen even when we have trouble with questions.”</p> <p>“An agency person should give the person a chance to talk; don’t like it when people push you to saying things you don’t want to say.”</p>
<i>What would your parents or direct support person say is most important about your health?</i>		
	Health behaviors	<p>“What I hear from my doctors and my mom are me exercising and dieting---that’s what they say is most important for my health.”</p> <p>“Another factor is what kind of medication are you taking? Or with a condition, it’s not as simple for us because medication plays a side effect.”</p>
	Trust/privacy	<p>“It’s mostly about what people want to share with them about their health; like some folks tried getting too personal and I didn’t feel comfortable so I didn’t want to say it. Let us tell them what we feel.</p>

		<p>Sometimes we want to keep information to ourselves until we trust them more.”</p> <p>“Whoever gives the survey they need to be a friend and explain why it’s important for them to know.”</p> <p>“I understand when [other participant] talks about his asthma, like if someone says bladder infection, that might be more personal—deep things, they can be covered and don’t need to share with everybody.”</p> <p>“Staff—they come and they go, so I don’t want to tell them.”</p>
<i>How should information be collected and disseminated?</i>		
Accommodations	Clear language and visual supports	<p>“Use language and terms that are easy to understand.”</p> <p>“Short questions.”“Give examples.”</p> <p>“If we put in the time and effort, we can frame many of the questions in easy-to-understand language.”</p>
	Neutral support	<p>“Sometimes the DSP [direct service professional] plays a role, but you have to make sure they’re not persuading them to answer in certain way.”</p> <p>“A 211—they give you the guidance where to go, who to contact.”</p> <p>“Offering some neutral support, a lot of health information is private and might not want parent or</p>

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		DSP [direct service professional] to know; maybe someone from the research team.”
	Communication and challenges	<p>“With the words, don’t make it a long word –can’t pronounce them or read them, my friends have no clue what they are or how to read them.”</p> <p>“Give advice in words/language we may not understand. Nobody gives us information in ways we understand.”</p>
Methodology	Survey Methodology	<p>“If we get surveys filled out through agencies, I think we’ll get a better result.”</p> <p>“Go out to communities where they are and seek them out. We are so busy dealing with our disabilities we don’t have time [if you don’t come to us].”</p>
	Diversity among people with ID/DD	<p>“That we’re very diverse within the group.”</p> <p>“As a black person with DD but not ID, people think you’re smart because I have a degree, and think I’m fine; or they’ll see me as disabled and black and they’ll treat me as a child and ignore me.”</p> <p>“If they have limited English.”</p>

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Table 1. Key questions and probe questions used in focus groups with adults with ID/DD to determine health priorities, communication methods, and audiences for information.

Order	Key Question	Probe Questions
1.	Why do you think it's important for us to know more about health of people of IDD?	
2.	What questions do you think surveys should ask you about your health?	What do you want to know about the health of people with ID/DD?
3.	What should other people who are researchers, agencies and others know about the health of people with ID/DD?	For the ASAN Group, this was specified as "researchers and practitioners"
4.	What would your parents or direct support person say is most important about <u>your</u> health?	Do you agree with what your parents or care-providers say about your health?
5.	Do you agree with what they say is most important about <u>your</u> health?	
6.	How can we help people with ID/DD take surveys?	
7.	Who needs to get this information?	How do people with IDD get their information?

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8.	How should the information be shared with people with ID/DD, their families, and medical professionals?	
9.	How could the information be used to help people with ID/DD be treated as fairly as people without ID/DD?	How would you use the information to help you have a good life?